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**EXPLORING THE PERSONAL NARRATIVES OF MOTHERS
OF FORMER PRETERM INFANTS NOW AT PRESCHOOL AGE**

A Dissertation in

Nursing

by

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ABSTRACT

Having a preterm-born child is often fraught with ongoing challenges for the child's mother. Yet little is known regarding how that experience, over time, may influence the mother's health and well-being, how it influences her perceptions and practices of parenting, and the meaning(s) she attributes to it. The purpose of this study was to explore mothers' personal narratives of their experience of being the mother of a former preterm infant now at preschool age, what meaning(s) they attribute to it, and what nurses can do to support these women. Narrative Inquiry was the research method utilized. The theoretical perspective selected to guide the interpretation of what it is like to be the mother of a former preterm infant now at preschool age is Transformative Learning Theory. Six mothers whose former preterm infants are now at preschool age provided their personal narrative via in-person interview or in written form via email. Each study participant's personal story of being the mother of a preschooler born preterm was elicited and retained as the primary unit of data. Interpretation and analysis of the data was conducted using hermeneutic data analysis, identifying narrative functions (revealing patterns of thinking, memories, and identity), contexts, and central, metaphoric, participant-specific themes. Identified participant-specific themes include "I matter too," "savoring the moments," "honoring new paradigms," "against all odds," "affirming my worth," and "lessons from loss."

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The words of the prophet Isaiah proved to be exactly what I needed:

I will go before thee, and make the crooked places straight; I will break in pieces the gates of bronze, and cut in sunder the bars of iron; and I will give thee the treasures of darkness, and hidden riches of secret places, that thou mayest know that I, the Lord, who call thee by thy name, am the God of Israel. (Isaiah 45:2 & 3)

Those words have strengthened and encouraged me countless times since that night so long ago. Only God and I know of all the crooked places, gates and bars that I have encountered along the way; how I praise God for being faithful to straighten, break, and cut where it has been necessary. My wonderful professors here at Penn State have revealed what are often the treasures of darkness found in the intellectual pursuits of higher education. And the gracious women who participated in my study honored me with the privilege of learning about the hidden riches of the secret places within their very personal narratives; to them I owe my deepest gratitude.

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Chapter 1

Introduction

Preterm birth, regardless of the cause, is a birth that occurs too early. As the word suggests, a *preterm* human birth takes place before a pregnancy is deemed full term, that is, at least 37 weeks gestation. Under normal circumstances, infants born full term are physiologically stable and developmentally equipped for extra-uterine life, able to thrive with the provision of ordinary newborn care. However, in every preterm birth, vast human, clinical, and technological resources are required to maintain the life of the uniquely vulnerable preterm infant, to compensate for their physiologic instability and developmental immaturity. The typically unexpected and often urgent nature of a preterm birth only serves to compound the situation. Time to fully prepare for a preterm birth is a luxury many women facing such an experience are not afforded. For both mother and infant, potentially significant life changes enter the realm of possibility, whether the mother is ready for them or not. Therefore, in this environment of uncertainty, the mother experiencing a preterm birth is in her unique way, also vulnerable.

Preterm birth is a problem all too common in the United States. Despite efforts to prevent preterm births instituted by governmental initiatives such as Healthy People 2010 and private organizations such as March of Dimes, the proportion of live preterm births rose from 9.4% in 1981 (Martin et al., 2007) to 12.8% in 2006, an increase of 21% since 1990 (Martin et al., 2008). The rate of low birth weight (LBW) births in the United States also increased to 8.3% in 2006 in comparison to 7.0% in 1990, reflecting a 19% increase (Martin et al., 2008). The most recent statistics, from 2007, reveal only minor declines in these preterm birth and LBW rates, 12.7% and 8.2%, respectively (Heron et al., 2010). An infant's low birth weight status is typically attributable to either preterm birth (as what is commonly seen in developed countries) or

inadequate fetal growth (Southgate & Pittard, 2001). Uncertainties regarding an infant's future health status accompany all preterm births to some extent. Preterm infants who are also very low birth weight (VLBW) are at even greater risk for adverse health outcomes in the short- and long-term since they are more susceptible to infections (Baley & Goldfarb, 2001; O'Donnell & Merenstein, 1993), developmental disabilities (Van Baar, Van Wassenaer, Briet, Dekker, & Kok, 2005), and endocrine disorders (Cutfield et al., 2004).

Several studies have reported on the effectiveness of interventions aimed at reducing the stress experienced by mothers after a preterm birth. Melnyk and colleagues, in a randomized, controlled trial tested the effects of the educational-behavioral COPE program (Creating Opportunities for Parent Empowerment) aimed at reducing the stress in parents of preterm infants (Melnyk et al., 2006). Mothers in this study reported less stress while their infant was in the neonatal intensive care unit (NICU) compared to infants' mothers who received a comparison educational intervention. The COPE mothers also reported less anxiety and depression than the mothers in the comparison group when infants were at 2 months' adjusted age. Preyde and Ardal (2003) found that a parent "buddy" program was effective in reducing stress for mothers of very preterm infants (less than 30 weeks gestational age) at approximately 5 weeks after birth as compared to controls. The experimental mothers in this study reported less anxiety and depression as compared to controls at approximately 17 weeks after birth. Psychological support was identified as a means to reduce stress for parents of extremely low birth-weight and very low birth-weight infants, both during the hospitalization period and at the time of a study conducted by Elklit, Hartvig, and Christiansen (2007). At the time of their study, 60% of the infants represented were between 6 months and 1 year old, 23% were between 1 and 2 years old; the remaining children were between 2 and 3½ years old. Another intervention program designed to reduce the symptoms of trauma in mothers of preterm infants was found effective (Jotzo & Poets,

2005). This program provided psychological support within the first days of birth as well as during critical periods while the mothers' infants were in the NICU.

Unfortunately, many of these stress-reducing interventions take place early in the postpartum, a time which may not be well-suited for mothers to process new information or reflect on what has taken place during the neonatal period (Eidelman, Hoffmann, & Kaitz, 1993; Stark, 2000). Researchers suggest that introducing interventions aimed at preventing psychological distress in postpartum women in general may be ineffective if provided too early (Gamble, Creedy, Webster, & Moyle, 2002). This may be due to a woman's hesitancy to voice anything critical of the birth experience at the time, physical and emotional fatigue or trauma, feelings of being overwhelmed (Gamble et al.), and needing additional time to mentally process and frame a narrative about the birth (Creasy, 1997). Even if early stress-reducing interventions for preterm mothers are deemed effective, given the postpartum timing, questions remain regarding their long-term efficacy.

Several studies recommend providing support to mothers of preterm infants well after the birth. For example, in a study exploring psychosocial needs of parents of former preterm, extremely low birth-weight to very low birth-weight infants 2 to 8 years post-birth, nearly a third of the participants reported the need for long-term psychological support (Eriksson & Pehrsson, 2002), a clear indication that such support is needful beyond the early postpartum period. Interviews with Korean mothers of preterm infants revealed the need for culturally sensitive emotional support that extends beyond the transition-to-home period, particularly if the infant has serious health issues (Lee, Norr, & Oh, 2005). Holditch-Davis and colleagues recommend ongoing, post-discharge assessment and intervention for preterm mothers displaying emotional distress related to the preterm neonatal experience (Holditch-Davis, Bartlett, Blickman, & Miles, 2003). A phenomenological study exploring birth trauma revealed some mothers characterize a preterm birth experience as traumatic, re-lived every year on the birth anniversary, despite the

elapse of many years since that birth (Beck, 2006). Beck's findings also support mothers' ongoing need for emotional support and others' acknowledgement of the trauma they experienced. In addition, the study supports the need for healthcare providers to assess and provide pre-anniversary interventions to help prevent psychological crises for veteran preterm mothers.

Most studies conducted to date on experiences of mothers of preterm-born children also highlight other issues such as breastfeeding (Sweet, 2008), maternal-infant interactions (Tilokskulchai, Phatthanasiriwethin, Vichitsukon, & Serisathien, 2002), maternal and infant behaviors during feeding (Singer et al., 2003), kangaroo care (Roller, 2005) and the experience of caring for (Sankey, & Brennan, 2001) or parenting a preterm baby at home (Bakewell-Sachs & Gennaro, 2004), all of which focus on the experiences of mothers within the first two years of their preterm-born child's life. However, less is known about the experience of mothers at later periods of time, particularly for those whose former preterm infants are several years old. Questions remain regarding that experience, particularly for mothers whose former preterm infants are preschool age. Do those mothers feel comfortable reflecting on their experience of having a preschool age child born preterm? If so, how do they depict it? Has their experience changed them personally and if so, how and to what degree? What meaning(s) do they attribute to their experience? How did contextual issues influence their experience or the meaning they attribute to it? What kind of support (and from whom) have they found most/least helpful in the course of their experience?

Statement of the Problem

A mother may be unprepared for the often abrupt, potentially life-changing and long-term consequences having a preterm-born child can bring. As a result, it is reasonable to conclude that

having a preterm-born child may create circumstances that have the potential to significantly influence the mother's life for an indeterminate length of time. Little is known regarding the experience of adult mothers whose former preterm infants are now several years old, specifically preschool age. Consequently, there is a lack of understanding regarding how a mother's personal life may have been influenced by her experience of being the mother of a preschooler born preterm, how that experience may have influenced her perceptions and practices of parenting, and the meaning a mother may derive from or attribute to her experience.

Purpose of the Study

Literature in nursing, medicine, social sciences, and psychology indicates a deep interest in fostering a better understanding of the risk factors for preterm birth in general and ways to enhance both immediate and long-term health outcomes for children who are born preterm. It is also clear researchers in these disciplines are working to explore the relationships and environments in which those children live in an effort to understand what factors are best for them to thrive physically, mentally, and psychosocially. This focus on a preterm-born child's physical, mental, and psychosocial well-being is certainly worthwhile. However, given the potential threat of ongoing challenge, stress, and life change that often accompanies the experience of having a child born preterm it is reasonable to wonder if and how the life of the child's mother has been influenced. The purpose of this study was to explore how participants depict the experience of being an adult mother of a preschooler born preterm and what meaning(s) they attribute to it, in order to gain deeper understanding regarding that experience.

Narrative Inquiry: The Research Method

Little is known about what it is like to be the mother of a preterm, preschool age child or of the meaning mothers may attribute to that experience. Therefore using a qualitative research design is the most appropriate means for exploring this phenomenon (Morse & Field, 1995). To that end, the primary research method for this study is narrative inquiry. An established research method in many disciplines with the social sciences (Polkinghorne, 2007) as well as medicine (Charon, 2006; Charon & Montello, 2002; Kleinman, 1988), narrative inquiry is relatively new but growing research method within nursing (Charon; Frid, Öhlén, & Bergbom, 2000; Holloway & Freshwater, 2007). Not to be confused with merely the designated type of data often used in qualitative studies (i.e., written texts and/or spoken/transcribed participant narratives), *narrative inquiry* is in its own right, a unique qualitative research method. Narrative inquiry, termed narrative research by some, seeks understanding the nature of and meaning derived from others' experiences, communicated via participants' stories (Duffy, 2007).

Stories are the primary way that people make sense of their experience and through some form of oral or written conversation reveal and share that experience with others....meanings that people give to their experience and that shape their lives are collected and organized into story form (Duffy, p. 401).

Through data interpretation and analysis, the narrative researcher identifies the gist of the story, i.e., what the story is about, and re-presents it to the reader by explicating its meaning (Clandinin & Connelly, 2000; Duffy; Mishler, 1986).

Narrative knowing underlies narrative inquiry. Narrative knowing and paradigmatic knowing are two distinctly different yet complementary forms of cognitive knowing (Bruner, 1986). Paradigmatic knowing reflects knowledge that is acquired in a de-contextualized, formal way and seeks an objective, universal truth. In contrast, narrative knowing reflects and is

grounded in human context and seeks subjective lifelikeness or verisimilitude. Each form of knowing orders experience and constructs reality in a different way and are equally necessary in order to fully appreciate the scope and variety of human thought (Bruner). “Narrative knowing is a fundamental mode of understanding by which people make sense of their own and others’ actions and life events” (Polkinghorne, 1996, p. 77). In the telling of one’s story in narrative inquiry, there is no single, true version reflecting the facts of what happened during an experience; rather it is acknowledged that *reflections on* and the *meaning of* past experiences change and as a result, so do the story-versions depicting those experiences (Clandinin & Connelly, 2000).

Narrative inquiry is informed by criteria of life experience, i.e., interaction and continuity (Dewey, 1938), in addition to the view that life experience is situated in place (Clandinin & Connelly, 2000). These three notions create a metaphysical “three-dimensional narrative inquiry space” (Clandinin & Connelly, p. 54) that embraces personal and social context (interaction), acknowledges phases of time (continuity), and addresses place (situation). These criteria are best understood in the light of five key features found in narrative inquiry: temporality, people, action, certainty, and context. *Temporality* means a life experience is positioned in time and as such it has a past, a present, and a future. *People*, refers to the notion that people are in the process of ongoing personal change and where they are in that process is important. In narrative inquiry, an *action* is a sign requiring interpretation in the light of one’s narrative history; once an action is interpreted, its meaning can be understood. *Certainty* expresses tentativeness regarding the meaning of an event, that other interpretations are always possible, resulting in a degree of uncertainty. Finally, acknowledging *context*, and more specifically, the existence of various contexts, is a constant in narrative thinking and necessary for understanding to occur (Clandinin & Connelly).

In contrast to other qualitative research methods, narrative inquiry does not seek to reduce data in order to identify themes across cases, to develop theory related to a phenomenon of interest, or interpret the shared meaning of those within an identified cultural or social group. The purpose of narrative inquiry is to discover a participant's personal experience and the meaning they attribute to it (Riessman, 2008). Sources of data for narrative inquiry are typically limited to written or verbal sources of rhetoric (Patton, 2002) from the participant first-hand (Coffey & Atkinson, 1996) although some argue that art and other visual data sources may be utilized (Riessman). The primary unit of analysis in narrative inquiry is the cohesive narrative or story offered by a participant (Mishler, 1995; Riessman).

The individual and unique story of each participant and the meaning they attribute to their story (or narrative) as it pertains to the phenomenon of interest is elicited and retained in narrative inquiry. While it is possible to examine multiple narratives within a given study for possible common threads or themes across cases, this is not the ultimate or only goal of narrative inquiry (Clandinin & Connelly, 2000). Individual narratives are potentially so diverse, so disparate, that the hope of discovering collective themes or a meta-narrative within a given study may not be a feasible or appropriate outcome.

Narrative inquiry acknowledges and expresses the aesthetic pattern of knowing in nursing as identified by Carper (Holloway & Freshwater, 2007), specifically "the aesthetic perception of significant human experiences" (Carper, 2004, p. 227). Empathy, a condition of narrative inquiry (Holloway & Freshwater) as well as a means of expressing the aesthetic pattern of knowing (Carper), is "a state of being between two people, where one is entering the world of the other while maintaining an awareness of his or her own world" (Holloway & Freshwater, p. 149). Empathy is a necessary skill for the narrative researcher, enabling them to create a safe environment for the narrator (Holloway & Freshwater).

The intersecting field between the subjective worlds of two people (the intersubjective space) is where empathy and caring occur and the creation of this intersubjective space comes only after each party communicates their subjective world to the other (Munhall, 2004). Narratives are the means of communicating one's subjective world; narratives in nursing are born out of interpersonal exchange and are dependent on a sensitive, empathetic nurse-listener who co-creates the narrative (Frid et al., 2000). Narratives provide contextual insight regarding one's personal experiences and how those experiences are thought to influence one's current and future life (Frid et al.). Attempts to mutually understand, interpret, and analyze what occurs between nurse and patient in the intersubjective space "reflects the nurse and patient communicating, reflecting, and validating the meaning of the patient's experience" (Munhall, p. 241). Given the nurse's co-creative relationship to the narrative, her/his witness to newly derived meanings and how those new meanings reframe self-defining memories may be healing for the narrator (Charon, 2007; Gaydos, 2005). Therefore, eliciting patient narratives of experiences and the meaning attributed to those experiences are a source of aesthetic nursing knowledge that can inform nursing practice.

This understanding informs the relational quality of narrative inquiry as it tries "to make sense of life as lived" (Clandinin & Connelly, 2000, p. 78) and to figure out "the taken for grantedness" (Clandinin & Connelly, p. 78). The researcher in narrative inquiry is not merely recording the details of another's experience; she/he is also drawn into the experience explored, be it concurrently as it unfolds in the telling or through personal reflection on one's own former experiences, reflection sparked by hearing or reading about the other's experience (Clandinin & Connelly). In collecting and analyzing participants' stories of experience, narrative inquiry researchers must simultaneously keep in mind the existence and influence of their own stories as well as the larger social context within which experiences occur (Clandinin & Connelly).

Exploring individuals' experiences and the meaning they derive from those experiences creates a

therapeutic environment for both narrator and listener; through reflection on the derived meaning personal transformation can occur, influencing one's present and potentially future life (Holloway & Freshwater, 2007).

Holloway and Freshwater (2007) argue that the case-centeredness quality of narrative inquiry is an appropriate fit with explorations of human experience within nursing research in that nursing, with its historical focus on caring, holism, and personal agency recognizes that giving place to the voice of the individual is essential in order to enter into and understand others' personal experiences, essential factors in establishing a therapeutic nurse-patient relationship. They note that the voices of both patient and nurse are acknowledged in narrative research in an attempt to equalize the power that exists when members of the health care system interact with consumers of that system. In addition, they note that in this day of increasingly de-humanized health care, narrative research's focus on the participant's perspective reflects a narrator-centered versus researcher-centered approach to health care research and ultimately in obtaining new health care knowledge.

As described earlier, scientific literature suggests mothers of preterm infants experience stress and for some, trauma, during the neonatal period. The literature also suggests that stress endures for these mothers 12-18 months after the birth. But given the paucity of information in the scientific literature regarding mothers of preterm infants beyond that timeframe, it is not clear what they have experienced by the time their former preterm infant reaches preschool age. Do their children require diligent management of medical or developmental needs and if so, do mothers face repeated stressors or crises as a result? Do mothers feel supported by health care providers and if so (or if not) how? How do they view the prospects of sending their preterm-born child to school for the first time? Have they known personal change as a result of being the mother of a preschooler born preterm and if so, are those changes characterized by frustration or satisfaction? By exploring the personal narratives of mothers of preschoolers born preterm,

mothers will have the opportunity for their voices to be heard, to be taken seriously on these or other issues they include in their stories, and to educate health care providers regarding their real life-world situations. “Understanding occurs in the process of reshaping one’s perceptions and opening up the self to the possibility that the narrative of the other has something to teach, either about the other or about oneself” (Freeman, 2007, p. 938). The insight gained through hearing and ultimately reading the interpretations and analyses of these narratives and the meaning they reveal is not only uniquely personal but privileged (Katz & Mishler, 2003); as such, what is discovered through the personal narratives of mothers of preschoolers born preterm will help inform nurses’ and other health care providers’ knowledge and understanding of these mothers’ experiences.

Theoretical Perspective

Transformative Learning Theory provides a way to understand the immediate as well as the long-term maternal response to the experience of having a former preterm infant now at preschool age. Transformative Learning Theory is centered on the life experiences of adults, one’s interpretation of those experiences, and the potential for new or revised meaning derived from them (Mezirow, 2000). Change resulting from a transformative learning experience represents a deep shift in one’s perspectives (Cranton, 2006) versus merely adapting to less than ideal circumstances; as such the change, the transformation, is life-altering.

Transformative Learning Theory posits that transformation is preceded by a disorienting dilemma, an event that leaves one unable to cope or problem-solve as usual, one that sets in motion the process of reflecting on and then questioning held beliefs, assumptions, or perspectives (Cranton, 2002; Mezirow, 2000). A dilemma provokes reflection; without a dilemma reflection would not likely occur (Dewey, 1933). The end result of transformation is not only

revised assumptions or perspectives but also action that is congruent with these revisions, indicating an integration of the new assumptions or perspectives into one's life (Cranton; Mezirow, 1997b, 2000).

Mothers' narratives in this study revealed whether they underwent or are in the process of personal transformation. To date, no other studies have been found to suggest other researchers have explored the narratives of mothers of former preterm infants now at preschool age, the meaning attributed to their mothering experience, or whether these mothers characterize their experience as transformative. How study participants frame their experience of being the mother a former preterm infant now at preschool age is key to understanding their narrative and the meaning(s) they attach to it.

Significance of the Study

If a woman has stressors related to her experience of being the adult mother of a former preterm infant now at preschool age, and if those stressors, through the lens of Transformative Learning Theory, are such that the mother's historically successful problem-solving strategies are ineffective in relieving and resolving them, this may signify that a disorienting dilemma is underway. Depending on a woman's personal context, factors may contribute to stalling or postponing dilemma resolution and movement forward toward restored personal well-being. Dwelling in the disorienting dilemma stage may endure, sustaining a mother's stress over time and increasing the risk for negatively influencing her health and well-being.

Individuals vary considerably in how they perceive and respond to stress (Lazarus & Folkman, 1984). One's genetic disposition, behavior, and experience during childhood and adulthood help to determine perception and response to stressful events. When stress accumulates over time, what McEwen (2001a) calls allostatic load, it can cause immunosuppression and organ

damage. Psychological factors as well as one's social environment can either relieve or worsen the burden of allostatic load (McEwen; Smyth, Stone, Hurewitz, & Kaell, 1999). The toll of maternal stress history has been demonstrated biologically. For instance, in a study of mothers (aged 29-55 years) of children with cancer, elevated allostatic load (based on a 10-indicator composite score of various biologic samples) was demonstrated in those with posttraumatic stress disorder symptoms compared to controls (Glover, Stuber, & Poland, 2006). Early postpartal exposure to the effects of maternal stress may serve as an epigenetic influence on a mother's offspring, effectively altering the offspring's phenotype and ultimately their health and well-being (Meaney & Szyf, 2005; Szyf, Weaver, & Meaney, 2007; Weaver, et al., 2004). Therefore, gaining a deeper understanding of stress as it relates to the experience of being the mother of a preschooler born preterm has the potential for not only influencing the immediate health of mother and her child but conceivably the health of future generations as well.

“Experience is meaningful and human behavior is generated from and informed by this meaningfulness...narrative...[is] the primary form by which human experience is made meaningful” (Polkinghorne, 1988, p. 1). Personal narratives or stories demonstrate the importance and relationship between life events (Polkinghorne). Sharing their personal narrative of being the mother of a preschooler born preterm and the meaning they attribute to that experience gave participants in this study an opportunity to share the truth of their experience; in other words, their storied truth (Duffy, 2007; Holloway & Freshwater, 2007). In the course of reflecting on and telling their story, there was opportunity for self-defining memories and the meaning attributed to those memories to change (Gaydos, 2005). Although the goal of this study was not to provide an intervention per se, the benefit for mothers to share their narratives is acknowledged (Charon, 2007; Gaydos; Holloway & Freshwater). It is reasonable to conclude that engaging in this process may have been therapeutic for the participants, particularly for those whose mothering experience

was stressful, thereby enhancing maternal health and well-being. This in turn has the potential to positively influence the relationship between the participant and her preschool child born preterm.

Mercer (2004) argues that while becoming a mother is a transforming experience for many women, the establishment of a maternal identity is not automatic. It is a process that includes successfully moving through a series of stages, each dependent on several factors including maternal, infant, and social contexts (Mercer, 2006). Becoming a mother is also a dynamic process, influenced by life transitions, such as one's child entering school. "The maternal persona continues to evolve as the child's developmental challenges and life's realities lead to disruptions in the mother's feelings of competence and self-confidence. ... '[B]ecoming a mother' ... [connotes] the initial transformation and continuing growth of the mother identity" (Mercer, 2004, p. 231). Given the potential for a wide array of challenges for mothers of preschoolers born preterm, this study lends insight into how participants' maternal persona has been influenced by and continues to evolve within their unique contexts.

The findings of this study have implications for nursing practice. Gaining a deeper understanding of the experiences of adult mothers of preschoolers born preterm and the meaning attributed to those experiences will enlighten nurses regarding how and to what degree these mothers' health and well-being may be affected as a result. Mothers' perceptions of the support they have been given as the mother of a preterm-born child are also instructive in terms of what specific forms of support nurses can provide. Narrative research is an appropriate vehicle for informing nursing practice since it reflects and "examines the process and product of nursing, suffering and caring in a meaningful way" (Holloway & Freshwater, 2007, p. 30).

Theoretical Definitions

Adult: at least 18 years old (U.S. Department of State, n.d.)

Preterm: synonymous with premature; prior to 37 weeks gestational age

(McCormick & Behrman, 2007)

Low birth weight (LBW): birth weight less than 2500 grams (Southgate & Pittard, 2001)

Very low birth weight (VLBW): birth weight less than 1500 grams (Southgate & Pittard)

Extremely low birth weight (ELBW): birth weight less than 1000 grams (Southgate & Pittard)

NICU: Neonatal Intensive Care Unit

Neonatal: the period of time surrounding the birth of a child, typically the first 4 weeks

Postpartum: after the birth; the period of time immediately following birth as it pertains to the mother, typically lasting 4-6 weeks; synonymous with postpartal

Health: "...dynamic life experiences of a human being, which implies continuous adjustment to stressors in the internal and external environment through optimum use of one's resources to achieve maximum potential for daily living" (King, 1981, p. 5)

Maternal context: features, unique to each mother, that describe and/or characterize her person (e.g., personality, educational level, cultural orientation, values, marital status, etc.)

Stress: The effects of physical and/or psychosocial environmental challenge (McEwen, 2001b)

Maternal-infant interaction: references the behaviors that reflect the bidirectional, emotional attachment relationship between mother and infant (Klaus, Kennell, & Klaus, 1995); this attachment relationship has 3 critical attributes: proximity, reciprocity, and commitment (Goulet, Bell, St-Cyr Tribble, Paul, & Lang, 1998).

Narrative inquiry: A mode of qualitative research used to gain understanding of the nature of and meaning derived from others' experiences, communicated via participants' stories (Duffy, 2007).

Reflection: A consecutive mode of thought that is linked to previous, immediate, and future ideas moving toward and culminating in an end point (Dewey, 1933).

Aesthetic knowing: A pattern of knowing that “involves the perception of abstracted particulars as distinguished from the recognition of abstracted universals. It is the knowing of a unique particular rather than an exemplary class” (Carper, 2004).

Assumptions

This study acknowledges the following assumptions:

- 1) Being the mother of a former preterm infant now at preschool age is different from being a mother of a former full-term infant now at preschool age.
- 2) Being the mother of a preschooler born preterm may entail multiple crises depending on the child's health and developmental status; these crises have the potential to suspend a mother's normal problem-solving and coping strategies.
- 3) Being the mother of a preschooler born preterm has the potential to influence the mother's overall well-being over time.
- 4) Adults' learning contexts are varied and include those which are formal or informal as well as those connected to personal experience.

Research Questions

The following research questions under girded this study:

- 1) How do participants depict what it is like to be the mother of a preschooler born preterm?
- 2) What role has a child's prematurity had in the life of her/his mother?
- 3) What meaning do participants derive from or attribute to being the mother of a former preterm infant now at preschool age?
- 4) What kinds of support do participants identify as having been most/least helpful to them as mothers of former preterm infants now at preschool age?

Chapter Summary

Many researchers have studied mothers during the months following a preterm birth but little is known about the mothers' experiences beyond the first postpartal year. Therefore more needs to be understood regarding women's experience of being the mother of a former preterm infant now at preschool age and the meaning they attribute to that experience. Transformative Learning Theory, which centers on the life experiences of adults and the potential for fundamental change (transformation) life experiences can produce, is the theoretical perspective informing this study. This study is significant in that the findings will serve to inform healthcare providers regarding how participants depict the experience of being the mother of a preschooler born preterm, the meaning mothers' attribute to the experience, and the possible implications for maternal (and indirectly, child) health related to it.

Chapter 2

Review of the Literature

The purpose of this research study is to explore the personal narratives of mothers of former preterm infants now at preschool age, to better understand the meaning these mothers attribute to their experience. This chapter reviews literature pertinent to the research topic including a conceptual discussion regarding what is known about the experience of giving birth to and being the mother of a child born preterm. In addition, the theoretical perspective selected for this study that informs an understanding of the phenomenon of being the mother of a preschooler born preterm is presented.

The primary vehicles for the literature search were the electronic databases PubMed, ProQuest (Multiple Database), and ERIC with English, humans, and scholarly journals limits employed for each; the electronic database PsychInfo (limits being English, female, adulthood) was also searched. A variety of terms and phrases were used in searching these electronic databases. PubMed MeSH terms included infant, premature; mothers; premature birth; object attachment; parent-child relations; and narration. In addition, hand-searches were conducted, culling pertinent sources from reference lists of choice journal articles and books.

Conceptual Discussion: The Preterm Experience

The Infant's Preterm Experience: An Untimely Birth

Preterm birth, from a developmental view, is an untimely birth. The infant has entered the extra-uterine environment too early and as such, is uniquely vulnerable physiologically

(Gluckman, Cutfield, Hofman, & Hanson, 2005). Given their physiologic immaturity, even simple physiologic tasks such as temperature regulation are challenging for the preterm infant and require the support of temperature controlled incubators or warmers (Bialoskurski, Cox, & Hayes, 1999). Basic life support measures for the most medically stable preterm infants must be available for preterm infants, from supplemental oxygen (Martin, Sosenko, & Bancalari, 2001) to intravenous or naso-gastric forms of fluid and nutrition (Kalhan & Price, 2001). Naturally, should an infant's medical status deteriorate the level of intensive intervention and care needed to restore and sustain the infant's health would substantially increase beyond these basic measures.

Birth weight and gestational age are indicators of the degree of physiologic maturity of an infant. Since there is an inverse relationship between birth-weight and associated morbidity and mortality, the lower an infant's birth-weight, the higher an infant's chance for untoward health outcomes. Preterm infants who are very low birth weight (VLBW) are at an increased risk for adverse health outcomes in the short- and long-run, being more susceptible to infections (Baley & Goldfarb, 2001; O'Donnell & Merenstein, 1993), developmental disabilities (Van Baar et al., 2005), and endocrine disorders (Cutfield et al., 2004).

Typically preterm infants are admitted to the NICU immediately after birth. While the modern NICU is designed and equipped to provide the highest level of medical and nursing intervention and care for preterm infants, unfortunately that same environment has the potential for introducing sensory over-stimulation, a source of stress for these vulnerable children (Gardner, Garland, Merenstein, & Lubchenco, 1993). Due to regulatory immaturity (Klaus & Fanaroff, 2001; Levy, Woolston, & Browne, 2003), a preterm infant's exposure to stressors is known to induce physiologic instability (Annibale & Hill, 2006; Lou, Lassen, Friis-Hansen, 1979) which can have deleterious effects in the short-run including increased respiratory workload (Hagedorn, Gardner, & Abman, 1993). This can increase the severity of existing respiratory problems such as bronchopulmonary dysplasia, a chronic condition characterized by

lung inflammation and scarring common in preterm infants (Hagedorn et al.). Activities that increase respiratory workload also impact cerebral blood flow; this in turn can contribute to the formation of intra-ventricular (cranial) hemorrhages (Anand, 1998; Annibale & Hill; Gardner, 2005; Minarcik & Beachy, 1993). These hemorrhages can lead to marked disability such as cerebral palsy and developmental delay (Anand; Annibale & Hill). In addition, altered respiratory function can adversely impact infants' immune system leading to an increased susceptibility to infections such as pneumonia and necrotizing enterocolitis (Baley & Goldfarb, 2001).

Some researchers suggest that preterm infants' exposure to stress has the potential to permanently alter their autonomic nervous system stress response patterns (Phillips, 2007; Phillips & Jones, 2006), an effect sustained in adulthood. The development of adult-onset diseases such as hypertension and insulin resistance has been linked to preterm birth (Dalziel, Parag, Rodgers, & Harding, 2007; Gluckman et al., 2005). Clearly, whether immediately post-birth or for decades to come, the potential for untoward health outcomes is a reality for one born preterm.

The Mother's Preterm Experience: The Neonatal Period

The anticipation of birth and transition to motherhood is wrought with the hope that the event will be a smooth and healthy one. However, the realities of a preterm birth present a sharp contrast to that picture, distinctly different from the realities of a full-term birth. When a preterm birth occurs, it comes at a time that is typically unexpected and is often urgent in nature. As such, mothers faced with preterm birth usually have little or no time to prepare for it. For the woman giving birth to a preterm infant the transition to motherhood is more complicated (Flacking, Ewald, & Starrin, 2007; Jackson, Ternstedt, & Schollin, 2003; Shin & White-Traut, 2007), compounded by uncertainty regarding not only whether or not the baby will survive, but if she/he

does, what the extent of their health needs will be for the short- and long-term. Instead of mother and baby arriving home together at the expected time, baby remains hospitalized for an indeterminate amount of time and with an unknown health trajectory. Scientific literature makes clear that the entire neonatal period (including the birth event) is not merely unexpected or too early; rather, it is consistently depicted as a trauma or crisis (Affleck, Tennen, & Rowe, 1991; Als, 1986; Beck, 2004, 2006; Eriksson & Pehrsson, 2002; Jotzo & Poets, 2005; Kersting, et al., 2004; Libera, Darmochwal-Kolarz, & Oleszczuk, 2007; Reid, 2000; Roller, 2005; Shaw et al., 2006).

Given the traumatic nature of a preterm birth, it is a source of significant stress for the mother. The stress the mother experiences stems from a variety of issues, many related to the abrupt nature of the birth, made manifest in a variety of emotions. These emotions are best understood against the back-drop that a preterm mother's expectations of and hopes for a normal pregnancy, birth, infant, and motherhood are often suspended if not dashed completely (Affleck et al., 1991). Preterm mothers' emotions include anger, shock, uncertainty, denial, and a sense of being numb (Affleck et al.).

When compared to mothers of full-term infants, mothers of preterm infants have more negative emotions very early in the postpartum period (while still hospitalized) such as anxiety, depression, helplessness, guilt, and fear regarding the infant's health (Libera et al., 2007). In comparison to both full-term and near-term mothers, preterm mothers have been found to score significantly lower ($p < .0001$) in the psychological/baby domain of the Maternal Postpartum Quality of Life (MAPP-QOL) instrument early in the postpartum period, at 1 and 3 weeks (Hill & Aldag, 2007). This domain of the MAPP-QOL addresses 8 items including amount of perceived control in one's life, happiness, peace, and life worries as well as perceived infant health; scores reflect both satisfaction and importance per item (Ferrans & Powers, 1985). Mothers of high- and low-risk VLBW preterm infants (i.e., infants with and without bronchopulmonary dysplasia,

respectively) were found to have significantly more global psychological distress symptoms than mothers of full term infants 1 month postpartum ($p < .005$ and $p < .05$, respectively) (Singer et al., 2003). Similarly, 39% of mothers of high-risk preterm infants and 21% of mothers of low-risk preterm infants scored positively for post-traumatic stress syndrome symptoms as compared to only 4% of full term mothers (Muller-Nix et al., 2004). In that study, infant risk was determined by the 18-item Perinatal Risk Inventory which addresses a variety of perinatal health factors such as Apgar scores, gestational age, and need for ventilation; the Perinatal Posttraumatic Stress Disorder Questionnaire (administered retrospectively at infants' 18 month corrected age) was used to assess mothers' perceptions of their immediate neonatal period and what post-traumatic stress disorder symptoms endured beyond one month.

The neonatal period is also a time during which mothers of preterm infants can experience other distressing psychological symptoms. For instance, self-reports of high stress in mothers whose infants were born less than 32 weeks gestational age have been found to have, at one month postpartum, a statistically significant ($p < 0.01$) increase in their chance of having symptoms of depression compared to population norms (Davis, Edwards, Mohay, & Wollin, 2003). At one month postpartum, mothers of both high- and low-risk VLBW preterm infants have been found to report more depression, anxiety, poor mental concentration, indecision, and obsessive-compulsive behaviors compared to mothers of full-term infants (Singer et al., 1999). The same study's findings also revealed that among the mothers of VLBW infants, the greater the infant's medical risk, the more severe the mothers' distressing psychological symptoms. These findings are supported by Elklit and colleagues who found that factors contributing to the psychological distress of parents of VLBW and extremely low birth weight (ELBW) preterm infants during the neonatal period include the infant's physical status and periods of grave illness for the infant (Elklit et al., 2007). Preterm infants' appearance (Fowlie & McHaffie, 2004) and

behavior are also sources of stress for their mothers (Miles, Burchinal, Holditch-Davis, Brunssen, & Wilson, 2002).

Maternal feelings of loss and grief often accompany the preterm neonatal experience (Jackson et al., 2003). Sometimes mothers of preterm infants experience anticipatory grief related to the uncertainties associated with preterm birth causing the mother to avoid becoming attached to their infant out of fear of possible loss (Schenk, Kelley, & Schenk, 2005). For some mothers feelings of loss and grief are confusing and hard to communicate to others. Grief over not only the loss of a normal pregnancy but also the potential loss of a normal child are compounded by the simultaneous emotion of joy that despite everything, their baby is alive, a challenging phenomenon that Golish and Powell term *ambiguous loss* (2003). If others fail to understand these conflicting emotions, many mothers opt to say nothing, and instead suffer with their feelings in silence, adding to their load of stress (Golish & Powell). Cultural, social, and religious beliefs regarding preterm birth influence mothers' perceptions and emotions (Fowlie & McHaffie, 2004; Shin & White-Traut, 2007) and can inhibit the preterm mother from talking about them, particularly if her emotions are negative (Lee et al., 2005).

Unfortunately, visiting the NICU to see their preterm infant may induce additional emotional problems for the preterm mother. Contemporary NICU environments are high-tech, public, and described by some as tense, hostile, and alien (Siegel, Gardner, & Merenstein, 1993; Affleck et al., 1991). The NICU's physical environment is typically unfamiliar, frightening, and stressful for preterm mothers (Affleck et al.; Miles et al., 2002). The NICU environment is often perceived as an overwhelming. Affleck and colleagues (1991) shed light on this with how some mothers describe their perceptions of the NICU environment:

The unit was overwhelming because of all the equipment needed to keep the babies alive. It made us see our baby as so fragile that we hesitated to touch her for the longest time.

When you walk into the unit it's like walking into an iron lung. You have trouble breathing. It's like being in an *Alice in Wonderland* nightmare. It's a strange world, with its own atmosphere, different even from the rest of the hospital. The reality is that babies are dying here, but you can't cope with that....

That whole place is very scary and crazy. There's nothing normal about it, nothing at all.

(p. 5)

The NICU can also be a source of information overload for preterm mothers, compounded in the early postpartum period when mothers' mental concentration is not optimal (Eidelman et al., 1993; Stark, 2000).

NICU nurses' behavior and interaction may adversely affect the preterm mother, further compounding her stress. NICU nurses, empowered by their specialized knowledge regarding the care of preterm infants, are often perceived by mothers as the legitimate experts and caregivers of their newborn; NICU nurses view themselves in that way as well (Fenwick, Barclay, & Schmied, 2001; Roller, 2005). Unless the NICU nurse purposefully welcomes the mother as a care-partner she may feel too intimidated by the nurse's knowledge and ease with her infant to participate in infant care (Feeley, Gottlieb, & Zerkowitz, 2007; Jackson et al., 2003). Due to their responsibilities of caring for preterm infant patients, NICU nurses may appear protective and possessive, guarding against those who seek access to the infant, including the infant's mother (Fenwick et al.). This protectiveness is warranted in part due to nurses' legal, ethical and professional liability concerns but it can have a negative effect on a preterm infant's mother. Mothers of preterm infants may feel unwelcome when visiting their infant, that their presence in the NICU is seen as an intrusion (Jackson et al.).

Not surprising, attaining a maternal role is often delayed for preterm mothers, something that is yet another source of distress for them and that often requires a degree of negotiation with NICU nurses in order to be successful (MacDonald, 2007; Shin & White-Traut, 2007). Preterm

mothers value collaborative interactions with NICU nurses (Jones, Woodhouse, & Rowe, 2007). But if there is a power struggle between nurse and mother regarding care of the infant or if mothers do not feel emotionally safe and supported in their relationship with NICU nurses, mothers feel frustration and powerless (Fenwick et al., 2001; Heermann, Wilson, & Wilhelm, 2005). Under such circumstances mothers are compelled to limit their presence in the NICU or leave altogether (Hurst, 2001).

The Mother's Preterm Experience: Beyond the Neonatal Period

Lingering effects of maternal stress induced during the neonatal period are indicated in the literature. Symptoms consistent with post-traumatic stress disorder have been noted in some mothers who have had a preterm neonatal experience, including re-experiencing, avoidance, and heightened arousal, enduring at least to the infants' 6 months adjusted age (Holditch-Davis, Bartlett, et al., 2003). In a prospective longitudinal study exploring the post-traumatic stress responses of mothers of VLBW preterm infants, preterm mothers reported experiencing significantly higher post-traumatic response symptoms at 1-3 days, 2 weeks, 6 months, and 14 months postpartum as compared to mothers of full term infants (Kersting et al., 2004). For mothers describing their traumatic birth experiences (including preterm births) post-traumatic stress disorder symptoms have been found to be particularly problematic on the anniversaries of the birth and for some women the symptoms remain acute for many years postpartum (Beck, 2006). In light of the findings from this study, it is conceivable that memories of a traumatic preterm birth could last up until and beyond the child reaching preschool age.

Although not every preterm mother's reported or observed stress symptoms will be consistent with post-traumatic stress disorder, having access to psychosocial support appears to remain important to mothers often years after a preterm birth. For example, in a study exploring

the psychosocial needs of parents of preterm, ELBW-VLBW infants 2 to 8 years post-birth, nearly a third of the participants reported the need for long-term psychological support (Eriksson & Pehrsson, 2002), a clear indication that such support is needed into the child's early school-age years. In addition, interviews with Korean mothers of preterm infants revealed the need for culturally sensitive emotional support that extends beyond the transition-to-home period, particularly if the child has serious health issues (Lee et al., 2005).

As demonstrated, the literature is replete with examples of the preterm neonatal experience as stressful and traumatic for a preterm mother, yet some women may not appraise it as such. Ayers (2007) studied the thoughts and emotions of mothers during and after full-term birth and found that some but not all of the women developed post-traumatic stress symptoms after birth. Even though Ayers' study did not address preterm births, the point is well taken that individual differences exist and not every woman with a potentially traumatic neonatal experience will perceive it that way; some may be equipped with unusual strengths or abilities to effectively cope with such experiences, limiting any negative effects. These findings are consistent with an earlier cross-sectional study by Wijma and colleagues investigating the occurrence of postpartum post-traumatic stress disorder symptoms. Unfortunately, that study did not clarify how many of its 1640 participants experienced a preterm birth but of the sample, 28 women (1.7%) met the criteria for having a post-traumatic stress profile in relation to their most recent delivery (Wijma, Soderquist, & Wijma, 1997). That study also highlighted the fact that birth is not an event in isolation; multiple factors in a mother's personal context may contribute to how she appraises it, including one's cultural orientation (Lee et al., 2005).

Chronic Maternal Stress

Maternal contextual features. For the purpose of this study, the personal narratives of adult (versus adolescent) mothers of former preterm infants now at preschool age were explored. An adult mother brings her own context to the preterm mothering experience. She is not simply the mother of a child born preterm; rather, she is an individual woman who has amassed many years of personal history, the context and details of which have brought her to that given point in time. Her unique cognitive development, emotional status, physical health, spiritual proclivity, educational level, socio-economic status, cultural orientation, temperament, personality, attitudes, values, fears, hopes, dreams, and memories, not to mention her genetic phenotype, contribute to who she is and what she has experienced as a human being. Other contextual features also pertinent to the narratives of mothers of preschoolers born preterm include a mother's coping style and sense of coherence (Libera et al., 2007), her perceptions of birth reality compared to her expectations (Beck, 2004; MacDonald, 2007), her perceptions of the type and degree of support given during and after birth from significant others and healthcare personnel (Cigoli, Gilli, & Saita, 2006), and cultural norms that influence maternal thoughts and feelings (Lee et al., 2005).

Maternal personal characteristics can influence how a mother of preschoolers born preterm perceives and deals with stress. In a study exploring personal distress and growth in mothers of medically fragile infants (67% preterm), maternal characteristics such as education, sense of mastery, family satisfaction, and perceptions regarding their infant's illness were found to impact maternal distress (Miles, Holditch-Davis, Burchinal, & Nelson, 1999). Temperament and personality style can also influence how a mother appraises and responds to stress surrounding the experience of being the mother of a preschooler born preterm. While exploring every aspect of one's personal context is not feasible, participants in this study revealed the personal context features they feel have been salient to their mothering experience and which

ones contributed or attenuated the stress often associated with being the mother of a preschooler born preterm.

Maternal health and well-being. Although scientific literature does not clearly indicate the specific effects of being the mother of a preschooler born preterm on maternal health outcomes, literature is replete regarding the effect of stress on one's health in general. Chronic stress has been clearly implicated in alterations in immune system regulation. This immune system dysregulation is the result of disruptions between the otherwise functional connections linking the central nervous, immune, and endocrine systems. These disruptions are induced by psychological stress and result in a variety of health problems including delayed wound healing, prolonged recovery from infections, decreased response to vaccines, recurrent viral infections, and cancerous tumor growth. In addition, research indicates that the trajectory and time interval involved in chronic psychological stress plays an important role in the kind of immune system changes and resulting health outcomes that can occur (Godbout & Glaser, 2006).

The impact of chronic stress on the health and well-being of mothers of preschoolers born preterm is not clear. In a study exploring the stress and coping of mothers of 8 year-old, former VLBW (low-risk and high-risk) preterm infants compared to former full term infants, personal maternal health issues explored were limited to those related to psychological distress and coping mechanisms (Singer et al., 2007). Nevertheless, this study discovered that mothers of former VLBW infants reported less harmony with life partners, less conflict with their VLBW child, and greater unease regarding the child's health. In addition, mothers of former high-risk VLBW infants reported the highest degree of family and personal strain among the groups studied. While these findings add insight to parenting former VLBW infants at school age, they are not explicit with regard to the impact of chronic stress on a mother's overall health and well-being.

Depending on the infant's level of medical risk during the neonatal period and resulting sequelae

in the following years, a child's enduring status as preterm may serve to chronically reinforce the mother's psychological distress first experienced during the neonatal period (Elklit et al., 2007). Such distress, including the potential burden of silence, may serve to further hinder a mother's movement toward improved psychosocial functioning.

Child behavior, family function, and demands placed on the caregivers of children (mean age, 10.6 years) with cerebral palsy were identified as factors strongly influencing both the psychological and physical health of the children's caregivers, most of whom were their mothers (Raina et al., 2005). In this study, caregiver self-perception and effective stress management strategies were related to their enhanced psychological health. Unfortunately, the study did not indicate how many of the children with cerebral palsy were born preterm; however, given the risk of developmental disability including cerebral palsy with preterm birth, it would be reasonable to conclude that many of the 468 participants were caregivers of former preterm infants. Therefore, the findings in this study that suggest that the chronic, daily caregiver demands associated with caring for a child with cerebral palsy may influence the caregiver's health and well-being, may also apply to mothers of preterm infants.

Maternal-Infant Attachment/Interaction

The mother-infant separation necessitated and sustained by the preterm infant's admission to the NICU post-birth delays the initiation of maternal-infant attachment or interaction. Few would argue that high-tech NICU physical care is a necessary ingredient for preterm infants' survival; however an infant's emotional connection to those in her/his environment is also an important contributor to their overall health and development. Under ideal circumstances this connection is formed between an infant and her/his parent(s). The bi-directionality of the complex, binding emotional relationship that takes place between parent and

infant is captured in the phrase, *parent-infant attachment* (Klaus et al., 1995). Goulet and colleagues identified critical attributes of parent-infant attachment in their concept analysis: *proximity* (being close to the infant physically and psychologically), *reciprocity* (whereby the infant elicits parental response), and *commitment* (pertaining to the enduring relationship between parent and child) (Goulet et al., 1998).

Immediately after the birth, the physical survival of the preterm infant is paramount. Attachment opportunities will be sacrificed if necessary in favor of stabilizing the infant's health in the NICU (D'Harlingue & Durand, 2001). Once in the NICU, if the infant is undergoing a procedure or is surrounded by life-sustaining equipment, the mother's personal contact with her infant may be unavoidably limited.

The sensory environment of the modern NICU may further thwart maternal-infant attachment efforts during the neonatal period. Auditory stimuli have been documented as particularly problematic (Bremmer, Byers, & Kiehl, 2003; Byers, Waugh, & Lowman, 2006; Catlett & Holditch-Davis, 1990; Krueger, Wall, Parker, & Nealis, 2005). NICU sound levels are typically in excess of the U.S. Environmental Protection Agency's and American Academy of Pediatrician's recommended decibel level (< 45 dB) for the acceptable day-time average sound level for hospitals (American Academy of Pediatrics, 1997; U.S. Environmental Protection Agency, 1974). Multiple sources of sound contribute to these excessive sound levels, including equipment/monitor alarms, running water, drawers closing (DePaul & Chambers, 1995), communication devices, verbal communication, music (Brandon, Ryan, & Barnes, 2007), use of supplies and infants crying (Trapanotto, Benini, Gobber, Magnavita, & Zacchello, 2004). Amidst such stimuli, a mother's voice may be lost. For a mother wishing to begin or further cultivate the attachment process by speaking to her infant, the elevated sound levels in the NICU can be a daunting and frustrating obstacle, yet another source of distress for the preterm mother.

The preterm infant's medical status determines to a large extent how and when a mother and her infant can engage in attachment behaviors, not only during the immediate neonatal period in the NICU but after discharge as well. For instance, the medical status of an infant was found to have more impact on the degree and kind of maternal-infant interaction than an infant's gestational age at birth (preterm or full term) alone when maternal-infant dyads were observed interacting at 6 months adjusted age (Holditch-Davis, Cox, Miles, & Belyea, 2003). Similarly, greater maternal involvement has been noted in mothers of sicker preterm infants (Holditch-Davis, Schwartz, Black, & Scher, 2007) at 6 and 18 months.

The traumatic nature of a preterm birth along with maternal psychological and physical co-morbidities (Bialoskurski et al., 1999; Fowlie & McHaffie, 2004) have the potential to impact a mother's capacity to interact with her infant, contributing to her attachment starting point (Fegran, Helseth, & Fagermoen, 2008). Maternal depression has been found to be correlated to a mother's perceived stress level; in turn depression increases a mother's vulnerability, making it harder to deal with the stresses of a preterm birth and impacting both her readiness to engage and her level of engagement in attachment behaviors (Davis et al., 2003; Feldman, Weller, Leckman, Kuint, & Eidelman, 1999; Miles, Holditch-Davis, Schwartz, & Scher, 2007; Poehlmann & Fiese, 2001). There is substantial evidence to suggest that maternal contextual features such as a mother's thoughts, feelings, and personal characteristics also influence the quality of maternal-infant interaction which in turn impacts infant cognitive and physical health outcomes (Egeland & Farber, 1984; Feldman et al., 1999; Josefsson, Larsson, Sydsjo, & Nylander, 2007; Leckman et al., 2005; Magill-Evans, Harrison, & Burke, 1999; Mantymaa et al., 2003; Muller-Nix et al., 2004).

Factors informing maternal-infant attachment/interaction have the potential to influence maternal parenting style. Due to having been born preterm some mothers hold an enduring view of their children as being simultaneously special, normal, and vulnerable, a view which impacts

parenting style into and conceivably beyond the child's preschool years. For instance, *compensatory parenting* was identified among mothers of 3 year old children born preterm (Miles & Holditch-Davis, 1995). In that study this parenting style is described as one in which mothers "provided special experiences and avoided other experiences in an attempt to compensate the children for their neonatal experiences" (p. 246). Specifically, *compensatory parenting* included over-protection, over-stimulation, over-attention, and a lack of limit setting. Factors that influenced the development of this parenting style included pregnancy complications, negative NICU-related memories (and the distress associated with those memories), and health problems of the child in the intervening years.

The enduring maternal perception of the vulnerability of their child born preterm has contributed to the recognition of the Vulnerable Child Syndrome. This syndrome refers to healthy children who have recovered from a life-threatening event, whose parents view them as medically or developmentally vulnerable, and whose parents engage in a maladaptive parenting style (Culley, Perrin, & Chaberski, 1989). One of the features of the Vulnerable Child Syndrome is parental overprotectiveness (Lamb, 2002). Culley and colleagues (1989) examined predictors of the Vulnerable Child Syndrome with a sample of preterm and full term 3 year old children and their mothers; a child's preterm status was found to be the strongest predictor. Maternal experiential and developmental factors influence the risk of the Vulnerable Child Syndrome. Children born preterm whose mothers have higher levels of education and income, are single and primigravid are at increased risk for Vulnerable Child Syndrome (Miller, 1993). This syndrome has been found to be associated with unfavorable developmental outcomes in children born preterm, specifically in relation to adaptive and motor functioning (Allen et al., 2004) as well as aggressive behavior and being socially inhibited (Estroff, Yando, Burke, & Snyder, 1994).

Clearly, characteristics and context of both mother and infant contribute to the quality of maternal-infant attachment/interaction and the synergistic relationship that is formed. Chronic

maternal stress first introduced during the neonatal period may further impair the quality of the maternal-preterm-born child relationship. While the focus of this study is on the narratives of mothers of former preterm infants now at preschool age, it appears that those whose primary interest is maternal-child interaction would also find value in exploring in a deeper way, features of the mother's experience that may influence that interaction. Without addressing a mother's experience, attempts to fully understand why a mother thinks about or behaves toward her preschooler born preterm as she does would yield at best, speculative results.

Theoretical Discussion

The theoretical perspective selected in order to guide the interpretation of what it is like to be the mother of a former preterm infant now at preschool age is Transformative Learning Theory. With the increasingly inter-disciplinary focus within graduate level nursing education and nursing research, the utilization of this adult education theory when exploring the nursing phenomenon currently under study is both appropriate and timely. Transformative Learning Theory is presented and evaluated regarding its overall fit with the experience of being the mother of a preschooler born preterm.

Transformative Learning Theory (Mezirow, 2003), originally developed in 1978 by Jack Mezirow, is concerned with fundamental change in how one sees themselves and their world. A prominent theory in adult education, Transformative (or Transformational) Learning Theory addresses more than the acquisition of knowledge; it is centered on the life experiences of adults, one's interpretation of those experiences and the resulting new or revised meaning derived from them. As a learning theory, cognition takes center-stage yet not at the expense of other ways of knowing such as the affective and aesthetic (Mezirow, 2000). Change resulting from a transformative learning experience is not merely adaptation to an altered environment or to a

novel circumstance. Rather, the change is so personally profound that one is “never the same again” (P. Cranton, personal communication, September 14, 2006); as one looks back, prior to the transformative experience one can say, “I was a different person then” (Cranton, 2006, p.71).

Transformative learning is “learning that transforms problematic frames of reference – sets of fixed assumptions and expectations...– to make them [frames of reference] more inclusive, discriminating, open, reflective, and emotionally able to change” (Mezirow, 2003, p. 58). It is through *frames of reference* one filters sensory experience through cognitive, affective, and conative domains. Frames of reference give context for meaning-making (Mezirow, 2000). Many frames of reference are taken-for-granted and include those related to interpersonal relationships, political views, stereotypical attitudes, moral-ethical norms, religious beliefs, occupational mindsets, and cultural bias (Mezirow, 2003).

Assumptions inform frames of reference and construct a means for understanding life experience (Mezirow, 1997a). Assumptions form a set of codes taken from various areas of experience in one’s life including the ethical, psychological, spiritual, political, cultural, economic, and scientific. In turn, a set of codes influences the two components of a frame of reference, that is, *habits of mind* and *points of view*. Habits of mind (habitual thoughts, feelings, and actions) are manifest in a variety of ways including the socio-linguistic, ethical, epistemic, philosophical, psychological, and aesthetic. Points of view (or the collection of beliefs, value judgments, attitudes, and emotions that interpret a given subject) articulate habits of mind, determining how we see ourselves and the world, often operating outside immediate awareness (Mezirow, 1997a; Mezirow, 1998; Mezirow, 2000). Habits of mind and points of view are closely linked to one’s self-concept; therefore the changes in both that come about through transformative learning alter by necessity, one’s self-perception (Cranton, 2006).

Integral to transformative learning is critical reflection (Mezirow, 2003). *Reflection* alone has various meanings, from basic awareness of an event, perceptions or thoughts, to one

considering options in the process of making a decision (Mezirow, 1998). However reflection with regard to transformative learning requires a deeper understanding of the term. Reflection is not merely a sequence of ideas, rather it entails

a *con*-sequence – a consecutive ordering in such a way that each [idea] determines the next as its proper outcome, while each outcome in turn leans back on, or refers to, its predecessors. The successive portions of a reflective thought grow out of one another and support one another; they do not come and go in a medley. Each phase is a step from something to something...[t]here are in any reflective thought definite units that are linked together so that there is a sustained movement to a common end (Dewey, 1933, p. 4-5).

Dewey, in his seminal work, *How We Think: A Restatement of the Relation of Reflective Thinking to the Educative Process* (1933), adds that reflective thought is a conscious, purposeful cognitive activity that seeks to establish a degree of evidence to support a belief or accepted form of knowledge, through inquiry and scrutiny; believing or accepting the supposed knowledge comes only after some means of justification.

Reflective thinking involves two phases, the first being a state of doubt, uncertainty, hesitation, or perplexity, often occurring abruptly and unexpectedly, when one is presented with a *dilemma* (Dewey, 1933). Transformative Learning Theory terms this experience as the *disorienting dilemma*. A disorienting dilemma is perceived as a life crisis, such as the loss of a job, the death of a loved one, or the loss of a normal pregnancy. It can also be an event that initially, on the surface, may appear relatively benign such as an unexpected or unwelcome question. The crisis event is such that previously familiar problem-solving or coping strategies are found to be no longer reliable or effective. At this point the individual undergoes self-examination which includes one to critically assess held assumptions which then leads to the recognition that others have experienced a similar process (Cranton, 2002; Merriam & Caffarella,

1999). The disorienting dilemma is the trigger that initiates reflective thinking; in the absence of such a dilemma there is no cause for reflective thinking (Dewey).

The second phase in reflective thinking is portrayed by active and scrutinizing inquiry, in an attempt to discover resources that will best resolve the dilemma. According to Dewey, “[d]emand for the solution of a perplexity is the steadying and guiding factor in the entire process of reflection” (1933, p.14), therefore, one could argue that without reflective thinking, the disorienting dilemma could persist indefinitely. In Transformative Learning Theory the second phase in reflective thinking incorporates two steps, identified as *exploring options* (including the creation of new roles, relationships, or actions), leading to constructing a *plan of action*. Finally, having gone through these steps, Transformative Learning Theory suggests that one experiences “a *reintegration* back into ones’ life” (Merriam & Caffarella, 1999, p. 321), having had one’s perspectives transformed.

Reflection in and of itself does not imply assessing or judging the object of the reflection and in this way is distinct from *critical reflection*. Critical reflection is either implicit or explicit, depending on whether choices made are due to the automatic employ of one’s assimilated values (habits of mind) or due to conscious awareness of the reasons behind the choices. When one reflects upon an assumption, the potential for frame of reference change is increased. Critically examining an assumption that one has identified as problematic for oneself entails *critical self-reflection*. The outcome of such reflection can be important personal transformation (Mezirow, 1998).

In addition to critical reflection and critical self-reflection, transformative learning entails “discourse to validate the critically reflective insight” (Mezirow, 1997b, ¶2). Discourse is not merely discussion but rather a special kind of dialogue where participants seek common understanding of the justification for a particular belief. Discourse is an important facet of transformative learning in that it provides a unique process in which “active dialogue with others

to better understand the meaning of an experience” (Mezirow, 2000, p.14) takes place. Such relational communication, reflected in listening to others’ perspectives, often via stories, as well as the telling of one’s own perspectives and stories, has been identified as an important vehicle through which women resolve conflicts and dilemmas (Gilligan, 1993).

There are conditions for discourse which help to create a safe environment for participants engaging in this kind of communication (Mezirow, 2000). These conditions are not presented in any particular order of significance since all are instrumental to successful discourse. For instance, participants seek to examine complete sets of evidence for a given position, including alternate perspectives. Participants must be willing to critically assess one’s assumptions and must have a measure of emotional intelligence and maturity. There needs to be acknowledged feelings of trust, security, empathy, and open-mindedness among the participants as well as a lack of both coercion and distorted views. Participants need to possess an awareness of the context behind the ideas expressed and a willingness to promote and engage in consensus. While these conditions are admittedly ideal they provide a guide to design opportunities for those who participate in discourse to better understand their own life experience and the experiences of others, thus enhancing the potential for transformative learning. In order “[t]o assess and fully understand the way others interpret experience requires discourse, and to understand and assess the reasons for their beliefs and understandings requires the ability to become critically reflective of their assumptions and our own” (Mezirow, 2000, p. 15).

Not every adult is equipped to participate at this level of discourse. For instance, Belenky and colleagues (1996, as cited in Belenky & Stanton, 2000) found that in their study, *Women’s Ways of Knowing*, some women’s style of knowing is best described as “silenced.” These women, who live in deep isolation, are “[u]nable to give words to what they know...[they] think of themselves as voiceless. They also find it difficult to acquire new understandings by listening to what others might have to say...[they feel] incapable of both hearing and speaking” (Belenky &

Stanton, 2000, p. 82). For such women, being part of a safe and caring environment that fosters dialogue may be necessary before they can engage in the kind of discourse Mezirow suggests (Belenky & Stanton). For other adults, the collaboration experienced in dialogue or discourse may not be necessary for critical reflection of assumptions (Mezirow, 1998) or subsequent transformation to occur (Cranton, 2006).

The product of transformative learning is revised assumptions or perspectives. However transformative learning is not complete until one has acted in accordance with those revisions. One's thinking, talking, and behaviors need to display congruence with the transformed assumptions or perspectives (Cranton, 2002; Mezirow, 1997b). One way to initiate this is to formulate a course of action. Others may need to acquire new knowledge or skills in order to implement the planned action. Acting in line with one's transformation may mean seeking opportunities where trial-runs in new roles are attempted. As competence and self-confidence in the new roles are built, the new assumptions or perspectives can be integrated into one's life (Mezirow, 2000).

Transformative Learning Theory fits within the larger framework of Habermas' theory which suggests three kinds of knowledge: instrumental, communicative, and emancipatory. Instrumental knowledge is objective, cause-and-effect knowledge while communicative knowledge involves understanding ourselves as well as others, within known social norms, through language. Emancipatory knowledge is the knowledge born of self-awareness and is the result of both critical reflection and critical self-reflection. All three forms of knowledge are useful to adults, but only emancipatory knowledge can provide hope for transformation; it has the power to release constraints (Cranton, 2002).

The complexion of Transformative Learning Theory has changed somewhat over the years, incorporating a more holistic view of transformative learning, to include ways of knowing beyond merely the rational or cognitive. For example, Dirkx advocates for the need to

acknowledge not only the personal aspect of transformative learning but the sociocultural as well, recognizing that domains other than the cognitive play a role: “[w]hile at once personal, it [transformative learning] is also deeply social and engages the learner in collaborative relationships with others....developing awareness of these relationships involves cognitive, affective, somatic, and spiritual processes, mediated by reflective analysis, story, symbol, or ritual” (Dirkx, 2006, p.19). Dirkx goes on to explain that emotions play a key role in the process of critical reflection, that such inner work is often accompanied by a host of emotions including guilt, fear, anxiety, shame or sense of loss. Too, one’s unconscious emotions related to a learning experience may seek and eventually find voice within that context. As important as emotions are to critical reflection, an appropriate media for the expression and understanding of emotions may be found in image-communication versus the verbal or written language commonly used with cognitive aspects of critical reflection (Dirkx). Others embrace an integrated approach to transformative learning which sees the virtue of both the rational/cognitive and the extrarational/imaginative perspectives at work instead of an either/or approach (Cranton & Roy, 2003).

For this study, how participants depict their experiences of being the mother of a preschooler born preterm and what salient contextual features are associated with those experiences were of interest. For some of the participants, a preterm birth and the ongoing care of a former preterm infant stimulated change in their personal perspectives. Each participant’s narrative revealed the woman’s personal level of engagement in reflection regarding her experience; for those engaged in reflection, the narratives also revealed how a participant’s perspectives were revised and integrated into her life. Such integration is evidence that fundamental change or transformation has taken place.

Transformative Learning Theory principles can provide a base from which nurses can lend support to mothers of preschoolers born preterm. Nurses can facilitate discourse with these

mothers, to elicit their thoughts regarding their mothering experience, providing them the opportunity to speak-out about their experience (Als, 1986; Sankey & Brennan, 2001) and the attributed meaning. Nurses' awareness of the potential for transformation in the context of a woman's experience of being the mother of a preschooler born preterm will serve to remind nurses to be sensitive to the possibility that transformation may have already occurred or that these mothers may be in the process of transformation during the years subsequent to a preterm birth.

Chapter Summary

While there are examples in popular literature of mothers' experiences of having a preterm infant such as *Born Too Soon: The Extraordinary True Story of One Infant's Fight to Survive* (Mehren, 1991) and *The Premature Baby Book: A Parents' Guide to Coping and Caring in the First Years* (Harrison & Kositsky, 1983), gaps remain in the scientific literature about a mother's experience when her former preterm infant is now preschool age, specifically regarding the meaning mothers may attribute to that experience. Much is known about the objective, external circumstances contributing to, surrounding, and immediately following a preterm birth. And much is known about the impact on the infant born preterm and the neonatal experience for a preterm mother. This study seeks to move beyond the neonatal period and beyond the objective scene, to give adult mothers of preschoolers born preterm the opportunity in the telling of their individual stories, to reveal what they have experienced, how their lives have been changed, what they have learned, and who they have become, because of being the mother of a preschooler born preterm.

Transformative Learning Theory provides a practical perspective from which to view and better understand the experience of adult mothers of former preterm infants now at preschool age,

including the effect of stress that accompanies that experience. Combining Transformative Learning Theory with narrative inquiry reveals how some of the participants have derived and revised personal meaning from their unique experience. This combination also lends insight into what these mothers can do to further enhance (or for some, begin to restore) their personal well-being, even though the circumstances of having a child born preterm are unalterable.

Chapter 3

Research Methods

The purpose of this dissertation research is to explore the personal narratives of mothers of former preterm infants now at preschool age. This chapter will explicate the selected research design, methods, sampling, and procedures employed for collecting and analyzing data. Specific steps to ensure the protection of enrolled human subjects are also presented.

Design

This study followed a qualitative research design, using narrative inquiry as the primary research method. Study participant's personal story of being the mother of a preschooler born preterm was elicited and retained as the primary unit of data analysis.

Sample

The "aim of narrative inquiry is not certainty but believability, not control but insight and understanding" (Pellico & Chinn, 2007, p. 63). In addition, one of the over-arching principles that direct sampling for qualitative studies, appropriateness, guided the sampling design for this study (Morse & Field, 1995). Appropriateness refers to recruiting participants who can best enlighten the study based on its theoretical underpinnings (Morse & Field).

Thirty-seven mothers who participated in previous prospective studies exploring their preterm infants' biobehavioral responses to stress constituted the sampling frame for this study (Haidet, 2005; Haidet, 2006). The previous studies were conducted between 2004 and 2007 at the

Children's Hospital at Penn State Milton S. Hershey Medical Center (HMC), Level III Neonatal Intensive Care Unit (NICU) in south central Pennsylvania. Eligible infants in the previous studies were relatively healthy preterms, without congenital anomalies or known intra- or peri-ventricular hemorrhage greater than grade II. While prematurity was the primary diagnosis for all the infants, several infants experienced common morbidities associated with prematurity including: hyperbilirubinemia, respiratory distress syndrome, chronic lung disease, neutropenia, apnea, sepsis, intra- or peri-ventricular hemorrhage (developed post-enrollment), patent ductus arteriosus, gastrointestinal reflux, retinopathy of prematurity, renal failure, and post-hemorrhage hydrocephalus. In addition to the above, one infant was diagnosed with osteopenia and perforating necrotizing enterocolitis.

Procedure

After approval from the Institutional Review Board (IRB) of the Penn State Milton S. Hershey Children's Hospital (see Appendix F), potential participants were mailed a letter introducing the study including its connection to the previous biobehavioral studies. The letter made clear that the purpose of the study was to explore what it is like being the mother of a former preterm infant now at preschool age and that each mother would be asked to talk about her personal story of that experience during an audio-recorded, face-to-face interview with the researcher. The letter instructed mothers to complete, detach, and return a brief form at the bottom of the letter (using the provided SASE) indicating either a "yes" or "no" response regarding their willingness to be contacted by the researcher by phone. Those who checked "yes" were asked to add their current phone number(s) to the form (see Appendices A and B for copies of the letters). The researcher telephoned interested mothers to discuss the study further and to answer any study-related questions; a script was followed to ascertain their willingness to meet

in-person for an audio-taped interview (see Appendix C). Mothers interested in participating in the study were asked to meet the researcher at the conference room at the Penn State University School of Nursing in Hershey for the purpose of reviewing the informed consent form and if signed, to conduct the interview. Conducting the interview at a private location was important to minimize distractions and interruptions commonly encountered in one's home such as telephone calls, unexpected visitors, and child-care demands. Each mother's travel expenses to Hershey were defrayed by providing her a \$25 gas card, presented at the close of the interview.

For all but one participant, data collection began with a digital, audio-recorded interview. The interview was in-depth and unstructured, beginning with a global request for information related to the phenomenon of interest: "Tell me about a time that stands out for you, a time you'll never forget, that will help me understand your experience of being the mother of a child who was born preterm and is now preschool age." Pertinent probes and follow-up questions were posed during and after the interview as needed to elicit additional information or enhance clarity (see Appendix D). Approval was requested and granted by each participant for the researcher to contact the participant as needed for additional information and validation of interview data during analysis. After the interview the participant was asked to update existing demographic and obstetric history data initially obtained with the mother's participation in one of the biobehavioral studies (see Appendix E). These data addressed current educational and work/profession status, gravida and parity (including if additional children were born preterm), and marital status.

One participant, who had moved out of state just before receiving her forwarded invitation letter asked to participate even though an in-person interview was not feasible. The IRB subsequently approved a revision to the study protocol allowing her communicate her narrative in a written format, via email. This IRB approval also included obtaining her verbal consent to participate as well as the completion of the Demographic and Obstetric History Questionnaire telephonically (see Appendix E). This participant and the researcher eventually exchanged hard

copies of her signed consent form. All the other elements regarding the procedure for data collection, including the provision of a \$25 store card pertinent to her new locale were followed.

In addition to the interview data, the researcher kept written field notes and a journal throughout the data collection period. Field notes documented the researcher's salient objective observations related to and during interactions with participants for example, a participant's non-verbal communication or behavior, details in the physical environment, factors contributing to or detracting from the quality of an interaction, or trouble-shooting issues (e.g., related to audio-recording equipment) (Creswell, 1998; Morse & Field, 1995). Observations captured via field notes were incorporated with the interview data to enhance clarity and synchrony of data (Morse & Field). The researcher maintained a journal to document subjective impressions, insights, concerns, questions and biases, as well as decisions that may influence the process of data collection (Creswell; Morse & Field). Both the field notes and journal provide an audit trail, to ensure any changes in the course of data collection and the rationale beyond those changes are clearly documented (Morse & Field).

Data Analysis

The analysis of narrative data springs from the data itself versus *a priori* expectations (Holloway & Freshwater, 2007), with the ultimate goal of explaining the meaning(s) inherent within a participant's story (Mishler, 1995). To accomplish this, the participant's story must be carefully deconstructed and interpreted without fracturing or dismantling its coherent structure, keeping intact the temporal and spatial connections within it (Holloway & Freshwater). There are various ways to that end including linguistic analysis of texts, analyzing narrative's function (related to its purposes and consequences) (Mishler), analyzing stories from a psychological perspective or from the perspective of identity development (Duffy, 2007), thematic analysis

(focus on content), structural analysis (focus on form), dialogic analysis (focus on character interaction), or visual analysis (when using visual art forms or video data) (Riessman, 2008).

There is no rigid hierarchical ordering to these approaches. Instead, the narrative researcher can combine approaches to accommodate data-specific analytical needs (Holloway & Freshwater).

The narrative data analysis for this study incorporated aspects of three different methods or perspectives. Data analysis began with a naïve reading of all the transcribed interviews. This period was followed by a re-reading of each of the transcripts, moving back and forth within the hermeneutic circle (that is, continuous reflection on the whole in light of the parts and the parts in light of the whole), in order to avoid premature interpretations of the interview data. These initial steps are in keeping with those posited by Paul Ricoeur's hermeneutic theory of text interpretation (Geanellos, 2000). Throughout this process of digesting the data the researcher purposefully stepped away from the data allowing "a period of incubation" (Holloway & Freshwater, 2007, p. 81) during which the researcher was relaxed mentally and the internal creative processing of data was at work. The final level of data analysis involved "interpretive decision making" based on textual clues, using the participants' words (Geanellos, p. 116). The justification for the interpretative decisions should be clear to the reader and meaning(s) derived from the data should be made explicit (Polkinghorne, 2007). These interpretive decisions were made acknowledging that narrative data interpretation and analysis is a contextual endeavor, subject to multiple perspectives, and ever-evolving (Geanellos).

Simultaneous to the hermeneutic process just described, participants' interview data were analyzed using narrative term analysis. Narrative term analysis identifies the elements of interaction, continuity, and situation found in the "three-dimensional narrative inquiry space" (Clandinin & Connelly, 2000, p. 54) and can serve as the starting point for organizing and understanding the meaning in each narrative. In the re-reading of interview transcripts, each participant's transcribed data noted characters, relationships among characters, facets of time,

shifts in location in relation to actions and events, as well as seeming gaps in a participant's narrative (Clandinin & Connelly).

The third method of data analysis used for this study was focused on narrative functions as described by Mishler (Mishler, 1995). This means of analysis addresses “the ‘work’ stories do, on the settings in which they are produced, and on the effects they have” (Mishler, p. 107). Data were analyzed from the perspective of how narratives reveal patterns of thinking, memories, and identity. Narratives were also analyzed from the perspective of the contexts (interpersonal and institutional) in which they were situated (Clandinin & Connelly, 2000; Mishler).

Participants' narratives were re-told by the researcher with these analytic perspectives in mind. The goal of re-telling participants' narratives is to communicate in a cogent manner the meaning attributed to the experience (Duffy, 2007; Mishler, 1995; Polkinghorne, 2007).

Participants were given the opportunity to review and respond to the researcher's re-telling of their narrative for trustworthiness and credibility (Duffy; Polkinghorne); none of the participants communicated disapproval or disagreement with the researcher's interpretation and analysis of their respective narrative.

Human Subject Protection

This study was submitted to the Institutional Review Board (IRB) of the Penn State Milton S. Hershey Children's Hospital. Informed consent forms for participants included information regarding risks and benefits or participating in the study, withdrawal information, and IRB and researcher contact information. A copy of the signed consent form was given to each participant for their records.

Information obtained for this study was kept strictly confidential. Every effort was made to conceal identifying information regarding the participants for this study's dissertation; the

same will apply for any future publications resulting from this research. Participants' real names have not been used; they were asked to select a pseudonym for the purpose of identifying their data in the data files and written findings while ensuring anonymity. Only the researcher knows the participants' real names and corresponding pseudonyms. Electronic data were uploaded and stored in a password-sensitive computer accessible only by the researcher; hard-copy field-notes and transcripts were kept in a locked file cabinet under the direct supervision of the researcher.

There were no physical risks associated with this study however there were minimal psychological risks. Relating their experiences was somewhat distressful for some participants. Participants were informed that they could withdraw from the study at any time. A list of community resources including parent support groups and free mental health support services in central and south central Pennsylvania were available if needed. Had it been evident to the researcher that a participant was in need of immediate psychological support at the time of the interview or at subsequent contact points during the course of the study, the researcher would have strongly suggested to the participant to see her primary care provider. A telephone call would have placed the next day to determine if the participant had followed through with that suggestion. Fortunately, none of the participants displayed or indicated the need for the level of psychological support requiring such intervention; therefore, taking these steps was not necessary.

It is not clear if there are direct benefits to subjects for participating in this study. Extant research suggests that mothers of preschoolers born preterm who verbally express their personal narratives may find such expression therapeutic. Findings from this study have relevance for healthcare providers. The experiences and attributed meaning(s) derived from personal narratives of mothers of preschoolers born preterm provide information on concerns related to care-giving practice in the NICU as well as practice exemplars. Such information is vital to optimize parent-provider relationships and ultimately improve healthcare for these mothers and their children.

Chapter 4

Results

The purpose of this study was to explore the personal narratives of mothers of former preterm infants now at preschool age. Thirty-seven mothers whose preterm infants participated in previous prospective studies exploring biobehavioral responses to stress constituted the sampling frame for this study. One mother replied to the invitation letter indicating she was not interested in participating. In the course of recruitment it was discovered that another mother from the sampling frame had died. Of the remaining 35 eligible mothers, 9 replied positively to the invitation, indicating they wished to learn more about the study. After speaking with the researcher, all 9 mothers agreed to participate; 8 of them scheduled interviews. Two of the mothers repeatedly canceled scheduled interviews or did not keep their interview appointments. The remaining 6 mothers consented to participate; 5 local mothers met with the researcher for an in-person, audio-recorded interview and 1 out-of-state mother provided written narrative data via email. At the close of each interview participants were asked to complete the Demographic and Obstetric History Questionnaire (see Appendix E). Data from this questionnaire constitute a profile of each participant and are presented in Table 4-1.

The narrative texts of each participant are presented in this chapter. In order to retain the integrity of each narrative as well as the voice of each participant, the transcribed verbatim texts are provided with minimal text reduction. In the course of each interview, participants were asked to identify a word or phrase that describes their experience of being the mother of a former preterm infant now at preschool age. That word or phrase, along with the participant's pseudonym, titles their respective narrative text. Participant profile data and participant characteristics noted by the researcher during each interview introduce each narrative text.

Table 4-1 Participant Profile

Participant Pseudonym	Age	Marital Status	Total # Children Born Preterm	Occupation
Judy	38	Married	1	QI Director, Long-term Care
Jane	32	Married	1	Director of Education
Patty	26	Single	2	Homemaker
Kellie	33	Married	2	Homemaker
Ann	34	Married	1	Hospital Housekeeper
Jennifer	26	Married	2	Insurance

The researcher's interpretative comments are interwoven throughout each narrative, signaling a change of direction or expansion within the narrative. The data-based analysis of each narrative follows the respective narrative text. That section is distinguished by a metaphorical narrative theme identified by the researcher that encapsulates the results of the analysis. Analyses of participants' narratives centered on disclosed contextual elements, revealed patterns of thinking, memories, participant identity (Mishler, 1995), and thematic analysis, focusing on content (Riessman, 2008). The goal of data interpretation and analysis for the current study was to identify not only the substance, but also the meaning of each narrative (Clandinin & Connelly, 2000; Duffy, 2007; Mishler, 1986), made explicit in the re-telling of the narratives. Participants were given the opportunity to review and respond to the researcher's re-telling of their narrative for trustworthiness and credibility (Duffy; Polkinghorne, 2007); none of the participants provided disapproving feedback to the researcher.

The narrative texts and the researcher's interpretation and analysis of each narrative answer the research questions under-girding this study: 1) How do participants depict what it is like to be the mother of a preschooler born preterm? 2) What role has a child's prematurity had in the life of her/his mother? 3) What meaning do participants derive from or attribute to being the mother of a former preterm infant now at preschool age? and 4) What kinds of support do participants identify as having been most/least helpful to them as mothers of former preterm infants now at preschool age?

Judy

“A Willing Sacrifice”

Judy is a 38 year old, married mother of 2 children. Her first child, a son, was born preterm in 2004. Since then she has given birth to a daughter born full-term who at the time of the interview was 2 ½ years old. Judy is employed as a risk manager in long-term care. She appeared relaxed, comfortable, and eager to talk as the interview began.

Judy started her narrative by providing a contextual back-drop, setting the stage for her expanded narrative of her experience as the mother of a child born preterm. From the outset Judy made it clear that despite what has been an often arduous effort for her and her family, her son has made gains in the past 5 years. She explains that those gains were facilitated once she stopped attributing his size and limitations to his preterm birth history.

Well, we've come a long way in our family from when [my son] was born...2 more months and he'll be in kindergarten. We can't believe it. And for a long time...I was told there was no reason that this happened and that nothing I did caused...him to be preterm but of course every mother always feels that in her heart, that there was something that I

did and I could have done something else. And for many, the first few years of his life he did receive ...intervention which helped. But I was always very quick to make excuses for him if anyone would ask me...“Oh he’s so tiny.” “Oh, he was preterm.” Or you know, everything had an excuse of why he wasn’t as perfect as another child and going through the years and, and seeing him grow and being completely healthy never ever needing really anything while he was in the NICU...just he was small, he was 3 pounds 3 oz. and he just needed some help to get started. And I now am able to let that go and say, it was God’s will....we’re very fortunate.... There’s a reason now, a positive reason why he was born at the time he was born. I don’t know what that is yet but I’m turning that around to be encouraging to him and not making excuses for him anymore but really pushing him and encouraging him...and letting him explore things and find out who he is and what he likes and that took a, a long time, that was a long road for us.

Judy went into detail explaining how her son’s preterm birth status has strongly influenced her and her husband’s decision making process as they consider when to initiate kindergarten and in what setting, either public or parochial. Judy’s investment in the decision making and her willingness to make sacrifices on behalf of her son were evident. Judy voiced ambivalence regarding how she views her son’s capabilities in light of his preterm birth status. She wants to see him as normal and yet she acknowledges that his preterm birth status is associated with potential school problems. She also admits that despite her resolve to see him as normal and her son’s apparent acceptance of himself she struggles to resist treating him as different because of his preterm birth status.

And now we’re at the point where we have to make decisions for him for school. Now my husband and I are very educated...my husband’s a chiropractor...I am a risk manager in long-term care...it’s very important for us to, to have education...So the decisions we’ve been struggling with...for the past year, is do we hold him back because he was a

preterm baby...? What do we do? We talked to multiple people. We've talked to educators, we've talked to psychologists...we've, I've read multiple articles about it...you get so much information. I just finally looked at [my son] and said, "He's fine!" He's tiny and if we hold him back it's because he's tiny, it's not because he's you know...developmentally behind or...socially behind. He goes to daycare fulltime, he's well-liked, he plays wonderfully. So, our decision was he's going to go to school...when he's five and we'll see what happens. And then after we came to that decision we had to decide where's he going to go? What's going to be the best environment for him? ...choices were a private school or...city school and I did a lot of research on both. And the things that I think that are important for children as they get older and go through their school years is not only academics but their social atmosphere and their extra-curricular activities are just as important....my faith is important too. I went to Catholic school my whole life. And I thought, "That is how I deal with difficult situations, that's how I got through [my son's] whole life," is prayer and support from my church and so I thought that was important as well and I wanted to be able to incorporate the, his Catholic faith and his education and religion somehow in that. So, I really didn't think that he would be able to handle [city] middle school, [city] high school. ...we live just...down the street from...Catholic school and I remembered the wonderful experience I had. However, [the]...Catholic [school] is very small, 11 children per class in the kindergarten class, no real extra-curricular activities, no sports...like a regular high school would have. So, when you're weighing that out, wow, that's a 2 totally different worlds to grow up in...my husband and I really had to make that decision based on him and it always came back up: he's preterm. You know, he is behind. And I didn't want to feel that way anymore. I didn't want to think that way. But if you take a look at him, he's still skin and bones. He's 5 years old and he's not even 40 pounds yet. But he's so smart. And I think, I

don't want him to be held back and be bored for a year and, and start to act out. So, we chose the smaller group, we chose [city] Catholic. We're very happy with our choice. It's going to be...a financial struggle...but that's ok, because it's in his best interest. And one thing we did find out after making that choice is they have 2 kindergarten classes, so if indeed he needs to, to try again, he can move to the 2nd kindergarten class, not know that he's being held back...and then he'll be able to grow a little bit physically and, and--- you know, add up. But...something that's interesting about [my son] which I've learned about is, he doesn't care that he's smaller...it doesn't make a difference to him. I think WE are going to be the problem...WE are going to be the people that make him realize that he's not like everybody else....So that's been...what is on our minds all the time in our house, is, how's [our son] going to do in school this year?

Judy's attention to the evolving developmental needs of her son are clear as she explained how she learned the value of her son being with other children, despite her desire to protect him from real or potential risks to his physical health at daycare. Judy's appraisal of the decision to eventually place her son in an expensive daycare indicates the move in her view was divinely appointed, providing the unexpected opportunity of establishing close relationships with the families of her son's daycare friends. Judy sees her primary responsibility now is to adequately prepare her son for formal education, a responsibility she takes very seriously.

...[H]e has always been away from home. He actually started out in daycare...they wouldn't accept him until he was 5 months old so he was home with me for the first 4 months. And because he was so small and he came home at like 4 pounds and his immune system was like nothing, we had to stay inside, just me and him, for pretty much 4 months, with no visitors...which was a challenge....he then went to daycare and I found that I was very nervous. He had significant trouble with his ears...he had multiple surgeries, he's had 7 in his little 5-year life...with ear tubes...adenoids taken out, skin-

grafts of his ear-drum, so, he's been through it...anything that could have happened to this poor little guy happened, and he always came out smelling like a rose, never bothered him, he didn't know any better. And I think he, I got my strength from him, because, or God was really blessing me, so, 'cause He only knows you can handle so much. ...[A]nd then I decided, he's too...precious to be in an environment with a lot of sick kids. So I got him a nanny. That was the worst thing that I could have done because it was just him and the nanny. And, from year 1, between 1 & 2, he had his nanny and as he was getting his early intervention, they were measuring him and he was doing well with everything else except for socialization. So, that was kind of on the decline because he wasn't getting any anymore. So I'm a huge advocate of a quality daycare environment, which I've found. ...[W]e put him back in school and he has excelled...early intervention...saw the difference. They recommended somehow getting him involved with children, that was their recommendation, not necessarily how, maybe play-dates or something, and I just said, that's it, we'll send him back to daycare. Found the best one, we, you know, really pay a lot of money for this daycare, a lot more than we had been in the other daycare...he's remained going there ever since. He loves it. He doesn't like to leave at the end of the day, which is wonderful. When you walk into a daycare and your child doesn't want to stop playing, it's a beautiful thing. And we've actually found out that we've made many good friends through our children at daycare and the 4 closest friends...that we've become very good friends with, their children are also going to [city] Catholic. So it couldn't have been a better decision. But we made our decision on our own. And I guess God, you know, is intervening again and saying alright, your buddies are going to go with you too now, so good choice. These little extra gifts we get. So he won't be alone. Um, he deals fine with change. He was also very...fortunate to have his grandmother...she watched him...on Mondays and Fridays for the most of his 4 years.

...[W]hen he was about 4 ½ and he was in preschool...my husband and I chose to...put him in a structured environment of learning 5 days a week. So he's getting prepared for 5 days a week of kindergarten. Um, and you know, for the whole school year this past year he did that; when summer started, we let him go back to grandma's 2 days a week.... So, you know, we focus everything on education and um, development and that's kind of how we've raised both of our children.

As Judy recounts memories of her daughter's birth and status and about the parenting experience in comparison to her son, Judy reveals what had been hyper-vigilance behavior with her son. She also reveals an attempt to re-frame his birth event and subsequent life as non-preterm. Similarly, Judy appears to be distancing her son from his preterm birth, both in her monitored speech and in the limited number of visual reminders of the event on display in her home.

I've had...a daughter...who's fine, not that [my son] isn't fine. See, there you go. She was born 3 weeks early, very healthy. ...I think he...was very used to having mommy and daddy dote on him a little too much maybe and I can't do that with [my daughter]...you just don't have the time to dote and she doesn't need it either. So she is...a challenge for him, he doesn't have our full attention any more, which I think is good, because he maybe got too much of our attention, too much coddling, and too much, um, safety because he was premature, he's a premie. And...the only thing we have in our house that reminds us of that now is up in his room I have a little shadow box of the ittiest, bittiest, onesy that he, that was too big on him. And that is the only reminder of how small he was and how he's grown. So I, we don't really even, I don't even think he knows that he was a premie or that he was different. ...[A]nytime we drive past the medical center we'll say, there's your house, first house...he asks questions sometimes but he doesn't understand...

Judy indicated that when her son turned 4 years old she experienced a shift in her thinking about what it meant for her son to be a former preterm infant. The label, “preterm” and its perceived stigma no longer fit with how she and her husband viewed their son, particularly when he appeared to blend in inconspicuously with other 4 year olds, nor did it fit with their expectations for him.

...I know when he turned 4 that was when we said, you know, he’s ok, you don’t have to make excuses anymore. Yeah...maybe the reason for that was...he went into a bigger classroom at school with 22 other children...when he went into the 4 year old room, you could definitely see...kids at that age, they are small, they’re big...some of them are skinny as a bean pole...it’s so diverse in here that he fits right in. And he probably always did. But it was just kind of like this, you could take a breath. And at that point when we were going to his...well-baby appointments, we stopped using...the premie chart. We just stopped using that. And, and so we almost said well, I don’t want to know what percentile he is because it, it doesn’t matter. But, um, my husband, you know, being the doctor, said we really should keep track of that so we know...how much he’s growing and how we need to help him do that physically. So, whether he needs...extra vitamins, or extra butter and sugar and syrup as the doctors always encourage, because he literally has always been, and this is so awful, a skeleton with skin on it. ...I’ve also seen him grow. He just went through, and this was wonderful, like, we took him to swimming lessons, you know, the 1st thing we let him do when you start putting your kids out to lessons and music lessons. We started when he was 4, swimming lessons; that was a big step for us, to test him...not test him, but, see where he is doing things, with other kids besides just running around and playing and coloring. And...he didn’t do so well in swimming lessons. He was definitely, you could tell, he was smaller and he wasn’t ready. ...[B]ut we let him do the whole thing because we always told him, “You’re not a quitter.

I know it's not fun, you might not have a good time, but we're doing the whole thing and we're doing it together." And he finished. ...[I]n the...spring...he started T-ball. And he was going to be in these little tykes, 4 years, 3 and 4 year olds. But there was not enough players... in the T-ball, which is I guess, 5 and 6 and...he moved up.... So, we're like, wow, you know, he's really small, you, you could see it, their team was really, really small. And, and the 1st game he was right by my side, didn't understand, was very stand-offish, didn't understand the team or how to interact with people like this, and have a coach. And we worked on it, every night. And it was so beautiful, the last...game of the whole season he literally jumped out of the car and ran to find his team and he didn't even need me, didn't even worry where I was. 'Cause he knew, "This is my team, I'm comfortable with them." And he was. I was very, very proud of all of us for that. So...just letting go a little bit and knowing he's ok. And that started when he was 4, definitely.

During the interview I reflected on a comment Judy offered during a phone conversation when she stated, "I think my story is meant to be shared." In response to my request for her to elaborate on that comment, she explained in some detail her experience of post-partum depression and the transformation she experienced after having received treatment for this disorder. She attributes the current stability and health of her family to the fact she identified a problem then sought and obtained treatment for her post-partum depression. Judy sought redemption for the negative consequences of her depression on her family by trying to create a perfect environment for her son.

Well, this is difficult and I will cry, so I'm glad there's tissues. ...I'm a different person as a mother now. And I think that the reason we're all ok is because I identified a problem with me. ...[W]hen I had my 2nd child, my daughter, I was very ill, I was mentally ill. I had severe post-partum depression which, um, I was not diagnosed with

when I had [my son]. For the 1st 3 weeks of her life, I don't remember it. Didn't want any parts of her, every single symptom, I'd no idea what was wrong with me. I didn't call for help because I didn't know and it was really taking a toll on [my son]. ...I would plan my esc---, I couldn't believe that I was planning my escape every morning. Now never wanting to hurt myself or my family, but my way of that was, how am I going to leave here and never come back? That's what I wanted to do every day. And, at one point my mother helped me, she said, you need to go get help. And I did. I was put on medication for post-partum depression, I did therapy. And what I realized, and what my doctors realized was, most likely you don't...have post-partum depression with the 2nd child and not have it with your 1st child. But I think that what happens with mothers of premie babies is, that's sometimes not identified because the moms are so sad about their babies, are so worried and are just trying to keep their babies either alive or healthy, pumping, getting milk to the babies, driving back & forth to the NICU; there's no time to be depressed or to show signs of depression. It's identified really as worry or sadness or something else. And I do believe that after going through what I went through I was depressed with [my son] and I never got help. So I kind of wrapped all of that up in not letting him maybe mature as much as he should have and holding him back and making, like making excuses for him and making excuses for myself, that I didn't do anything wrong. ...I really believe mothers of premie babies or mothers that are just...or any pregnant woman going through...childbirth classes have someone to know this is a possibility and these are the symptoms that you should be looking for, and it's ok to ask for help. Because if you don't, you are going to hurt yourself and...your child is going to feel it. ...[N]o one ever told me that. And plus, when you have a premie baby, you don't even go through all of the classes. I went to 2 and then I had [my son] and I didn't have a lot of time to understand. I really would love to be able to sit down with moms and say,

this is a tough road. Your body's not, wasn't ready to have a baby, your body wasn't ready to give it milk yet. You're going to be depressed, there's hormones going crazy in your body. And...this was my story and...it's ok to be like that. And it can destroy your family. I saw my family, my husband...my nuclear family was not doing well. And, and this might be why at 4 years old that was the time when we said, everything's ok is because when [my daughter] was born, [my son] was 2 ½ so when he was 3, that's when I really was starting to do better on medication and, and talking to someone. So by the time 4...came around, our whole entire household was different because I was different as the mother. I was able to see more clearly, to not be as anxious, and to not be just sad all the time and want to have a little bit of fun and not worry about, ok I have to make sure that [my son] is well-fed, well-dressed, bathed, has a story, like everything has to be perfect because I have to make this better, because look what I did. So...I think...that's where that depression was coming from. So that was kind of why, and this is just going to be so awful to say, but...kind of tacky a little bit, too, but... I don't if you follow the Jon and Kate Plus 8 thing, well I was in the NICU with Kate and the babies. Our kids were all were born at the same time. So we nursed together in the NICU, in the Feeder and Grower Room and I had like kind of a little connection with her. And I didn't really follow that program but of course of late, everyone wants to see what's happening. And I feel so terrible for that family because I really believe that some of that rift that happened with her and her husband was because she probably was feeling the same thing I was, didn't get help like that, and I know that that could have torn my family apart too. If I wouldn't have gotten help, my husband would not have been able, and my family would not have been able to function. And I saw it falling it apart, I really, really did, now that I look back. I even said that to my husband last, night, you know, thank you so much for staying here and supporting me and, and working through this. Because now that I look

back, it could have...been that Jon & Kate Plus 8 experience. I don't care how many kids you have, having children is hard, especially when you're chemically imbalanced, your hormones are messed up and you're depressed. So, that really helps and I think that that probably, for a lot of mothers with preterm babies, that's an issue, because your hormones are working a lot harder than maybe another mother who's, you know, has a normal birth and your...body's not trying to catch up to make milk and all of that stuff. ...I think that's so important and something that, you know, I've found that has made it better for [my son].

Judy revealed that her wholeness, mentally and emotionally, has been something she has identified as necessary for her son's well-being. In contrast, she finds it justifiably necessary to neglect herself physically in deference to what she perceives to be his needs. Judy reveals that the variety of sacrifices she has made for her son has been the price she has had to pay in order to assuage the guilt associated with her post-partum depression. The scope of her sacrifice includes betraying her own feelings regarding the need to tell her son's future teachers about his preterm birth status and instead, defers to her husband's preference on the matter.

...me being healthy in my heart and healthy in my mind [is key to my son's well-being]...and I guess are we supposed to be, it sounds a little narcissistic, its' about me, me, me, but, it does reflect on, on the child. And when people have always said to me, make sure that you take care of yourself. And...before I...had [my son] I ran a marathon, I was an avid runner. I ran all the way up until he was born...I got down to the power-walk at the end.... Health and exercise was a key part of my life. I have not exercised one minute in 5 years, ever. And I...miss it desperately. I know it's very important. ...I gained weight. ...but I put that aside because that means that's time that I'm not spending helping [my son] move forward in his life. And I do see...the importance of being healthy and taking care of yourself. And I feel like I'm not physically...as healthy

as I was because maybe I'll skip dinner because I'm trying to make sure that [my son's] having a good dinner because our dinner time is really a little messed up with my husband working, but... I would make sure he has the best dinner in the world. And my, both my kids, they eat broccoli and zucchini and...I focus on health for them. And if that means I don't have time for me, then I don't. But if I would make time for myself I would absolutely feel that that would be time I was taking away from him and I can't do it. But definitely, being mentally stable and healthy in your heart is...and guilt-free, you know. It's hard to take that guilt away when, you know, you're depressed. I think that whole guilt thing came about and so that was very important for me. And I've definitely seen a difference. And I'm excited, I'm, I'm actually nervous in 2, less than 2 months...it happens quickly. ...[P]eople say it happens over night, but for a mom that has a premie baby, it doesn't happen overnight. ...I had...almost 3 extra months to wait before he spoke or you know, those 2, 2 ½ extra months that he didn't sleep through the night because, you know, that's just the nature of it. But it took so long for him to get where he is, that it's kind of a relief for me. I'm not saying, oh, it was like I blinked and he was 5; no, it was, when is he going to be 5, you know? So, and now that he is and we can have a conversation with each other and he has thoughts that I can help him through. ...it's wonderful to see that all that work and all of that anxiety and sacrifice, absolute sacrifice, that you make, is, is benefiting him now and that's a treasure for me. But it was a true sacrifice. ...[A] sacrifice of, I don't know, my work, I'm, I'm a career-oriented person and I did sacrifice a lot. ...I would even say to my boss, I cannot wait until I can give you 110% again because I'm giving you about 90 right now. And that's not my personality. But I don't know that, you know, over the, over this research if 100% of people are like me, they're not, you know. I will be the 1st one to say I would never make it as a stay at home mom. ...I don't think it's healthy for my kids for me to stay home; I'd

be doing them a disservice. I can't do what his teachers can do for him, I can't. And I pay an arm and a leg for him to go to the best, I even don't like to call it daycare 'cause we call it school, they've been teaching him things since he was 2. I take no credit for potty-training; they potty-trained him. ...I just...thank them very much for all they did for me. And...another thing is my husband is very, very insistent that we do not share with people, the teachers...at school, at daycare or with his teachers at his new school, that he was premature, at all. ...he said, that's the worst thing you could do for [my son]. And I tended to want to say, well, remember, like that was just one thing, remember, and he said, "No, because you're putting a stigma on him right away with his teachers." And he, we want him to be the same. So they don't know. I don't think they need to know that. He's just a regular kid. So that was one of the things that...kept...creeping back to me is, maybe we should let them know. And on the health form that you have to fill out it says...should we know anything else and I have such a tendency to want to write down, yes...he was...a premature baby...but [my husband] said, "No, he doesn't need that and the teachers will treat him differently and we don't want that." So that was...another thing...I'm glad that I have him to bounce things off of, and really say, yeah, you're right, I'm glad you thought of that.

Judy spoke of the practical support she gets from her parents and mother-in-law and clarified it is her religious faith and not her church per se that provides her with emotional support.

...I shouldn't say it's my church. I think I should say it's my faith. ...[M]y church, I would go there for solace every Sunday to regenerate my feelings. ...for God to say it's ok, you know, you're doing a good job...it's like...my cheering section, was for me to go...and re-charge. And that would get me through a week. Because that's all I could really do, is get through a week. I was not looking to get through to the next birthday. I

was getting through the week. So that was my support. And I would never have been able to do what...I've done without that faith. ...[M]y family support has been incredible because they physically watched [my son] and I knew that when I was at work he was getting love from people that, you know, you can't get love all the time from daycare. Daycare's a great place to learn and develop but you also need that grandma love. And my mother and my mother-in-law both shared in that. And my children are so fortunate to have both grand-parents...to really play active roles in their lives and, and mold them. And my mother-in-law who is in her 70s, very church-going, different religion, but her faith is very strong. They live 2 blocks from their church. And she would continually take [my son] to church with her...during the week and you know, just, clean the church, she's very active in...the behind-the-scenes of church. ...[A]nd she taught him about Jesus first. And, and he would talk about it. And, and some of the things...that he is now, I know are her. And that was very important because not only was she allowing me to find myself at work, because I don't have a job, I really have a part of me where I work. That is not just a job. It's not even just a career or a stepping ladder, it's part of me; aging service is a part of me and I would not be whole if, if I didn't work in that environment. Which I think is very...healthy for [my son] as well. ...[B]ut, she was just being an extension of me...while he was with her and then also allowing me to be whole myself in different ways. ...[W]e don't really agree on a lot, my mother-in-law...and I, but she is, was my right arm and, and I love her for that. My parents live about 45 minutes away, so their role was, let me, let's take the kids, or let me take [your son] for the weekend and you re-connect with [my husband] and you spend some time together alone and work on that part of your life, which is so important, so important. You can't let that go, which is what I really think happened with, you know, that Jon and Kate and you have 8 kids. Who's going to take 8 kids so you can connect? That was just, you know, that was very

hard to do. So my husband and I always made sure we had time for ourselves. And my parents understood that. They're younger, they're hip...and...they wanted...to see that fun in my life which, you know, I worked for 4 months, there was no fun in my life, his 1st 4 months. It was all work, no visitors, making sure he was healthy, making sure he was breathing at night, making sure he was fed on time, all of his medications were, you know, how they needed to be...that was for 4 months, no fun. And that was ok, but as soon as that started to lighten up and he's now getting older...that is key too, is to have that wonderful connection with your husband, as a husband, not just a father. Not to see each other as a mom and a dad, but as a husband and a wife too.... Those are my supports, that make me a whole person. And I think they both saw that when I was just in my darkest place, that I really needed that kind of support.

When asked if there were sources of support that she would have liked to have seen or maybe she expected that just did not materialize, there was a long pause before Judy answered. She eventually revealed that her husband's emotional and practical support has been lacking; she resents that it has been tangential at best. His lack of support has served to strengthen the assumption verbalized by Judy that it is her responsibility as "mother" to keep it all together, to make all the sacrifices. Sensing she has no choice but to do what needs to be done and to do it alone most of the time, by necessity she has had to rely on her own strengths to keep things running smoothly. Consequently, she concludes her behavior has left her husband with the impression that she is fine without his support. Ultimately, Judy tries to minimize her need of her husband's emotional support since in light of everything (including his lack of support), she counts herself fortunate.

...I didn't expect anything because being a 1st time mom, and having a premie baby 1st time, I didn't know what to expect. So I didn't know...anything. ...[I]n retrospect it's always easy.... ...[W]hat I...now know, what I would have liked to see more of but I

didn't expect it because I didn't know to, was, and this is going to sound terrible 'cause I'm, not a bad thing about my husband but...I would have liked to have heard more affirming things, like, you're doing a good job and wow, you're really a good mom or, thank you for all the work you've done with [our son]. Didn't really hear a lot of that. And...I don't think it's 'cause my husband didn't think that; I just don't think that men in general do that. ...I'm a very strong and independent person and I think my husband always felt like I had it under control because I always let, made everyone think that I had it under control. I had lists, and you know, plans, and times, and, it made me crazy, but if I didn't I would have thought I failed. And I was, I knew I was failing inside but I could not let anybody else see that. So I wish my husband would have sacrificed a little bit more of his life than he did. ...I was the one that stayed home from work, I went on maternity leave, I hated every minute of it. ...[B]ut knew I had to do it, I was a mother, I do the right thing all the time, my whole life. *I do the right thing. Whether I want to or not.* And I try and do it with a smile, but sometimes I complain. But my husband really didn't change his life very much and still hasn't. ...[A]s I said before, we were...exercise people, we go to the gym...I ran marathon. ...[H]e has not changed that part of his life. He continues to do that...even if that means that...the kids are all ready for bed when he gets home. I...couldn't do that because I would have missed out on something, teaching them something, reading them a book, you know.... And maybe I'm a little resentful of that because I wish I could say it's ok to step away. And he's probably right, it's ok to step away sometimes, but who's going to do it if I don't do it? So, I guess that's the only thing, a little bit more of, you know, being treated like a girl or a woman, you know, and not just a mom with a towel strapped over her shoulder washing bottles. But that, I think is secondary. I'm, I was, I'm very fortunate to have, I do think God plays a wonderful part in what's happening in my life. Yeah.

Judy described herself as being necessarily independent and self-sufficient for the sake of others, particularly her son. She indicated that her post-partum depression started after he was born, associated with what became chronic neglect of her own needs.

...I just have a good...strong personality that I can take care of myself. And I can pretty much do anything that anyone asks me to do. And that's what I did when [my son] was born; I just did what I had to do. And I forgot about myself. And if I was really watching or taking a little closer look at me I would have known I was really going to a dark, dark place. And I was not going to be able to get out of there by myself. And by the time I had my daughter it was really bad.

Judy made clear that Judy the woman, the person, *not* Judy the mother or wife, got lost along the way. She has forgotten who Judy is. As her son grows and becomes more independent of her, she is realizing that she needs personal renewal, to become re-acquainted with the person she is now, to find fresh purpose in life apart from her son. This realization holds both fear and the fulfillment of long deferred, long-awaited self-care and growth. Judy's conflicting feelings about self-care is compounded by the prominent place she gives self-denial in good mothering. Failure to self-deny is failing to be a successful mother.

I have been...always interested in, in educating myself, reading...things that I like to do. And now that [my son] is at the point where he really doesn't need me very much anymore, he can go outside and play and I find that I'm standing there and all of a sudden I don't have anything to do. Moms can always find something to do, but if I really stood there and said, if I wasn't going to empty the dish-washer and I wasn't going to fold laundry, what would I do? And it scared me. This has been happening in the last couple weeks, because I don't know what I like anymore 'cause I don't remember. 'Cause I...and I know it's, that this isn't the end of it, because you're going to take care of your kids 'til you're, you know, 'til they're in college and what's going to happen when

everyone's gone out of my house and how am I going to remember what I, what did I like to do? Am I going to still like those things? What am I'm going to do with myself? And I know that's far off in the future and I don't have to worry about that now. But I hope to never have to worry about that 'cause I do want to be able to take the time and say, what do I, what do I like? And actually in my therapies when I was depressed, that's one of the questions that I was asked, "...if you could do anything, what would you want to do?"

And I was able to answer that question which is good because I think they call that a, a 3-second question, that if you can't answer that in 3 seconds, there is a real problem.

...[B]ut I was able to answer that in 3 seconds knowing that...I was never going to be able to do it in the situation I was in, but this is what I like to do, but now? I still probably could answer that question...but not as strongly, only because I've dedicated...such...a huge portion of my life to [my son]. And that's not a problem, but that's just the way it is. You know, when you have physical therapists coming into your house and occupational therapists trying to get him to where he's supposed to be and then worrying if he's not getting there, you kind of lose track of yourself. But I think that my support system in...my family...really helps that. Particularly I think, the first thing that you need to be aware of is, never lose, never lose your relationship with your husband. 'Cause they're always going to be there, hopefully...and if you don't, they're not going to be there and you're going to be alone and that's a terrible place to be too...and you've worked hard at that relationship as well and you just don't want that to go to pieces. So keeping that strong and having that is, is important and you'll find your way through being your person. But I do, I, I struggle still with...when is it, I don't know, when is it my turn, or how, you know, these books always say, put yourself as a priority. ...[I]f someone could show me how to do that, that would be great, without sacrificing something from either of my kids. And there's guilt associated with that as well. ...I feel very guilty saying that

out loud and even thinking it, because that might mean that I'm a failure. If I even want to think that, then, am I failing in being the mother? And I think I've been doing a great job so far in how I'm doing it because [my son] is doing extraordinarily well, you know. ...[W]e don't let him play video games and it's easy to say, oh yeah, you can have it because it'll sit and you'll be quiet for me so I can do something else for me. But I'm not interested in sitting him in front of a TV so I can do something for myself. I would never, never do that. If I sit him in front of the TV it's so that I can make him a healthy dinner; that's about it.

Judy indicated that most pediatricians, with the exception of pediatricians who are also mothers, do not understand the experience of mothers who have had children born preterm. She states a pediatrician has never asked her anything about her health status or how she is doing generally.

A pediatrician? No. No, unless they're a mother, and unless they ask the questions. Because when you're in a pediatrician office, the focus is always on the child, and their health and their development. Which is a good thing. But part of their health and their development is the, the status of the parent, the health, the mental status, and how they're doing is definitely a part of how that child's going to grow. But never has a pediatrician asked me. And...I don't think it's a negative thing, it's just, they're a pediatrician; they've never asked a parent a question of, "How are you doing? How are you feeling? How are you interacting with your child?" They're there to measure, weigh...and get kids vaccinated. You know, that's...their goal. And keep them from being sick. And...that's not a negative statement. I'm glad somebody's doing that because they, you know, children need to be, you know, checked, make sure, to make sure they're growing. But yes, absolutely, something is missing.

Judy indicated that the only time she *clearly* recalls any of her own physicians or nurses inquiring about her overall well-being in the context of who she is as a mother was during her 6-week post-partum appointment, when she was tested for depression. She cites that as another reason why she would love to communicate her story to women in childbirth classes, to help prepare and educate them for what can occur after birth. Judy reveals such awareness would have helped her avoid the destructive post-partum depression she experienced after her second child was born.

When I went to my 6 week appointment I took a test for depression. And that, it, I was off the charts. So they came back and...Dr. [____] here saved my life. He absolutely saved my life. ...I was so overwhelmed with [my son] that I, maybe someone came to my hospital room and said something to me, but there's no way I'd ever remember that. Maybe, maybe someone gave me something to read; whose reading that when you have a baby in the NICU upstairs? I was in the hospital for...5 days before he was born on complete bedrest and 5 days after with you know, a possible uterine infection and a baby upstairs that was 3 pounds and went down to 2.8 pounds... Who in the world is listening to, you might have some signs of depression and these what, are what they are? Even with [my daughter] somebody might have come in and said that to me but...at that point...you're not hearing it. So, you know, maybe, like, when, I don't know, somebody should say something. 'Cause usually first-time moms don't hear that anywhere else...that's why I would love to be able to go to childbirth classes and tell that story, because truly, you don't get the whole story in the childbirth classes. ...I don't want to say that wholly because I didn't go to all of them, but what I went through was not like the real story. It hurts, it's unpleasant, there's a lot of blood, you know. Those things like, epidurals hurt, don't, you know...people don't tell you that stuff. And this is going to sound very crass, but people don't tell you that they're going to take you into the

bathroom after you have a baby and shoot water, you know, while you are sitting on the toilet, into your vaginal area. I mean it's very, just, it's an awful experience, if you want to know the truth and I think that's why God let's you forget about it so you actually want to have it happen again, but I won't forget it. And anyone I come in contact with is, if you want to hear the real story, come to me, I'm going to tell you. ...[T]hey miss a lot of things. And the one thing I think that they miss is...I think they don't say it because they don't want people wanting to think it's, you know, the baby blues are depression and get all upset, so maybe if you don't educate people and you don't teach them they won't have this like, neurosis, that oh, I'm going to have postpartum depression. ...Interestingly enough, I guess with my education in the, in my health care field...when I was...7 months pregnant with [my daughter], right before I had her, I think the day that...Dr. [____] checked me and she said, "I'm going to send you over to the hospital because you are having contractions," I wanted to say to her, is there any such thing as pre-partum depression? But I thought I felt stupid saying that. Because I already felt something's not right with me. And...I'm embarrassed to ask that question. And so I pushed it to the back of my head. ...I wish I would have asked that question now, because I don't know if there is, but I was really starting to feel like I was going just a little downhill, before I had her. So, you know, maybe it's just me, and you know, could be just me...I wonder how other people just don't have that problem, it's just amazing to me. And I think maybe sometimes people don't even know that they do. ...I didn't know that I did with [my son]...I almost destroyed my whole life.

Judy reveals bonding with her son and the experience of becoming a mother were delayed. Caring for her son was initially perceived as a God-given responsibility she was expected to fulfill regardless what emotions she lacked at the time. The birth of her daughter introduced renewed burden and heightened lack of control over her circumstances in association

with her role as “mother,” reflecting again Judy’s perceived association between imposed self-denial and motherhood. The level of her current involvement in her children’s lives has taken a long time to develop and has been a means of relieving the guilt she has felt for not being more emotionally present during their earlier years.

...I think that my bond with my kids didn’t hap--, well, my bond with [my son] certainly didn’t happen for a long time. My focus was: this is something that I, God gave me, and I’m going to take care of it. ...I don’t even want to say it was motherly instinct, it was, this is what I need to do to take care of this item, not what I need to do to take care of my son. ...[B]ut when we brought him home finally, that’s when it became, this is my beautiful child, and when I kiss him, I kiss the face of God, and when he looks back at me I can see in his soul and, and I want to do the best for him because he’s a part of me. And with [my daughter], that didn’t happen at all. It was: I know I need to care of this whether I want to take care of her or not. I have to because I’m a mother and that’s what you do. And that’s how I got through that... It was extremely hard, extremely hard. And I, I have tremendous guilt about that. ‘Cause I wish I could go back, feeling like I do now. I wish I could go back and do it over again and I know that time is gone. But you can’t really lament on that. You have to just focus on, you know, living through your kids’ eyes and, and exploring and I’m so excited to start school again with [my son] and, and learn the things that he’s learning again from a different perspective. And that’s kind of how we’re moving forward now, so. It was a long, long road.

Judy’s son’s upcoming entry into kindergarten is the product of a collaborative effort amongst members of her family. It also serves as a benchmark, as a means to compare her son’s outcomes (and what it took to produce them) to other children born preterm.

...we’re making a big deal out of it [going to kindergarten] because he’s a big boy, but boy is it a big milestone in our family that we’ve made it through all of this, to get him to

be able to go to kindergarten. ...[T]his is kind of an interesting side, but...my sister, who's 2 years younger than me, and lives very far away...she also had a preterm baby, the same amount, the same preterm as [my son], 1st baby. It was...very odd. ...[S]he lives a completely different lifestyle than I do and he is not functioning as well as [my son]. ...[H]er husband's...[in the military]...[h]e goes away, you know, for 10 days, comes home for 4, goes away for 10, so she is like a single mom, stay-at-home mom. So, it was only...her son and her and she was alone. And he is not as advanced as [my son] was at that age. ...[W]e did encourage her to get early intervention, which she did. ...[B]ut, yeah, it was very different. So I can definitely see the differences in how you work with your child...and the importance of not giving up and really pushing and not holding, coddling too much, and learning it's ok to let go. And if I would have let go a little bit earlier, I think he'd have been even better, but I don't know how you can be better than him. I would love for you to meet him, he's a fantastic little boy.

Judy reiterated the importance of healthcare providers inquiring about the well-being of mothers of former preterm infants so those mothers can access timely healthcare if needed. Judy reveals that from her perspective, such assessment and intervention is not only beneficial for the mother, but also for the child.

...I think it's vital for pediatricians to take, maybe even if it's a questionnaire of the mother...you might be able to gather some more information to help the growth and development of the child if you also have part of that well-baby check-up the well-mommy check-up too. You know, how you're doing in, in helping the child along, so that might be key in catching these things early. Because you do see the baby every month and you don't see the mommy every month. So that might be very, very important. I would like to see that happen. So that is what I'd like to add, it's important somehow to

find that out. I think there's more moms, particularly of premie babies, that are probably screaming inside for help but they don't know that they can get it.

At the close of her interview, Judy was asked if there was a word or phrase that comes to her mind that encapsulates or describes her experience as the mother of a former preterm infant now at preschool age.

Sacrifice. (*Long pause.*) I feel like I should add something before that sacrifice, um, a voluntary sacrifice...these first 5 years were hard and a sacrifice on many levels...that I wouldn't, I probably wouldn't change. ...I didn't want [a sacrifice] to be taken negatively....It was voluntary, I wanted to make this sacrifice, I was willing, a willing sacrifice, maybe that's, that's the word. ...I'm very proud, too. ...I can say that. It was a sacrifice but I'm extremely proud of the work that my family's done for him.

“I Matter Too”

In analyzing Judy's narrative, the over-arching message that emerged was “I matter too.” Evidence of the toll of *personal* (versus family) denial in deference to addressing real or anticipated needs of her son was repeated throughout her narrative. Judy voices frustration yet acquiescence with the assumption that failure to self-deny is failing to be a good mother. Areas of self-denial include how/when she thinks and talks about her son's birth history as well as the potential consequences of that history on his future development.

At several points in her narrative Judy also makes it clear she has denied herself opportunities for her physical and emotional needs to be met to the point where she feels guilt when she entertains the notion of personal need-meeting. Judy voices resentment that in contrast, her husband's level of self-denial since the birth of their son has been negligible. In an effort to maintain her obligation to “do the right thing...whether I want to or not” and in her subsequent

show of strength, she has inadvertently denied herself of her husband's emotional and practical support. In the midst of her self-denial, she reveals she knows it is not therapeutic; instead, she verbalizes a longing for the day when it is her turn to be the priority in her own life.

Judy's narrative reveals her resentment that despite her self-denial, she is not recognized for what she has done for her son or for the extent of her personal sacrifice that has been needed to make it happen. She reveals her need for affirmation, encouragement, and being valued as she describes the support she finds in her religious faith. She goes to church to hear God say, "It's ok...you're doing a good job." She also seeks this kind of support from her husband; unfortunately, she does not hear affirming words from him nor does his behavior communicate his appraisal of her value beyond that of being "mom with a towel strapped over shoulder washing bottles." The cost of her sacrifice, of doing "what I had to do" has been high; she has lost track of herself, forgetting about herself, to the point where she no longer remembers what she likes/dislikes.

Finally, Judy's narrative reveals that she, as the mother of a former preterm infant now at preschool age, also matters in terms of the attention and consideration given to her from healthcare providers. Judy acknowledges that her health status as a mother of a former preterm infant and the relationship between herself and her child are integral to the child's well-being and development. In addition, Judy notes that all pregnant women should be given information regarding the risk of post-partum depression and mothers of preterm infants should be carefully screened for this disorder in order to mitigate the suffering it can cause.

Jane

“An Adventure”

Jane is a 32 year old, married mother of 1 child, a son, who was born preterm in 2004. Jane is employed as a director of education. She appeared to enjoy the opportunity to share her narrative and interjected humor throughout. Yet, within the first minutes of the interview and for the duration of her narrative, Jane quietly shed tears as she spoke.

Jane’s narrative began, not with her labor and subsequent delivery experience, but with a prenatal hospital admission. The choice of this narrative starting point and the influence of her obstetric history on her perceptions during her hospitalization provided the first indication of the value Jane placed on the contextual elements that informed and framed her story.

...I guess I’ll just start from the beginning. ...[I]t was about 23 weeks that I entered the hospital. ...[M]y...obstetrician decided to refer me to a doctor up here...because I had been spilling protein in my urine. And it was actually the day I came up here to meet [that doctor]. I went home, took a nap and I woke up and I went to the bathroom and I realized...I was bleeding. ...I had had a miscarriage...prior to becoming pregnant with my son. ...[T]hat’s what had happened before...I had started to bleed and I went in and they told me that I was miscarrying. So that’s what went through my, my mind. So I went to the...[local] hospital...and um, my obstetrician decided that she did not want to have me there ‘cause she knew that if I delivered, there was nothing they could do there. So they transferred me by ambulance...up to here...I was so scared, ‘cause I was thinking, “Here I am at 23 weeks.” ...[T]he doctors came in, they did ultrasounds, checked my um, amniotic fluid and they were telling me they had no idea if this baby came if he would survive, so, um, they were scared.

As Jane continued to relate her narrative, it became clear that the details regarding the course of her prenatal hospitalization were of special importance to her. Whether enjoying the benefits of journaling to express her feelings, revising what had been a negative bias toward doctors and nurses, summoning the courage to undergo an invasive procedure, or making sure she made her own food choices every day, Jane found ways to exert and maintain some semblance of personal control and victory in the face of inconvenient, uncertain and often unpleasant circumstances.

...[O]nce I was in there and I realized that...I was probably going to be there for a little while, hopefully, I decided to keep a journal. ...I started it the day after I got in the hospital. ...I was able to get out all my feelings out and write it down, um, and I was just fortunate enough to have a journal at home. So...if I could suggest anything...the hospital could have maybe journals on hand to give to the mothers that are put in the hospital unexpectedly, to be able to write down what their thoughts are. Because...it was helpful for me that I could have a place where I could complain and not complain to my husband or complain to the nurses; I could get that out and not have to make everybody else have to, you know, suffer with that. ...[P]rior to having my son, I, I hated doctors, I hated nurses, not personally, but I hated...going to the doctor, being checked, getting my blood drawn. Um, in fact, when I had to get my blood drawn before I was pregnant the doctor had to give me some medication to calm me down so I, 'cause I was so nervous. But...here I was thrust into a situation where I was in the hospital, I had to have an IV, and I had to like pretty much suck it up and deal with it 'cause I was being stuck all the time. Um, I had people coming in and looking at me, and doing exams...even though I didn't like it I got used to it. And I felt...what I had to do was look at it from my perspective. When I went to college I had to go into a classroom and I had to practice with kids...before I became a teacher.... So, I just had to look at it: I'm helping these

nurses and doctors...that are training to learn how to do...their job. And my sister is a doctor of physical therapy, my brother's...an RN, my cousin and his wife are both in medical school, so I figured, you know, I'm helping somebody else...then in turn, maybe that will go back to my family because people are helping them out. So...even though there were lots of different doctors coming in and some of them weren't very experienced because they were just learning...I felt good about doing it because I was helping them learn to be doctors. So, um, that kind of made it a little better. Um, I don't know who it was that suggested it, but one of my wonderful nurses suggested a PICC line very early on, um, because I kept saying, "I hate getting stuck." And the possibility of me being in the hospital for a long period of time was there. And when they told me they were going to have to change my IV like every other day I was like, "You've got to be kidding me." And even though I was terrified to go down and get that PICC line, because they tried to do it in the room and it didn't work. So they took me down to, um, I guess like...an operating room type place, and it was very scary, it was very sterile and cold, and they put these warm blankets on me and it was...freezing in the room, and um, they were going to be injecting things into me and looking on monitors, and I was thinking, "Oh my gosh, they're going near my heart, you know, what could go wrong?" It was the best thing ever suggested to me because I didn't have to deal with them every time they wanted to draw blood, they didn't have to stick me again 'cause I, in the very first entry that I have I, I'm counting how many...times I've been stuck with the needle...to get blood work done. Which shows you that that's all I cared about, is you're going to stick me again? ...[T]hat...really made my stay a little bit better, because I didn't have to worry about getting stuck all the time. ...[T]he whole experience in the hospital, I felt...very much...out of control. There was nothing that I could control. Because if I started bleeding, you know, they would have to move me to another room...they would

come in and wake me up in the morning to do my vitals, and sometimes in the, at night...I had to, um, take a shower around the time that they were going to clean my room so that I would be out of the bed...and they could fix it while I was up... 'cause I wasn't allowed to walk around. ...I felt like...everybody was kind of managing my life. And the only, this sounds really silly, but the only thing that I could control was my menu, that I could pick what I wanted to eat that day. And...so, that was very important to me...that was really the only thing I could choose to do.

Jane recognized the value of the practical help she and her family received from the hospital staff. Recounting examples of this included a vivid description of the unique circumstances that led up to her son's birth and what took place immediately afterwards. Once again, the importance of contextual details within her narrative is clear as is the tone of personal victory.

...I feel like the staff in the hospital, for the most part were very understanding, very helpful. They listened to my husband talk their ear off 'cause he just can talk and talk and talk. ...[H]e didn't know what to do what to do with himself...he didn't know whether to stay, to go home, to go back to work, is this baby coming now, is it coming later?

...[O]ne thing...I did appreciate was that the NICU staff came up and visited me and said that they had a space set-up that they had baby [last name]...and they were keeping track of how many weeks I was...so they were ready to go at a moment's notice should he decide to arrive. Um, and the other thing that I really appreciate is that my sister and my mom were allowed (pause) to be in the room when I...started actually going into labor.

...[T]hat...happened...the night of the tornado that came through here. I think that that's probably why it happened, because of the pressure changing. ...I started having pain different than I had had the entire time that I had spent 5 weeks...in the hospital. And, um, all I can remember from that day is looking outside and thinking, why is it so dark

out? It was the middle of the day and it was, like, pitch black outside. And, um, I didn't really have any idea what was going on, I just got, heard little snippets that there was something, a big storm going on. Um, and I'm thinking about, if my memory correctly serves me, about 5, 5:30 I felt...that pain.... I called the nurse and they came in, they checked me, they decided, "Ok we're going to move you to labor and delivery." And I'd gotten hold of my husband. My mom and sister were able to come before he got there. He had to actually go around a road block to get here because there was a tree was down. He's like, "I'm coming through, my wife's having a baby and you're not going to stop me!" So...they were very busy that night and...there was only one nurse able to try to get a catheter in me and she was having trouble. And my mom, who's a...RN, slapped on a pair of gloves, and she's like, "Here, I'll hold, help you" and she helped get the catheter in 'cause I...was terrified of any procedures or anything. And, um, I kept saying, "Just knock me out, just knock me out, I don't want to be awake during this procedure," 'cause they were going to have to do C-section. And...they kept talking to me and telling me, "No, we should do a spinal." I'm like, "I don't want you sticking anything in my back, I just want to be knocked out." And they were persistent and finally they talked me into it, they got me to let them do that. And...I'm glad that I was not asleep during the procedure because I got to hear him cry. ...I couldn't hold him, they took him right away, but I heard this teeniest, tiniest little cry and I thought, at least he's breathing [Jane overtly crying]. So, um, they whisked him away. Um, I did not get...to see him that first night because I was recovering. But they, my mom and sister got to see him, and my husband, and they brought a Poloraoid of him. So that's what I had, the very first that I got to see of him which was very nice. Um, because we didn't have a digital camera or anything like that so, that I felt was very nice that they took that picture so that I could see him.

...[W]hen I was finally able to go down to see him, um, they were very helpful. ...I was

surprised at how the nurses handled him when they brought him, when they took him out of the...isolette...the one nurse just picked him up, put him over her hand like this and...I was like, "*What are you doing?*" ...I just felt that the staff was just so helpful and explaining things to us and telling us what all the monitors were for...because you live your life by those...you're looking at those monitors and looking at them going up and down and ok, is this all right or is this all right?

At this point in the narrative Jane delves in greater detail about her experience in the NICU. Jane reveals how precious the time during those early days and weeks was with her son. Although she cannot recall all the details of that time, she concludes she should have been with him in the NICU more than she was, to have had more memory-making moments together. She also makes evident the powerful influence of the NICU staff, both for ill and good, as they interact with parents and other family members of preterm infants.

...[T]here's only ever one time that I ever felt that...anything was ever said that upset me. ...[M]y grandmother came in and she got to him to hold him and she was sitting in one of those rocker chairs and she was rocking him and one of the nurses came over and...she said, "Oh please don't rock because...we've found that babies that are in the NICU that are rocked later on in life get headaches." ...[W]hich devastated my grandmother because she was like, "I didn't know, I didn't know!" And she was so upset...it was just a very gentle rock that she had and, and that kind of spoiled that moment for her. 'Cause she was holding him and...I did not want her to feel like she was doing something wrong. And I said, "Don't worry about it, don't worry about it...it's ok," and so she stopped.... ...[L]ooking back on it now I wish I would have spent more time at the NICU after he was born. I don't know if that was more because...I had to get rides to come up here...because I couldn't drive. ...[B]ut I feel like I should have spent more time. I, I look back on it and think, "What was I doing that I couldn't have...been at

the hospital?” And I wasn’t working...I was thinking about that the other day, I was thinking...“Why didn’t I spend a lot of time at the NICU?” And I don’t remember why I didn’t, but I wish I would have, because those are moments that I can’t get back.

But...life goes on.... ...[T]he best experience that...I had and scariest was when the nurse told me I was giving my son a bath. And I was like, “You, you want me to do *what?*” And she brought out this little round basin and I thought, “Oh my word...it’s not very big.” ...I was thinking, “Oh my goodness, what if I drop him?” Um, but just being able to ho--, that, that to me was a moment where I felt, “Ok, I can take care of him, he’s going to be coming home soon” [Jane overtly crying]. ...[I]t just amazed me that this little thing was growing...and now he’s 5!

Jane voices gratitude that despite the problems with her health discovered during her pregnancy, her son is doing very well and has not displayed any lingering ill-effects of having been born preterm. Jane depicts her son as a bright, well-rounded little boy who is a source of blessing. Watching him grow up healthy is all the more meaningful for Jane when considered in light of her health problems, and that because of them, she has been advised not to attempt another pregnancy.

...[W]e are so blessed because essentially he’s perfect. ...[T]here’s really not anything wrong with him. ...[H]e did have problems at the beginning with his ears, he kept having ear infections. ...[O]nce his tubes were put in he started talking and now we can’t get him to shut-up. He just talks and talks and talks. ...I just keep looking at him, I think he gets taller and skinnier all the time. ...[H]e’s very energetic, very smart. ...I took him to uh, kindergarten registration ‘cause I thought, ok, he turned 5, so we’ll see. ...I knew the...kindergarten teacher that was doing the...testing and I said, is he ready? And she said “No.” That kind of hurt me a little bit but then I thought, you know what, he was only due in October; if he was born in October he wouldn’t be even considered to go to

kindergarten yet anyway. ...[B]ut that educator part of me was like, "I gotta know."
...[H]e asks questions. ...[T]he other night he said... "What does 'before' mean?" And he makes me think. And I'm like, "How do I explain *before*?" ...[H]e asks questions, he loves to learn things. He's...very energetic, he's very athletic, he can pick up a bat and ball and he can play pretty good baseball...he likes to color, he loves to sing. ...I just find myself very fortunate because...my boss, her son was born at 29 weeks, however, she did not have that benefit of having 5 weeks...in the hospital with a controlled diet and steroids to help accelerate his growth. And...he's over a year now and still not walking, has vision problems. ...[my son] didn't really have any of that. He walked a little later than his peers but it wasn't an incredibly...long amount of time. ...[S]o, I find myself thanking God every day that we have such a healthy little boy. ...[E]specially since...upon having him early and the reason why I was sent to, to be checked because I was spilling protein...and during all of that they discovered I have kidney problems; I have proteinuria. Didn't know I had it before I got pregnant. Probably would have never found out I had it unless I had gotten pregnant. And so, um, they advised me, they said, that if I really, really wanted to have children they would...help me, but they really suggested that I do not try to have any more children because the chances of having another child that is preterm is very high. And the chances of it hurting my kidneys so much so that it really affects my health are very high. So...he's our one and only. ...I don't know how I could handle more than one child. ...[T]hat was a hard decision to make...but the doctors were very helpful. They did a lot of tests. ...[I]n the end my husband decided to have a vasectomy. Because he said I went through an awful lot to have him, he didn't want to send me back to have my tubes tied....

Jane indicated that in general, her most significant support came from her husband and other family members. When asked to elaborate on the type of support she had and had not

received, not only at the time of her son's birth, but in the intervening years, Jane focused on support from various sources that not only enhanced her son's well-being but met a variety of needs for her and her husband. Jane makes clear that a key ingredient regarding the issue of support was her willingness to accept what was offered, when her experience, knowledge, or resources were limited.

...[My son's doctor]...suggested early intervention and they came in... 'cause I didn't know what to do. I mean, I could read all the books...you know, "What to Expect When You're Expecting" and then you have those, "What to Expect in the First Year", and those milestones; I had nothing to compare to because I knew he wasn't going to meet, reach those milestones according to those books. ...But they came to the house and they said, "Ok, this is what you should be looking for. And if it's not happening, this is what you should be doing to help it." Like rolling over...or crawling, or grasping toys.

...[T]hat was very helpful to me to know, as a mother to know, ok, I, I could read all the books I want on how to help my child grow and... reach milestones, but, he's not going to make them there. And, and they said, "Ok, now he should be doing this, now he should be doing that." ...They gave me activities to do with him...I would get down on the floor and hold a toy and hold it over here so he had to roll, kind of roll over and reach for it....

...[L]ooking back, even a little further, um, just before we left the hospital where we got to spend the night in that room at the NICU...we were pretty much on our own, but if we had to, we could call a nurse to help. And that I felt was...great because I was a little scared to take him home. 'Cause I thought, oh my gosh, what happens if he stops breathing, what do I do? Um, how do I mix formula, that type of thing. ...[I]t was...not a crutch, but, but a way to step you down from totally being supported by the nurses, to going to home. It was kind of an in-between thing. ...[T]hat was very helpful. ...[W]e were close enough that we didn't qualify to live in the Ronald McDonald House,

however, money was very tight. Um, I was expecting to work all summer and I didn't, and my husband had lost time at work because he was with me. And...even though [our town is] not that...far, at the time gas money was a real...big burden on us. ...Isabel's Hope...helped us with some rent money. ...[W]e were able to give back later on...a friend of ours gave some donations for their fund-raiser. Um, my dad gave some, some things as well....so, that, that was helpful. ...[T]hat I think was another reason why I was held back from coming up to the hospital as much as I wanted to while he was there. ...I think I was able to make it every day, except there was one day that schedules didn't work out and I just couldn't get up to the hospital and I was devastated. I called the nurses and I was crying, and I said, "I can't come today!" And they were like, "It's ok!" ...[K]nowing that I could call at any time, that was also a good support. ...[A]s far as...my family being supportive, um, by helping me...getting him to doctor's appointments. ...[T]hat whole first year was hard because they told us not to put him in daycare. So...I was fortunate that my husband's schedule worked out so that I could substitute teach some. ...[F]or about the whole month of November my mother-in-law came from Michigan and stayed with us. Which looking back on it, she passed away in 2007...I am so glad that she had that time that she could spend with him. ...I wish he could be with her now, but he, he talks to her. When it thunders and lightnings, he says, "Hi Mamaw," 'cause my husband told him that it's...Mamaw bowling, saying hi. 'Cause he was always scared of the lightning and the thunder.... ...[T]hat was hard that first year...working around my husband's schedule and my schedule so that we could have income and be able to...keep him at home. Um, we did have to go on food stamps. ...[T]hat was harder for my husband because he had some experience with his own family members, some family members that were on assistance and were...abusing the system and he...was very much against it. And I said, "We, we have to, because we just

don't have," we didn't have the income to even get enough groceries. And so...we went on food stamps and I did get WIC and that was very helpful because he had to be on Neo-sure, which is a very expensive formula. We would have never been able to afford that. So that was very helpful. ...I'm trying to remember back if somebody said, "Ok, you need to do this, this and this" or if I just kind of figured it out on my own; I don't remember. ...[B]ut I have seen other people that...needed that help and have not gone after that help. And I don't know if it's pride that's kind of standing in the way or if it's that they don't know what to do, but...I wish I could remember...I'm pretty sure that somebody told me, ok...you should do this and this. ...[O]ur regular medical insurance was not going to be able to cover everything. And somebody came up to me in the hospital and said, "Here's the papers you need to sign and we'll get you Medical Assistance, we'll get it for the baby" and I would have never been able to do that on my own. ...[T]hat...was wonderful, that I didn't have to worry about that, my husband didn't have to worry about that...we knew that everything was going to be taken care of. ...[W]e didn't have the extra income to pay for it.... It was just somebody that showed up and said, "Ok, sign here, sign here" and it was taken care of. ...[T]hat was a big thing. ...[W]e had a...case worker assigned to us that helped...with getting a pump...so that I could have a pump to pump for [my son]...and also...for making sure that he had the right medical benefits...because he would have a lot of doctor's appointments. ...I always found that when I called [the doctor's office]...I got good help from the nurses when I called, if he was sick or...anything was wrong. In fact, I'm...trying to remember how hold he was, that they actually called me to double check on his information 'cause it had been a while since we had been there. And I was thinking, you know, it really has been, and, and we had been going a lot, I mean, pretty much every month I think we were probably there. And that's when I was kind of was realizing, you know...we have a, a

really healthy little boy here. 'Cause once his ears were taken care of he wasn't sick anymore. ...[T]hat's a turning point to me...when they called and said, we need to check your information, I'm like, "Has it really been that long since we've been there?" ...I feel like I'm jumping all around. ...(pause)...my parents have been very helpful as far as...little things like, I get stuck at work and I can't pick him up from daycare, they'll pick him up. Or...if we need a baby-sitter...they'll watch him. ...I feel fortunate because I know, I have friends that don't have that support system. ...[T]hey don't have people they could call in a pinch. ...I feel like...I'm fortunate because I have both my parents. ...[M]y brother lives in Boston so he really wasn't around a whole lot, but my sister...she was...in school at the time, but she happened to be home on a break...when this whole thing started. ...[B]eing able to have family around like that is really, really kind of helpful...I feel fortunate for that 'cause I know that there's a lot of people who don't have that.

When asked if there has been any kind of support particularly meaningful and helpful to her personally, Jane struggled to know how to respond.

Um (pause)...you mean as like, to help me? Mm (pause)...I don't know, I don't put the emphasis on me, it's more on him. Um (pause)...I don't know. I hadn't really thought about that 'cause, you know, my, my thoughts have always been...how am I going to help him, how are we going to, I don't know. I don't know! I don't think that...I can't, I mean, I don't know that there's anything that I, I ever needed that I didn't get, but, um, I don't know...maybe later that will come back to me or...come to me, but...(pause)...

Jane was asked if there was a word or phrase that comes to her mind when she thinks about what it has been like for her to be the mother of her son born preterm but who is now 5 years old.

The word that's coming to mind is adventure. ...[B]ecause...I feel like it's been, it's been like a, a roller-coaster ride. ...[W]e would get so excited, oh he rolled over. Or, I would call my husband with little things like that, like, oh...he can sit up by himself, or he picked up a toy by himself, or little, little things.... *We would celebrate the little things.* ...[S]ometimes, um, it's frustrating because I look at some other kids and I think, "Oh, well, why isn't he doing that?" But, at the same rate I can compare...to some of the other experiences of people that I know and I see that I really don't have anything to complain about. ...I mean, there were times that we were scared that he was sick or we weren't sure what was going on, he had a high fever...but he's never been like so sick that we were really, really scared. I mean, he's never had to be admitted to the hospital. ...[O]ne of the things that we agonized over for a long time was whether or not to get him circumcised. ...I think that was probably the, the biggest thing. ...[W]hen he went in to get his tubes put in...he was little...he didn't really know what was going on. Whereas when he went in to get his circumcision, he kind of knew what was going on a little bit more, and...it just kind of made me a little nervous. ...[B]ut the part afterwards was like the hardest part. When I saw how horrible his, his penis looked, I thought, "Oh my gosh, what did I do to this boy?" ...[N]ext week he's going to...have his penis looked at again because he was complaining that it hurt and the doctor thinks he has a small urethra, so we're going to go through that. ...[H]e's never had any major, major scare, but it's been little like ups and downs. ...[H]e, he just amazes me every day when I come home and...he says something. ...[W]e have a snuggle night...every now and then. ...[T]hat was a one thing we had to get away from is him sleeping in our bed. And I think part of that is because I wanted him close to me. ...I wanted to make sure he was ok. ...[S]o, we got him out of the habit of sleeping in our bed. And he can sleep in his own bed. And then every now and then we let him come in and...we call it snuggle night. And we were

just kind of all 3 in bed and just talking back and forth and I was talking and out of the blue, he goes, "Put a pork in it Mommy." And so...we had a laugh at that because it's not a pork, it's a cork, you know. ...[H]e makes me laugh, he makes me mad...I mean, probably any emotion that...any mother feels...I feel.... And another word that comes to mind is very fortunate because it could have turned out a lot worse. ...I know that he was, he was taken care of very well in the NICU. I was taken care of very well in the hospital...I think that's pretty much why he is the way he is. And...even though it was a hardship to be in the hospital that long, I know that that was the best thing that ever happened. So...I'm proud to be his mom...I think he's going to...just out-shine us all. 'Cause ...I think he's got the best of...my husband and I...in him. And I see, I see nothing but potential for him. ...[S]o, I have great expectations for him. And as long as he just keeps eating...but I look at my husband's history...and my history. My brother was a little skinny, he was skinny when he was little, so's my husband. ...[I]t's interesting to think, "Ok, is this because he was born early or is this because he would he have been that way anyway?" ...[M]y brother and sister needed tubes in theirs ears.... Would he have needed tubes if he was born full-term? Probably so. ...[W]ould he have had issues with his penis...because he was born early? I don't know. ...[H]e hasn't had anything that we can really trace back and say it was because he was born early. ...I was always worried you know, they'd tell us his oxygen had to be monitored very carefully.... He can...see probably better than I can. And...one story that I, I can't believe this. ...[H]e's very used to doctors and getting checked out, 'cause...that was the whole beginning of his life. But I took him to the eye doctor once and he fell asleep in the waiting room. And the eye doctor did the entire exam with him asleep on my lap. This was when he was little, and I mean shining...his bright lights in his eyes, and I thought he's going to wake up. He slept the entire time. He had to have his tooth fixed because

when he was about, I would say 1 ½, 2...he was running around and he fell and he chipped his tooth off. And just recently we got it fixed. And he laid there on that chair, they were filing and drilling and putting goop on it and in his mouth, and shining light and sucking stuff, and he laid there, perfectly still the entire time. And I thought, I'd be wiggling in that chair if that was me. So...he just amazes me every time something else happens, you know?

Jane was asked to imagine that she was given the opportunity to talk with a group of nurses, none of whom had ever encountered a mother who had a preschool aged child born preterm. She was then asked what she would want the nurses in that scenario to know about her, about what her experience has been like as it pertains to *her*.

Well, I've for one become more used to people looking at, at me and doing exams, um, because I had to get used to it in the hospital. ...(pause) [I]it's hard to think about myself when I...I don't, I don't know, I mean (pause). Well, that, I guess that I was nervous that there was something wrong with me that made him come early, which in a sense, yes there was. Um, but I know that with some preterm babies, they don't, you don't know why they came early. So...just to, I guess, make me feel, I don't know...like, they're on the look-out to make sure there's nothing else wrong. Um, (pause) I, I mean (pause) I think it's important to be honest with me, to tell me what's going on, you know. ...I don't like to know gory details, but, you know...I don't know...it's so hard, hard...I don't know.

Jane struggled once again regarding how to verbalize elements that pertain to her alone. Her quiet weeping begun at the start of her narrative continued, yet this non-verbal behavior seemed incongruent with the content of her spoken narrative. In an effort to clarify what she was intending to communicate, the following observation was made by the researcher:

Cherie: You know, it's interesting, I can tell that...you're easily touched by this topic...I can tell by...the look on your face...and your tears that this really touches you. ...I'm wondering, what about *that* element of it? Maybe they [the nurses in above scenario] wouldn't understand, this [experience] is so important to me, this is so meaningful to me and this is why. What's the "*why*?" Why is this so, why does this touch you so deeply?

Jane: Well, [crying] because I'm done having children. And as much as I feel like I'm ok with having one child, um, there's a part of me that still would like to have more. Um, *I feel kind of broken*. Not that I usually think about it that way, but... I feel like (pause) I'm kind of sad that I can't have any more children even though I know there's lots of other...options for us. We...could adopt (pause). I don't...know if this is appropriate to go into, but...I sometimes get a little jealous...of women that kind of flippantly talk about being pregnant. I never thought about how difficult it was to be pregnant and have children until I had my 1st miscarriage and then after I had [my son] then they said, you know, you really shouldn't have any more. Because, um, growing up I had, I have an aunt, she has 7 children, she just kind of like popped them out. And....so to me, having a baby just seemed like, you just did it. ...[T]here was never...that experience within...my family of having difficulty with pregnancy, at least that I knew. [T]he other...part that...I felt bad about was...I did not produce very much breast milk. ...I pumped and I pumped and I pumped and it would just barely cover the bottom of the bag that I would take in. ...[T]his is kind of funny: there was a lady that was in the crib room with us. She had triplets. And she brought in her bags of milk one day...when my husband was in there. She had bags that were like, brimming with breast milk. And my husband goes, "You can get that much milk out of a breast?" And I said, "Yes honey, mine don't work." ...I understand why, I mean...he was born early...my milk just never came in, I didn't have

him there nursing to stimulate the...milk production.... I felt like I was being pressured to pump and to produce breast milk. In fact it went so far as I...asked my mom...for money to get some, uh, pills...natural supplements. I can't even remember what it was called, but I took them and I broke out in a rash from head to toe. So I couldn't take them and I felt bad 'cause...I didn't have the money to, I was trying to do everything I could to try to produce this milk and...when I finally was able to try to nurse with [my son], he was not having any of it. ...And, and at that point I was thinking, you know...I'm putting myself through a mess because I'm not pumping and then I get depressed because I'm not...producing milk, and then it's kind of a vicious cycle. And...then when I told...the nurse that I was not going to be pumping any more they kind of made me feel bad about it. ...I understand how important it is...there are nutrients and things that are in that, but...it wasn't working for me and that...was one thing that I felt...could have been handled maybe a little differently. ...[B]ecause I was feeling bad because I wasn't producing milk and then when I decided, "Ok, we're going to go a different route," then I was still made to feel bad because I didn't follow through with it. ...[A]s, as I'm talking, these things are coming to mind. And...I know that's their job is to try to get mothers...to breast feed but, be a little understanding as far as you know, ok, we tried. I mean...I pumped for, I'm thinking 2 good months. ...[P]art of the reason I think...when I left the hospital after having him, I came back to the hospital not too long after that 'cause I had...an infection in my uterus and blood-clots. Then I went home for a little while longer. I was back in the hospital because my bladder had backed-up into my kidneys and enlarged my kidneys. So, I was back and forth in-between the hospitals. ...[T]he 1st time I came back I came here, next time I came back I went to [the local] hospital. So I couldn't see [my son]. I...was trying to pump in a hospital room with somebody else in the hospital room with me, it was female, but at the same rate there was somebody else in

the room, it wasn't a private room. ...[S]o, I had those issues on top of worrying about him being in the hospital...so...all of that helped to not make pumping and trying to give him breast milk to be successful. ...[T]hat's another reason I didn't visit him in the hospital; I was in the hospital myself. ...[L]ike you were saying, support, you know, support not necessarily to help me to pump but to support me in my decision to stop doing that, that it was ok to...not do that. ...I guess that would be something...about me that...would have been better.

Despite a lack of nursing support for her decision regarding breast-feeding, Jane stopped trying, finding an effective way to regain control over the situation, on her own terms. Jane reveals the importance of healthcare providers being sensitive to how their words and actions may be perceived by a mother and of approaching a mother from her perspective. She makes clear that a mother's perspective encompasses more than the immediate situation; it includes the elements of her child(ren), other family members, work, and various stressors, with the underlying goal of making it all work.

Well, and I think that sometimes...the intention is not to make you feel bad.... ...I find that even in my...job...you have to kind of sometimes step back and take it from the perspective of the other person.... ...I'm sure that that nurse didn't or wasn't intending to make me feel bad that I didn't pump and that I was stopping. But, but that's what happened. That's how I felt, that's how it was perceived. But, I mean, overall I feel like my experience was good...not that I'd ever recommend having a child early to anybody. But...I feel very confident...in the facility that's here and staff that's here. ...I feel like for the most part they were very helpful...I had questions or concerns...I could ask. ...[M]y husband got to know the hospital very well...it was like a 2nd home. And...it's stressful on the families, too. Because my mom and dad had, they had to re-arrange their schedule to come up and visit me. ...I stressed my job out. I was glad they took me back

because I was supposed to teach all summer for them and they had me on the schedule every day. I taught one day of the summer schedule and then I was gone. ...[T]hey had to scramble and...find somebody to replace me. But they were so willing to take me back then afterwards. And...one thing that I would say is just to be understanding that in the hospital, that's stressful...first of all you're stressed 'cause you're in the hospital but then you're worried about all the things going on outside the hospital that you have no control over. ...[I]t's not surprising to me that I don't remember a whole lot...because there was so much going on. ...[M]y husband did a lot of the worrying for me...he would tell me not to worry 'cause he didn't want me to stress out while I was in the hospital. But, thinking back on it, you know, it was a crazy time. And...even as he was growing up...one day...I wanted to vote.... I remember...[my son] had come home from the hospital and I bundled him up...and I took off and I walked to the, the place to vote. Another day I did that and I got on the bus...to go to a doctor's appointment. ...[O]ne time I think I even went to a gynecologist's appointment with him in the stroller 'cause I didn't have anybody to watch him. And, you know, *you just did what you had to do*. ...I would just sit in the waiting room in, of the doctor's office and I think...I have a lot of stuff now...and then there's kids that are in wheelchairs and have oxygen tanks, and you know, made me appreciate what I had. And I think sometimes understanding that when mothers come in with children in the doctor's office and making them not feel looked over or rushed or you know, understanding that they have a lot of stuff with them, and...sometimes they can only get an appointment that's in the middle of the child's nap and the child is...horrible, just completely terrible.... ...I had an experience...just recently...at the dentist. This is...before he had his tooth fixed. He was a perfect angel when he got his tooth fixed. When we went the 1st time, he pooped in his pants and he had...been potty-trained...he pooped in his pants 'cause he didn't want to stop playing.

...[I]t was a new experience. ...[T]his is a dental office but the...person came out, didn't introduce herself, didn't say, "Hey [my son's name], how are you, thank you for coming, you know, we're going to do this and...". She just took him back, slapped him in a chair. I was made to sit on a little kid's chair. I didn't know what was going on. And...he was terrible, his behavior was awful because...it was in the middle of his nap time. ...[A]nd it was in the winter time and...his cheeks were chapped. The dentist came in and said, "Why are his cheeks all red?" And I said, "They're chapped from being outside." "Well, that looks terrible." And I felt like this big. And...he didn't even introduce himself, didn't say, "Hi [my son's name], how are you, we're going to look at your teeth today and...". He wasn't very kid friendly at all. ...I came home and said, "I'm never going back to that place again." Now thank goodness I went back...I'm anxious to see how my husband's trip is there this Thursday 'cause he's taking him there for his next dental appointment. But that 1st time...I was belittled as a mother 'cause...he pretty much yelled at me for having my...son's cheeks chapped. And...[my son] was not made to feel comfortable. I...kept saying to them, "This is his 1st time in a dentist's, he doesn't know what's going on" and they didn't make him feel comfortable at all. I was trying to make him feel comfortable. ...I love it when I go into the doctor's office and the nurses say, "Hi [my son's name], how are you? We're going to do this today" or... "How...are you doing?" ...[T]hat makes me feel comfortable to take my child there. Or, "...mom, how are you? What's going on?" ...[K]nowing...they are concerned about...asking me questions or telling me what's going on and saying, "Ok, this is what we're going to do" so I know what's happening so I...can make him feel better. ...I mean, those are...things that I think are helpful when you go into any doctors' offices, when they engage the child and talk to the child as well as the mother and...not like you're another millionth person that they saw that day. ...I know sometimes it's very hard because you have a whole

long list of kids and they're not always in the best mood and they're sneezing and coughing and grossing all over you.... But, just that extra step to be...courteous and smile and say..."How are you?" ...I mean, that's very helpful. ...I never had an experience like that until I went to that dentist. ...I've had good experiences at doctor's offices and...the hospital... When he had to have his surgery...they...gave him a toy...little things like that...that makes me feel better, makes my day a little better when you're nice to my kid, you know?

As Jane anticipates her son's eventual start at school, she acknowledges the reality that her son was born preterm and there may be issues that surface in a school environment related to that. She voices some concern regarding his social interaction with the other children but what is of greater importance is that his educational experience will be all it can be. Being an educator has helped her to see the wisdom of not pushing him to enter kindergarten quite yet but she admits to feeling guilt over not having prepared him adequately to do that right now.

...I worry 'cause he's small. I worry that he's going to get picked on. I worry that he might pick on the other kids. ...I look at it a little differently I think 'cause...I'm an educator. I want to be an involved parent but not...a bothersome parent. ...I want to...make sure that he's getting a good education and...to have...a successful, um, experience at school. ...I think his teachers should be aware that he was...an early kid but I don't want that to be limiting for him. Um, I want to make sure that they don't give him a, a break because he was premature. I want them to...still challenge him and still push him to do better. But I want them to know that, so that...if there are some issues....

...I want him to be able to be right there with his peers. ...I'm not too worried about it because...just in the last couple of months I've seen him mature a little bit and...I can see that he's starting to learn things that he didn't know before. ...I'm glad I waited to put him in. I could have probably pushed to have him put in, but...I think in the long run it's

going to make a big difference and that he will do much better because of it. ...[B]ut I had to check. It was one of those things where, I, if I had not taken him to kindergarten registration, I would have...always wondered...would he have been ok, you know. ...[B]eing in the position that I am, the...job that I have, I see kids coming in that parents have put them in early and they come back and they come to me and they're not doing well in school and they say, I wish I would have held him back. And...so...I'm being a little better with myself.... ...[B]ut at the same rate, I'm like, he's my son I should have taught him all this stuff, he should know all this stuff. ...[H]e told me the other day, "Mommy, when am I going to kindergarten?" I said, "Not 'til next year, not this year coming up, but the next year." "Well, I don't want to go to kindergarten".... And I'm like, "Ok, well, good, that's good 'cause you're not going." So...that was something I had to work through myself because I thought, you know, he's going to be older than his classmates...but, I, I've worked through that and I see the benefit of it and I think he'll do much better given that extra year.

As the interview drew to a close, Jane revealed that sharing her narrative had reminded her of things she had not thought about in a long time. She indicates that such a review was timely since the interview was conducted near her son's birthday. She associates the anniversary of her son's preterm birth and the treasured artifacts connected to it with good memories and gratitude, acknowledging that the outcome of his preterm birth could have been very different. Jane ends her narrative by voicing thanks for the help extended to her and hope that other mothers will benefit from her experience.

...I've talked a lot. There's a lot...that I had not thought about in a...long time, there's a lot of things...that you reminded me of, that...I didn't think about.... I think pretty much...I've gone over everything. I mean, this is a good time to do it, I think about this around this time of year all the time anyway. I...usually pull out the pictures, and look at

the pictures. I have a box at home that I have...one of those teeny, tiny little outfits that he wore, it has his little...blood pressure cuff and...he's old enough now that I can pull that out and say, "Hey [my son's name], you used to wear this, look how little this is."

And I pull out that little diaper and...it just reinforces to me how blessed I am. ...[T]here might be mothers that have premature children that don't do that, because that was not a good time for them...because they had...medical issues or things like that. ...[S]o, I feel like I'm fortunate. ...[B]ecause...I can look back on that time and, and have good memories. ...[T]hat's one thing that I just have to say over and over again, I'm very fortunate, because I know not all premature babies turn out as well as my son. ...[H]e's a pistol. He'd talk your ear off and...tell you how it is. He knows all the right answers. So...I think I've pretty much said everything I feel like...I wanted to say, even more, stuff I didn't even think that I would talk about.... ...I want to help other mothers have a good experience. If I can help any other way, just let me know. ...I feel like I was given so much.... ...I still have a lot more that I need to give back. ...[T]hat's really why I did this 'cause I feel like, if I can help just one other person have a good experience, then...I'm kind of paying back the good that was done to me....

“Savor the Moments”

In analyzing Jane's narrative, the distinct message that surfaced was “savor the moments.” The attention to contextual details was evident from the start and remained strong throughout her narrative, as if no aspect of her experience was too insignificant not to mention. Starting her narrative with her prenatal hospitalization versus her labor and delivery suggests every element of her experience as a mother was of special import and contributed to the meaning of her story. Reading Jane's narrative over and over again was a witness to her unpacking one precious

memory after another. As she recounted each detail, one could envision her telling the same to her son one day in the future, for example, of how his father was not to be deterred on route to the hospital, even in the face of a tornado (He's like, "I'm coming through, my wife's having a baby and you're not going to stop me!") and of how she will always be glad "...that I was not asleep during the procedure because I got to hear him cry. ...I heard this teeniest, tiniest little cry...".

The key in analyzing Jane's narrative came with her statement, "...I feel kind of broken." At that point in her narrative the deep meaning being a mother has for Jane emerges. She had hoped for many children; her son is their "one and only." The image she held of her *imagined* mother-self would never be fully realized. Her unsuccessful attempts at breast-feeding, despite drastic efforts to facilitate it, only compounded this. Jane treasures each and every memory and does not want to miss anything related to her mothering experience because she knows the opportunity will not come again.

The desire to savor every moment is also clear as Jane describes her experiences in the NICU. On one occasion, Jane's grandmother got to hold and rock her son. The dynamic of the visit changed as a result of a nurse's comment, "...we've found that babies that are in the NICU that are rocked later on in life get headaches." What should have been a special once-in-a-lifetime event it became one stained with unwarranted guilt and fear. Jane indicates that the comment "...devastated my grandmother because she was like, 'I didn't know, I didn't know!' And she was so upset...that kind of spoiled that moment for her." In contrast, Jane's description of "the best experience...and scariest" was when one of the NICU nurses told her she would give her son a bath. She explained, "[T]hat to me was a moment where I felt, 'Ok, I can take care of him, he's going to be coming home soon.' " Jane chides herself for not spending more time in the NICU, time that could have been spent making memories with her son (" 'Why didn't I spend a lot of time at the NICU?' And I don't remember why I didn't, but I wish I would have, because those are moments that I can't get back"). Only later in her narrative, as if remembering the past afresh,

Jane realizes that financial constraints and her own health issues that necessitated postpartum hospitalizations, prevented her from being in the NICU as much as she would have wanted.

Be it the celebrations of “the little things” in the course of her son’s life, the various kinds of support provided to her and her family since his birth, remembering the time shared between her son and now deceased mother-in-law, or the way healthcare providers interact with her and her son, Jane savors the moments associated with being a mother of her preschool aged son who was born preterm. Doing so has enriched her life with a sense of gratitude and a desire to help other women have an equally rewarding mothering experience.

Patty

“It’s Amazing”

Patty is a 26 year old, single mother of 3 children: a boy 3 years old, and twin girls, born preterm in 2007. At the time of her interview, Patty was expecting another child. Patty is a full-time home-maker. Although somewhat reticent and admittedly nervous, Patty communicated her narrative with thoughtful intensity.

At the outset, Patty was somewhat uncertain regarding where to begin her narrative of being the mother of former preterm twin infants who are now preschool age. With the reassurance that she could start at any point in her experience, she began with their birth.

Um, well, since they were born 8 weeks early, it was unexpected and I wasn’t ready. And I had a, a 1 year old and so there was, it was a little hard at first getting used to going to the hospital, especially when one got out of the hospital and the other one was still there um, and almost died I guess. First she got sick and almost died. And...when they came home it was when like...reality set in. And I had 2 little babies that weighed 4 or 5

pounds and not sure what their future would be like. But...as they were growing...never was a time where they, um, were behind I guess. And...they always met...whatever they were supposed to do. Like, I was so worried being so early that they wouldn't...progress like they would, like they should. But...I guess having twins was a little harder than having just one. But it was, um, challenging to get used to, first of all, them being so little for a long time and I guess being, having, um, the preterm problems, like the, um, acid reflux was one...stressed me out so much, that every time they ate they'd throw it back up, *every* time they ate. So, that was, it was hard for about the first 8 months. That's how it was until they started really sitting up and moving around a little bit more was when it started clearing up. So, it got a little easier after they started eating regular baby food....

...I really thought it would be different than --- but I see them as regular, born-on-time, 'cause they...what's the word, they like met all their expectations and went past it and gained weight. And...it was like pretty much like the whole thing is just went like...a blur and like it's hard to like pinpoint a specific moment 'cause things were so crazy. ...I guess I was just too worried about them and I kept them too safe and now I'm realizing that maybe I did that a little too much. But, try to protect them, but...they seemed to have turned out, um, pretty good for what they went through. And I tried like, from the beginning, with me staying home with them, I try teaching them and making sure they hit all their marks. And when they get evaluated, making sure that they were where they're supposed to be. And, it, it was hard...especially having another little baby...a 1-year old when they were born. ...I guess the only thing I was...worried about is them sitting up on time and walking on time. And they didn't do that I guess when, when full-term babies do, they were a little older when they sat up and walked...but they're very, very smart. And people can't believe like how, how good they are doing. And it's (pause) I'm getting a little emotional talking about it. I guess it's just um, surprising how, how I dealt

with it by myself basically. ...[T]aking care of them by myself all day. And...as they were growing they just turned out to be...great kids I guess. And it's just, I can't, I can't even picture them now being little tiny 3 pounds...it's hard to even think about that. I try not to think about them being in hospital but it's...I'm sorry, it's hard for me to just talk. It's...been like 2 ½ years, it seems like...they were just born, like time flies by, flew by so quick. I don't even...know how 2 ½ years went by and it seems like it's been a couple months. ...[T]hey keep me busy. ...[N]ow...they're, I guess, bigger, bigger than they should be. And...I always get...questions everywhere I go. That is...the most stressful thing, is people asking me questions everywhere I go. I guess it, I don't know, if it's the twins probably but...then they ask me like 20 questions about how were they were born, how much did they weigh, and people can't believe...they weighed only 3 or 4 pounds. ...[T]he worst stressful is going out and people asking me questions and questions and then they find out they were born early and then they ask questions about that. People just can't believe...how they are now...compared to what they used to be and, I don't know. It's hard. It's just kind of hard for me...to think about like, what to talk about.

Sensing Patty was struggling a bit with where to go next in her narrative, I reflected on her statements suggesting she has cared for her twins essentially by herself during the daytime. With this in mind, I asked her to talk about the support she has received as well as the support she hoped she would receive but did not get as a mother of twins born preterm. The twins' father provided practical support, getting up with the girls during the night so Patty could sleep. But she relates with a tone of disappointment how little support she received otherwise, even from immediate family members. She had hoped interest and support would have been there, if not for her, than for the twins, but it did not materialize. Being faced with the sad knowledge that she was more or less on her own during most days, she approached her mothering and care-giving with a determination to do it without that support and to do it well. With the positive

reinforcement from Early Intervention staff that she was doing a good job, Patty concludes she is happy to have done it her way.

Um, yeah. I mean...from the time they were born...I was mostly by myself from 10 in the morning 'til 8 o'clock at night is when their dad works. And I thought maybe like people would come over, or, I mean not just to help me, but...to check up on things. But...I guess it was not right away. People just, I guess people thought that I wanted them to stay away or something but I wish people would have came over and helped, but. I was really by myself mostly unless it was on the weekends and a few people stopped by here and there but Monday through Friday I was there by myself unless sometimes my mom would stop by to take my son and give me a little break from him, but. It was, it was tough but I think I, I got used to it. And, the only, the good thing was I got to sleep usually through the night because their dad, since he was gone all day, he got up with them at night. That was the, the one good thing, so. But I think just having to do it by myself I got used it, and after a while didn't really want anybody to help, 'cause I have my way of doing things now. But it, it would have been nice like if, even if family members or *somebody* would have stopped by, but. I guess...if you don't ask they won't do it.... And I...didn't want to...impose on anybody else I guess.... ...[I]t's so hard for me to even to try and remember back that far.... I just, it's so, so used to my daily routine of having 2, it was nothing, like, out of the ordinary for me. So I had to and that's what I did. And it was, it was hard at first, that they were so little, they didn't fit in the swing or the bouncy seat or stuff like that, they both shared the same boppy, sitting on the couch.... I guess I just got...a routine early, had their naps...made sure that they were, like, I guess...treated right. And that's what...the people from Early Intervention always like compliment on, how well they're doing compared to other preterm babies. And, I

just, I can't think of any other way of just having done it. And...I guess I'm happy that I did it by myself.

Although Patty agreed that she has a good sense of pride about how successful she has been caring for her daughters, she appeared uncomfortable receiving praise for her role in their success. Instead, she focused on them, that they deserve the attention given what they endured as preterm infants and what they may yet experience because of being born preterm.

Yeah, I mean...it's how I feel but, I really don't like to show that. ...I just want people to focus on my kids. Bec--- just, I guess, just 'cause, like they deserve it, for all they went through. You know, all that they, well, all that they still have to go through. But I mean, they're pretty healthy, and I'm glad for that, but, one does have to see a cardiologist twice a year and that stresses me out but she's ok for now I hope....

When asked if there is something about her personally that is different than what she would have expected as a result of having her twin daughters, Patty acknowledges new-found inner ease and overall purpose, both made clear only after the birth of her daughters.

...[Y]eah, let me see, so much has [changed], I guess I'm more, I would say more like settled down. And I'm more, what's the word for...I, I feel like more comfortable with my life...it's so hectic and busy but...I just feel like this is what like my life was meant to be. Like...having 3 [kids] it's like, like, this is what I'm supposed to be doing. ...[S]ome people are meant to be out working and...doing stuff, and some people are meant for other things, but like this is what, this is what I should be doing. And before, I didn't...really feel this way. I mean, I had 1 [kid] and I thought maybe that was it. ...I just was working and had him in day-care and didn't get to see him that much but now I get to stay home all day with the kids it's like, that's...how my life is supposed to be. And now I'm more, more calm now and I have more patience and like a whole lot has changed.

When asked if there is a word or phrase that describes her experience so far of being the mother of children born preterm, Patty stated, "It's amazing."

...[Let's see...it's like amazing. I mean...from being born early to how they are now it's like, amazing how they, how you'd think like, babies born early they have problems, they have like issues or developmental. And...just in 2 ½ years it's like things have changed dramatically and they have changed.... ...I mean, it's like a miracle...how they turned out healthy. And...they don't have any...developmental issues or anything and I don't know what I would do if they did. ...I believe it's just amazing...how they turned out.

Patty was asked to share what it is about her experience of being the mother of former preterm infants now at preschool age that she would want those in nursing to understand about the mother in that situation. In response, Patty reveals that underneath her calm exterior is a confident woman with strong opinions about what is right, particularly with regard to her children and how to care for them. She knows what works and what does not and she has a low level of toleration for different approaches suggested by others, especially those who think they know what her experience has been.

Um, well, me personally, um...I don't want to say I have high standards for certain things but I need, I, I really need things...my way and if somebody else tries to do things differently than I would do it, it kind of, I guess irritates me. 'Cause I, I guess I think, I think I know what the right way should be. ...[A]nd making sure like things happen the right way. ...I will take input but if it's not something that I think is right, then I would still just do things my way. Like...I'll listen to what anybody says, but...it comes in one ear and right out the other if you think, especially when people think they know...what I'm going through or they try to pretend or they try and they think they know. But I, I really just have become like so, I would say...uptight...if something doesn't go the right way...I have to change, like, change it and make sure things go the right way or the way I

think it should be. Because I think I know over, over *anybody* what's right. That's the way I feel.

In the following exchange, Patty agreed with the researcher's observation that she needs others, in this case, those in nursing, to value her input and point of view, and to consider her in decision-making versus being told what to do.

Cherie: So you really need them to understand you've got to be part of the plan (yeah), your, your opinion, your perspective, not just "do this because," (yeah) no, you need to be considered in this (yeah).

Patty: I guess, I'm, I'm a little over-bearing is the word.... ...I've become a little...I don't want to say controlling, but a little bit, just from being too over-protective and trying to get out of it, but just over-protective.

Patty elaborates on her awareness that being over-protective of her daughters is not a good thing. Although difficult to do, she has started to revise her over-protective behaviors, in response to others' comments and the realization that her daughters are getting older. In contrast to her resistance to taking others' advice on how to do things right, Patty is sensitive and more receptive to change in response to comments about her personally.

Um, it was...it's basically what other people are saying about me, I guess. ...I tried to keep them to myself and not let people take them or hold them and...I do remember when they were first come home from the hospital I didn't want nobody to hold them, I, I didn't. And people started...saying stuff, but, as they got older and I'm realizing now that, or I have been realizing that, they're ok...and I can let go a little bit. But it's hard. And I've been getting better at letting them go off my themselves and play, or leaving them with people, but, maybe it's just like any mother, just, my kids and I don't want nothing to happen to them.... I see they're ok now and I guess it's time to like, let go a little bit. But it's still hard.

When asked if she thinks about her daughters' eventual entry into school, Patty indicates she thinks about it occasionally but she tries not to think about it at this point. She reveals her biggest concerns are whether she will have adequately prepared them for school when the time comes and if in the course of going to school a cognitive or developmental impairment related to their having been born preterm is discovered.

...I think about it, I think about it here and there. I just, and I think about, I hope they're ready. Mostly it's I hope they're ready. And...that I've taught them enough; that's mostly what I worry about. 'Cause I really don't think about them going to school yet, but I just think like, when they go to school, I hope they're ready, I hope I've taught them enough. And I hope they know enough...and then I hope nothing happens or shows up later like developmental problems or something from the brain, being born preterm, but, I try not to think about that. I kind of just go day by day.... I try not to think about them in school yet, it kind of makes me sad.... Yeah...if I could I'd probably home school them. I think they'll be ok.

After a long pause, Patty was asked if either her own physician or her daughters' pediatrician or the nurses in those offices inquire about her welfare. She indicates that this does not happen at her children's doctors' offices, that the focus is on her children. Patty hints that as a mother, she has grown accustomed to having her needs unacknowledged.

Um, not, not really.... Now, now that I'm pregnant again they do, when I go to my doctor, but never really when I go to the kids' doctors. People mostly just focus on the kids, usually always, everybody always just focus on the kids. Yeah, kind of get left out, but...that's all right.

Reflecting on Patty's comment, "kind of get left out" I asked her to return to the issue of support and to address what she would welcome in addressing her own specific needs. She identifies the need to have a break from being with her children all the time, for personal time and

time with her significant other, yet voices conflict between this need and what has become a persistent state of worry regarding the children's welfare. This state of worry prevents Patty from being willing to be apart from her children. Although this dynamic is stressful for her, Patty sees no realistic hope for its immediate change, resigned to this way of life until her children are older.

Um, probably being able to, like get a break once in a while is what I, is like, one thing that I really haven't had at all. Um, I'm with them like 24/7 and like maybe like a break, like, even like a day by myself or going doing something by myself. But it's, it's so hard, I don't want to leave the kids at home. And of course, I'm sure they would be ok if I leave them, but I worry about them too much. And I just, mostly it's just like having some alone time, some quiet time.... I mean there have been a few days, probably about like 6 days total since they were born that we had like a date, a date night for a couple hours. But like I would just like to have somebody watch the kids for me so I just maybe go do something by myself or, or like a whole entire night where the kids sleep somewhere where we could just...stay at home and have like a date and relax and not be worrying about what time to pick up the kids or something. Other than that I'm pretty much all right. It's just having a break once in a while. But, I guess the time will come when they get older, but I'm just too worried about them now. Part of it is my fault too, that I'm too worried about them and I don't want to leave them for too long, but. It's stressful sometimes. But other than that...things have been pretty good for me. And I enjoy staying home with them every day.... And some people could say they hate staying at home everyday with their kids and having to listen to them all day but, I enjoy it. It makes you...happier to be with your kids everyday.

At the close of her interview, Patty was asked if there was anything else she wanted to share in order for the researcher to better understand her experience. Patty made it clear that she avoids thinking about her daughters' preterm status. This avoidance is related to the unhappy

memories of seeing them in the NICU and a means to resist the assumption (and associated stigma) that children born preterm are impaired. Patty's desire is to see and treat her daughters as "regular kids," those without a history of vulnerability, and she hopes others will do the same.

Um...um...I don't know. It's so hard 'cause like it's hard to think of them as, I, I try not to think about them, the, the girls being preterm. I try not to think about...them being in like, on machines and stuff. ...[W]hen they were in the NICU...I try not to think about it 'cause it wasn't...a happy time. ...I couldn't even tell you like the dates they got out or anything 'cause I try just like block that part out 'cause it wasn't a happy time. But, I don't know if it's just me or if other people do it, but, it's not something I would like to remember them being in the hospital for like weeks and weeks, and it's, it's just hard to think about them being in there so, even now, with the medicine and the tubes and stuff. I don't even want to think about it. From...the way I feel, I just...treat them like, just act like they're...regular kids and I don't want to make it like they're disabled or something, just 'cause they were born early. ...I just see them as...regular kids. And I hope that's how people see them, too, not little tiny babies in the NICU. ...[T]hat's kind of sad.

“Honoring New Paradigms”

The overarching message from within Patty's narrative is “honoring new paradigms.” The course of Patty's life changed with the preterm birth of her twin daughters. Not only did “reality set in” with their homecoming, but the paradigm, that is, the pattern and direction of her life, changed. Instead of becoming overwhelmed and paralyzed by the new responsibilities before her, those very responsibilities revealed what her life was supposed to be. Her life has new meaning (“this is what my life was meant to be...this is what I'm supposed to be doing”) and her sense of self is different (“I'm more...settled down...more calm now...I have more patience”).

Her life now makes sense. Such revelation has been empowering, promoting an inner locus of control. With this new paradigm in place, she has found the inner will and strength to do what she has had to do, despite a paucity of outward support. She has crafted her own set of convictions with the determination to carry them out, undeterred by the advice of others (“I will take input but if it’s not something that I think is right, then I would still just do things my way...I think I know over, over anybody what’s right”). Even when contemplating a change in her admittedly over-protective behavior toward her daughters, she indicates that such a change would be based primarily on what she has come to recognize (“I have been realizing that, they’re ok...and I can let go a little bit”).

Interestingly, apart from Patty’s explanation that her daughters arrived unexpectedly 8 weeks early and she was unprepared for their birth, Patty’s narrative contains nothing about her prenatal course, her labor or delivery. While she provides some information about her experience in the NICU and her daughters’ status while there, she makes it clear during the course of her narrative that she avoids thinking and talking about her daughters’ earliest days in the NICU; “I try not to think about them being in the hospital.” Even fielding questions from an inquisitive public about the circumstances of her daughters’ births is something Patty regards as stressful. Repeating her determination to avoid thinking and talking about the NICU in her narrative is another expression of her empowered life paradigm. As if serving notice on her audience, she makes it clear that she will not return to that sad place in her memory for an extended time (“...[W]hen they were in the NICU...it wasn’t...a happy time”).

This stance reveals a second new paradigm, one regarding Patty’s daughters’ potential. By distancing herself from the unhappy and distressing memories of the neonatal period in the NICU and refusing to carry into the future any foregone prospect of ill-health or impairment for her daughters associated with having been born preterm, she creates a new paradigm of hope for them. According to Patty, she sees them “as regular, born-on-time” and she does not “want to

make it like they're disabled or something, just 'cause they were born early." This new paradigm is based on the evidence of their well-being and development. They have always been on target regarding developmental milestones, they have gained sufficient weight, and according to the Early Intervention staff they are excelling in comparison to other children born preterm. As Patty states, "from being born early to how they are now it's like, amazing... ..I mean, it's like a miracle...how they turned out healthy." While willing to admit worries regarding their well-being linger, Patty has no legitimate reason not to be optimistic about her daughters' future. Refusing to dwell on the NICU memories is a way of fueling that optimism.

Kellie

"Blessed"

Kellie is a 33 year old mother of fraternal twins, a boy and a girl, born preterm in 2007. She is a full-time homemaker. Despite not being able to meet for a face-to-face interview due to a recent out-of-state move, Kellie was very eager to participate in this study. Her narrative was gathered over the course of two email exchanges, the second in response to questions posed for clarification. In order to aid the flow of her thoughts, Kellie was instructed not to edit her written narrative extensively. Narrative content from both emails was combined according to topic; in order to remain faithful, not only to the content but also the presentation of her story, Kellie's written narrative was otherwise left intact and is presented verbatim, as received.

Kellie's narrative begins with information regarding the various challenges she and her husband faced in their effort to have a child. In light of genetic and infertility issues discovered in the process, and despite the technology employed to assist her to become pregnant, Kellie credits

God for making it possible for her to conceive successfully. Once Kellie became pregnant, problems emerged again, this time during the early weeks of her third trimester.

I guess I need to start at the beginning, so that you can understand what the birth of my twins has meant to me. My husband and I tried to have a child for nearly 5 years. After many tests and different specialists, we found out that my husband has a chromosomal abnormality that would affect his ability to father a child. Our only option was to do in vitro fertilization with pre-genetic diagnosis. We were able to create 10 embryos, but 8 of them had severe abnormalities. That left us with 2 normal embryos. The doctor implanted both of them and by the absolute grace of God they both attached and I was pregnant with twins. This was such an emotional and wonderful time for us. I was so ultra careful as a pregnant person. I ate right, I was careful not to over exert myself, etc. The pregnancy progressed wonderfully until around 26 weeks. An ultra sound showed that my sons' growth was not progressing and increasing a problem called intra uterine growth restriction. The doctor said I should do limited activity and not work any longer to help the chance of the baby grow and thrive. At 34 weeks it was clear that the baby boy had stopped growing and that I needed to deliver as soon as possible. I opted to have a cesarean section to limit the amount of stress on the baby. My baby girl, on the other hand was progressing and growing normally and healthy. The section went well and the babies were delivered and sent up to the Neonatal Intensive Care Unit. This is where my reflection of having pre-term infants begins.

Kellie was asked if at the 26 weeks point, when her son's intra-uterine growth restriction (IUGR) issues were detected, if the possibility of a preterm delivery was presented to her as something that might occur and if so, to what degree she felt prepared for it. She indicates that a preterm birth was presented to her as a possibility. Although she was given some information

about preterm birth from her doctors and from her husband (a medical resident physician), she wishes she had been better prepared for it.

When I was 26 weeks pregnant and was presented with my sons growth problems, the possibility of a pre-term growth was discussed. That is the reason my doctor put me on limited bed rest. He wanted to try and help me get as far along as possible. I knew at that point that the chance of a full term pregnancy was slim to none. The doctors gave me little information about pre term babies. My husband was a medical resident at the time and he was able to give me the information to prepare me for what may happen. I think it is important to inform a patient about these risks. I know that there was no way of knowing exactly how far I would go, but I think the doctors should have preped me a bit more. My husband gave me info about lung development, eye development, brain development, etc. and at what week these usually develop during pregnancy. I did receive a steroid injection at I think 30 weeks to help with lung development. I had to adjust my thinking of what my birth experience was going to be. I knew that my babies would most likely go to the NICU and that I was most likely going to have a c-section. Because my spouse had rotated thru the NICU he was able to explain a lot of what goes on in there and tell me what to expect. This information made it so much easier to deal with when it actually happened.

After her delivery, several problematic issues surfaced for Kellie, most of which were related to her experience in the NICU. Despite having had some preparation from her physician-husband regarding the NICU and what she saw as the good care provided by the staff, her early experience of becoming a mother and bonding with her infants in that environment was difficult and disappointing.

I think the hardest thing for me at first was not having the babies near me in the hospital to look at and hold and feed anytime I wanted. I had to adhere to the NICU's hours. It

was hard to go up and see them in their isolettes and not just pick them up and hold them and love on them. I could only put my hands thru the portholes and feel them. I would talk to them and sing to them all of the time. The other very difficult issue was that their isolettes were in different locations in the NICU. So I had to balance my time going between them and it was very frustrating to me. Another very emotional part was the fact that I could not hold my babies after their birth. My husband was able to hold them very briefly before they were taken upstairs, but I had to wait to be stitched up and be able to stand up before I could go to the NICU. I was able to hold my daughter after 4 hours, but my son had to stay in the isolette for the first day. That broke my heart that I could not hold him. I feel that it was so unnatural to not be able to do that, but I understood the medical reasons for it. I wanted so desperately to bond with my babies and it was so awkward to hold them and talk and sing to them in front of nurses and doctors and strangers. The other bad part of having babies in the NICU was that I had to pump my breast milk. Instead of being able to bond and feed thru nursing I had to pump. It was uncomfortable and time consuming. I would have to go to a pumping room and it would take around 15 minutes to pump. I was doing this every 2 hours, which took time away from being with my babies. After I was discharged from the hospital it was even more difficult to see the babies. I hated driving home at night leaving them there. I would go home to a house with empty cribs. I had just had twins, but it felt like I didn't even have them at all. I hated that the nurses knew more about my babies than I did. They were all so great at the job and so attentive to them, but it was hard for me to hear them tell me how they were doing and little personality characteristics they saw in them. I wanted to be the one taking care of them and sharing them with others instead of the other way around. I would often cry myself to sleep just longing for them. It was a long 3 weeks

that they spent in the NICU. I would drive up and spend all day there. They were very long days.

Amidst the difficulties of the early days and weeks following her children's birth, Kellie found positive support from her immediate family, her mother in particular, and the NICU nurses. Over time she was able to revise her attitude about the NICU environment; it had become the means for her babies' to have good health outcomes, for which she is grateful. During the course of the first, isolating months at home caring for her babies, friends and church members provided additional support for Kellie.

Now with all those negative things, there were some positive aspects as well. My mother was able to be there with me for the birth and the first week. My sister flew in and spent another week with me. I had no family in PA. Their help and support was paramount for my recovery both physically and emotionally. My husband was a medical resident at the hospital and had very long hours. He was only able to get 3 days off. I know it was very difficult for him to not spend time with the babies and it was even more difficult to work near the babies but not go over and see them. My mother flew back out and spent the next 5 weeks with me. She slept in my bed at night and helped me take care of the babies around the clock. I would feed one and she would burp them and change their diaper. This went on every hour on the hour, 24 hours a day. We both looked and felt like zombies. Without her help, I would not have survived, honestly. She was amazing to have with me and her knowledge and experience gave me the confidence that I needed to then mother them alone. I remember taking them into the doctor's office for their first appointments being home for the hospital maybe a couple of days. The nurses all complemented me on how natural I was holding such tiny babies. They were so small. My son was born at 3 lbs and my daughter at 4 lbs. The nurses in the NICU did such a great job of educating me on how to handle and hold tiny babies. They showed my how

to bath them, wrap them tightly into blankets, breastfeeding positions, burping strategies, etc. We had such a positive experience with the nurses. They were a tremendous support also. The doctors were great also. As difficult as it was to have my babies in the NICU, I realizes because of being in there how truly blessed and lucky I was. There were very sick babies around us, some of which did not survive. It would help me feel better about my situation talking to other moms in the “pump room” and share experiences. My babies were healthy, they just needed to learn to grow, eat and stay warm. The first month of being a mother of pre-term babies was difficult, but I realized how lucky I was to have such beautiful healthy babies. I didn’t leave my house except for doctor’s appointments for the first 3 months. The doctors had suggested this due to the fact that it was RSV [respiratory syncytial virus] season and they were so small. I survived those long months and just loved having them home with me, taking care of them myself and feeling the satisfaction and accomplishment that came with that. I had support from friends and church members with meals and phone calls. I truly appreciated that. I know that some people thought it was crazy that I didn’t get out and do things, but these were preemies and there was no way I was going to risk their health for my selfish desires.

Kellie’s narrative reveals a degree of discrepancy as she voices the struggles she had during the twins’ first year of life. For instance, with regard to completing errands, it was logistically challenging, having to manage the twins, their gear, and something as cumbersome as a grocery cart, all at the same time. During such an outing however, her twins invariably drew attention from others, something Kellie found not only gratifying but fun. Kellie takes the simultaneous presence of such variant emotions in stride, as a normal part of the mothering experience.

The first year of their lives was the most demanding on me. But as they began to sleep through the night and eat solid foods, life got easier. My struggles during that time were

going grocery shopping and running errands. I always got looks and comments from people like “oh, you have your hands full” and “are they identical?” It was fun to get attention from people and to brag up my little angels. My difficult day to day errand running etc. was balanced out with all of the positive attention that I would receive. It was always a challenge getting to babies into the car seats and then into the car and then out of the car and into the store. I would push my double stroller with my left hand and pull the grocery cart with the other. So, of course, I looked like a three ring circus. I would get lots of comments and that made me feel good and helped make all the effort worth while. I think this is true of being a mother in general. It is harder than you could ever imagine, and yet you get these great moments that make you step back and think how truly awesome it is.

As the result of an Early Intervention evaluation, Kellie was made aware of differences in her daughter’s and son’s rate of development. Her daughter is on target for her age but her son has not caught up in several areas. She is devoted to her son’s success and voices gratitude for the practical help and support Early Intervention has provided. While Kellie attributes his behavioral challenges to his having been born preterm, she expresses hope that as he continues to make developmental gains, that and the other areas where he is behind will improve.

Because my twins were pre term they qualified for early intervention through the state. At one year they received an evaluation to see where they were at developmentally. My daughters’ evaluation showed that she was caught up to the developmental milestones for her age. My son, however, was behind in several areas. I was told from the doctors in the NICU that it is normal to have developmental delays in the first year. But it was still difficult to hear that your son is behind. We began special instruction and physical and occupational therapy. The support and information the therapists gave me was so helpful. I felt more empowered as a mother to know how to help my child succeed.

Their support really meant so much to me and I considered them my friends as well. My son began having more behavioral issues during his 2nd year. It was hard for me to take him to restaurants or play groups. When he would act out I would get looks and hear comments from others that were negative. I knew they didn't know my son or understand that he was premature and trying to catch up, but it still hurt to see and hear. My daughter has been a great model and friend to her brother and I think that her example has helped him reach his milestones faster than he would without her. I love to watch them interact and play together. They are both physically very small. They look much younger than they are. I often wonder if this is because they were preemies or if it is just how they are. My son is still receiving early intervention services today. He has behavioral issues, eating issues and is behind in other areas. I am hopeful that he will catch up and improve and that there is no serious problem or mental condition. It does worry me, and I do not know if these are the result of being born pre term and have roots with his IUGR condition while I was pregnant. But I am grateful for the early intervention program to help catch anything and provide services to help him be the best he can be.

When asked to consider a word or phrase that describes her experience as a mother of former preterm infants now at preschool age, Kellie identified the word "blessed." She recognizes that being a mother at all, being the mother of twins, and being the mother of her twins specifically, is not coincidental, but rather, a sign of special favor.

If I had to say what has been most meaningful to me as a mother of preterm babies it would be that I have the chance to be the mother of such special children. I am beyond lucky to have gotten pregnant with twins considering the infertility issues I faced. I am beyond lucky to have had pre term babies that didn't have severe physical impairments that so many do. I am beyond lucky to have the chance to help them progress and be the

best that they can be. I know that being a mother of premies comes with many more challenges and issues than those who deliver full term, but what they may not have is the knowledge that they have been blessed with a miracle, and in my case two miracles. A word that captures my experience is blessed.

When asked if she has seen any indication that being the mother of twins born preterm has changed her personally, Kellie noted it has, in many ways, and for the better.

Having my pre term twins has changed me as a person. I am more accepting and less judgemental of other moms and parenting styles. I am so much less selfish. My world revolved around them and they are my first priority. I feel more satisfied as a person and I feel so lucky to have them. I am more dedicated to be a better person for them. I am trying to be more active in my church and be an example to them.

Reading Kellie's narrative suggests she senses an underlying purpose, a bigger picture, behind her experience. She acknowledged that from the time she was told she was pregnant with twins that she realized her pregnancy was a divine gift.

I feel like the moment I found out I was pregnant with twins and the doctor told me that this was more than luck, that I realized that my conception and birth of these babies was a gift from God. I believe that science can only take it so far and that it is God's will that provided the rest. This experience has made me aware of the reality of a higher power.

Kellie again praises the nurses and doctors caring for her children and indicates they expressed concern for her well-being, too.

The nurses and doctors were very good about making sure I was doing ok. Infact, one of the NICU nurses said she was going to "tell on me" to my doctor because I drove earlier than 2 weeks. After a c-section my instructions were to not drive for 2 weeks. But there was no way I was going to not drive myself to the hospital and see my babies. The nurses were so good and making me sit down and asking how the pumping and

breastfeeding was going. They offered much advice and even told me to leave early one night from the NICU and go out to dinner with my husband. They said just getting out would do me a world of good, and they were right. I was in there almost all day and night. My doctor was fantastic and was very helpful and kind. My babies pediatricians staff was very great also. They always let me know that they were there to help and only a phone call away.

Lastly, Kellie noted she has enjoyed reflecting on her experience; doing so has reminded her of things from the past.

Thanks for the opportunity to do this study. It has been fun for me to reflect on the past few years and I have remembered little stories and things I had almost forgotten.

“Against All Odds”

The overarching message that emerges from Kellie’s narrative is “against all odds.” From the outset it is clear that given her husband’s chromosomal abnormality and the resultant abnormalities found in 8 of their 10 embryos, the chances for a successful pregnancy were not good, even with the use of in vitro fertilization. Yet, Kellie became pregnant not with just one of the two normal embryos, but both of them. As her third trimester began she discovered that another factor threatening the chances of a successful pregnancy emerged: her son’s intra-uterine growth restriction. The remainder of her pregnancy would not be routine; fighting the odds meant Kellie being willing to go along with the changed course of her pregnancy, to change her behavior and her expectations. She was put on “limited bed rest,” she received “a steroid injection at...30 weeks to help with lung development,” she had to “adjust [her] thinking of what [her] birth experience was going to be.”

Against all odds, Kellie began the processes of bonding with her babies and becoming a mother in the NICU environment. There was not adequate privacy between Kellie and her babies (“I wanted so desperately to bond with my babies and it was so awkward to hold them and talk and sing to them in front of nurses and doctors and strangers”) and time with her babies was limited in part because of unit policies and practice:

I had to adhere to the NICU’s hours....The other very difficult issue was that their isolettes were in different locations in the NICU. So I had to balance my time going between them and it was very frustrating to me.

Even though Kellie voiced appreciation for the NICU nurses’ care of her babies, she resented knowing that the nurses knew more about her children than she did:

I hated that the nurses knew more about my babies than I did. They were all so great at the job and so attentive to them, but it was hard for me to hear them tell me how they were doing and little personality characteristics they saw in them. I wanted to be the one taking care of them and sharing them with others instead of the other way around.

Despite the difficulties of her early days and weeks in the NICU environment, Kellie defied the odds of having a positive attitude about the NICU by revising her perspective about the nurses (“We had such a positive experience with the nurses”) and her babies’ time there (“As difficult as it was to have my babies in the NICU, I realize because of being in there how truly blessed and lucky I was. There were very sick babies...some...did not survive....My babies were healthy”). Having this new perspective regarding her babies, who against all odds were healthy, Kellie was determined to do all she could to maintain their good health by staying home with them during the first months: “...these were preemies and there was no way I was going to risk their health for my selfish desires.”

How quickly Kellie’s son will make developmental gains is uncertain. But in spite of the odds against him, Kellie is “hopeful that he will catch up and improve and that there is no serious

problem or mental condition” and that with ongoing Early Intervention services, he can “be the best he can be.” Instead of being overwhelmed and in despair with the responsibilities of having preschool aged children born preterm, Kellie states her experience has made her a better person (“I am more accepting...I am so much less selfish...I am more dedicated to be a better person for them.”)

Even though the odds were stacked against her, Kellie became a mother at last. Her experience confirmed to her the reality and role of a higher power at work in her life: “...the doctor told me that this was more than luck...my conception and birth...was a gift from God. I believe that science can only take it so far and that it is Gods will that provided the rest.” As a mother of former preterm infants now at preschool age, beating the odds has unique meaning for her: “If I had to say what has been most meaningful to me as a mother of preterm babies it would be that I have [the] chance to be the mother of such special children....I am beyond lucky...”.

Ann

“The Best Thing in the World”

Ann is a married, 34 year old mother of a daughter born preterm in 2007. Although normally employed as a hospital housekeeper, Ann is currently on medical leave due to a work injury. While at times Ann appeared unsure what to include in her narrative, she spoke in a calm, matter-of-fact manner. Her narrative was sprinkled with subtle humor yet a touch of sadness could be detected in her voice and expression.

After a brief discussion regarding at what point she might want to start, Ann introduced her narrative by indicating she and her husband were fortunate that their daughter had comparatively few problems associated with being born preterm and recalling salient features of

the early days and weeks after her birth. Born 7 weeks early, her daughter was diagnosed with necrotizing enterocolitis (NEC), a gastrointestinal infection that can cause serious morbidity and even mortality in preterm infants. In addition, her lung function was tenuous, a vulnerability that persisted for months. Despite the potential seriousness of these conditions, Ann minimizes both, indicating they were short-lived. Ann identifies two issues that created significant stress during the postpartum period: failing to produce sufficient amounts of breast-milk and the day of her daughter's homecoming. Both influenced her perceived capacity as a new mother. While her husband volunteered his emotional support to Ann during their daughter's stay in the hospital, Ann had to compel him to stay with her their daughter's first night home.

...[W]e didn't have as much trouble as some of the preterm babies, you know, because, I think we were very lucky. She, when she was born, she was, she was 5 pounds, she was big for a preterm baby, um....

She was 7 weeks early, so what was that, 30, what was that, 33 weeks? Um, yeah, I often thought, if she would have went full-term, I'd had a big baby. Um, but, she didn't have a whole lot of problems in the hospital. She had, what do they call it, it was a...intestinal infection, it's called NEC? She had that; that was one complication. They, they kept her for a month, her, to make sure her lungs were ok. And then...when she...came home and stuff like that, obviously it was very un-nerving because you have such a teeny, little baby. The first night I, I was in total panic. I had to make my husband stay home....

While she was in the hospital I was stressed out, you know, because, trying to breast-feed and I was up every 3 hours pumping and it just wasn't working for me. I don't know if it was just because we weren't together, that...my milk never came in. And I was so depressed feeling like I wasn't being a good mom because I wasn't producing milk. You know, that was stressing.... I know the one time I just had total melt-down. I just, my husband thought I was cracked. He, he didn't want to leave me to go to work. I just laid

on the bed and balled. You know, I just had total melt-down. But, and since, she's, she's been really good. She hasn't had whole lot of problems. They made her take, um, her first winter shots for her lungs to make sure she didn't get, I guess, what, a common cold would have been really bad for her, stuff like that.... But we haven't had a, a whole lot of problems with her. ...[T]o me she seems like a normal baby, you know, a normal little girl. You wouldn't think she was preterm. She, right now, when we were for her 2 year visit, she was 94 percentile for her height....

Despite evidence that suggests Ann's daughter is doing well physically, questions linger in her mind regarding her daughter's developmental status, given she was born preterm. Ann voices hope that since she and her husband have not seen anything specifically troubling about their daughter, that her fear of developmental delay is unfounded.

I wonder sometimes if she's behind for learning and stuff. That's a concern for me. And I always think, well, she was early, don't panic, you know. So, that's a concern for me. I often think, you know, she, I'm trying to teach her numbers and her letters.... Her favorite thing right now is, when you try to count, she'll say, 1-2, 1-2...she knows what comes next but she won't say it. You ask her, "What's after 2?" "No!" ...So...that's the biggest concern is, I just worry that she's developmentally behind. I don't know if I'm not pushing her enough. But we haven't, like I said, we haven't had a whole lot of trouble....

At this point Ann seemed unsure how to proceed with her narrative. I asked her to address whether or not she felt she had changed personally as a result of her daughter's birth and if so, how. As if considering the possibility of personal change for the first time, Ann vacillates between considering change in her and her husband as a unit versus change in her individually. Ultimately Ann concludes that she *has* changed; the changes she notes are related to her developing maternal persona, which in turn influence her relationship to her husband.

Well, obviously she's, she's our, our world now. We don't, like, before her we used to go out all the time with our friends and stuff. We don't do that kind of stuff. Well, everybody's married and has their own kids, you know, you don't do that anymore....

...I don't know, I don't know that I've really changed. I guess you have...that life to look after and be the mother tiger over her and you know (long pause). I don't know, this is hard. ...I guess in a way it does change, change you, because now you're, you're not just, not just *you* anymore, you're...that little person's mom, you know? Well, I guess it *has* changed because you know, she's, she's our world, she's (pause). I don't know, I guess...it *is* a big change then, but. 'Cause she's who we look forward to, even, even I guess towards my husband, you know...how do I want to say that you're still, not saying that you're not in love anymore, but you know what I mean, it's, you've got this other little person there too. ...It's not like just putting it on each other, you have her too. And she takes most of it. She, she definitely wants to, definitely wants your attention. 'Cause I've heard people say that it would be different if you had another child, that they have each other to play with, because when they're by themselves it's just, then they look for you to play with them.

Ann reveals that medical problems related to a genetic disorder put her at high risk for complications during her pregnancy. As a result, her doctors do not want her to try for more children, a hard thing to hear since she hoped to have a second child. As in an effort to convince herself and her listener of the wisdom in this decision, Ann voices practical reasons why her attempts for additional pregnancies would not be a good idea.

She's going to be our one and only. I have medical problems, I can't have any...the doctors don't want me to have any more. ...It's disappointing. I, I would have liked to have the second one, but at the same time, you think about how our, how the world is today, maybe it's best just to have just one, you know, bringing another baby into this

world the way it is.... I don't know, financially, you know, it's strapping, it's stressing financially with just one, how would it be with two? But, at the same time, I guess that it's disappointing. I was very disappointed.... And now he went and had a vasectomy, so we really can't. Well, I guess they can reverse that if I, if he really wanted to. ...[I]n 2006 I had blood clots, one in each lung.... ...[T]hey told me I have a genetic disorder called thrombin gene mutation. So I'll be probably on blood thinner the rest of my life. And because of that, you know, I'm higher risk to have blood clots, so my whole pregnancy was really...a very stressful pregnancy to begin with. I was off work almost the whole time. I was off 6 months altogether, including my maternity leave at the end.... Because I was bleeding and stuff like that I had uh, they said my placenta was pulling away. But, I was high risk because of the blood clotting and stuff like that so I was on, taking shots everyday, a blood-thinner. So, in the long run, I, I, we, we came to the conclusion too, that, it, because my hematologist said he would have worked with it, and that we could have, you know, tried for another baby. But we came to the conclusion that, was it, was it worth the risk of losing the mommy and daddy ending up maybe with not just one baby but maybe two? And he'd have them to take care, you know, so, we're grateful for what we have.

Ann indicated that her physicians denied a connection between her genetic disorder or anything she might have done and her preterm labor.

I asked them about that and I asked them if it was anything I did. They kept telling me it was nothing I did, it was nothing to do with my disorder or anything, it just happens sometimes they said.

To gain a clearer picture of the influence of her medical problems on her experience, Ann was asked to provide some of the contextual details surrounding her daughter's birth. She describes her experience with bleeding from a placental abruption several weeks before her due

date. With this episode of bleeding she was hospitalized, where she remained until her daughter was born. Ann recalls her fear of losing her baby during this period yet she minimizes the potentially grave consequences of a placental abruption as it pertains to her own life. She reiterates the physicians absolved her of any wrong-doing regarding the cause of the bleeding.

I spent the last 3 weeks in the hospital before I had her because I came in with bleeding. I was bleeding that bad they had me on a wheelchair, I was on, up on the delivery floor and they took me to the back where they ultrasound you and I left a trail of blood on the carpet, that's how bad I was bleeding. But they got it under control you know, and then they, they told me, pretty much make yourself comfortable, you're here till you have her. And my due date was August and I had her 7 weeks early. So I was like, I came in in June, I'm like, if I wait, if I go to my due date I'll be here almost 2 months, you know, till I have her. But um, it, I seemed to be fine, you know, I wasn't having any problem bleeding or anything like that and just all of a sudden, the one morning, it was, it was early in the morning, the doctors had been in and stuff and I was like, I was laying there and I'm like, all of a sudden I felt wet, and I'm like, "Oh, tell me I'm bleeding again." And I went up, and got up and went to the bathroom, like, "Oh, my water broke." So I, I flipped the thing and then about 5 nurses come flying in, looking at me and I said, "I think my water broke." And they tell me, "Get back in bed." And then I delivered her normal. They were worried, they were worried that they'd have to take her. Now once I got over into the delivery room I got up to go to the bathroom and...her heart rate had dropped, so then they made me stay in bed, but other than that, that's the only problem I had. It was, you know, I delivered her normal....

...[W]hen I went down to the hospital [the night I was admitted] ...I was very afraid. Because the whole way, almost the whole car ride down I didn't feel her move. We were almost to the hospital when I finally felt her move.... And I blamed myself because the

weekend before I had had a yard sale and I thought, doing all that extra had done it. And they, they told me, “No”...they said it just was part of the, the placenta abruption and stuff like that, so. And the thing that I’d asked, “Why was, like, was it something I did?” And they’re like, “No.” And...obviously you’re scared because there you are, you’re bleeding, you think you’re going into labor, you know, that would have been 3 weeks earlier, that would have been 10 weeks early. Um, and obviously you’re...really scared that you think you’re might lose her.... ...[B]ut then they got it all under control...right away they told me you’re going to stay a few days, like through the weekend. And I’m like, so you’re thinking you’re going home...but then the longer it went...finally they said, just make yourself comfortable. And then you’re like, I was discouraged that I couldn’t go home but I knew I was in the right place in case something happened....

...I know when my water--, you know, you’re, you’re afraid, you know, especially when it’s your first one, you never went through this. And then afterwards you’re like, “It’s done! And then you’re like, you want to see her and they, they gave me a quick glance and then they pretty much took her away. I didn’t get to see her then ‘til later on. I had to wait like two hours before we could actually go up. And then, and then when you come up in, into the NICU and you see her and she’s hooked up to all the stuff it’s like total shock, hooked up to all them, all them wires and everything and the hoses.

In the following exchange, Ann indicates she does not recall having a discussion with her physicians regarding the possibility of a preterm birth. It was not until Ann was admitted to the hospital that she fully realized that a preterm birth might occur. Ann explains that her bigger concern had been that her baby would die early in the pregnancy.

Cherie: When...they were monitoring you through the pregnancy...[a]t any point did anybody say to you, “You could go early” that that is a possibility? ...[D]id you have means of preparing for that or did it come as a big surprise...?

Ann: I guess at the beginning when, when I first was pregnant and stuff like that I didn't think about going early and nobody really said... "You could go early" to me. It was kind of, I mean, I had the bleeding problems, so I guess back in the back of your mind you had always thought that maybe, you know, something could go wrong, that you could lose the baby, that you could just go early....

Cherie: But...it was never an open discussion.

Ann: No. ...[B]ut once I went in, you know, when I came into the, the hospital and when I ended up staying, you know, there was always that, that they could, you know, might have to take you emergency C-section or something like that, you know. That's why, when I stayed then, you know, that's why I knew, you know, she could come early. ...I mean, with my bleeding and stuff from the very beginning, it always, I guess we were not really thinking about her coming early, it was just more the worry that, you know, you could lose the baby at the very beginning. So like, you know, like I said, I didn't really, not until I actually was in the hospital and I was staying, you know, that, oh this baby could come ear--, you know.

When asked to address the support she did or did not receive, both at the time of her daughter's birth and since, Ann took time to gather her thoughts before responding. Although acknowledging that her husband was her biggest supporter, Ann voiced disappointment regarding how little time he spent with her during her prenatal hospitalization. His behavior was particularly painful to Ann because not only were they both employed by that hospital (and therefore known by the staff) but the rationale for his limited attention was self-serving. Despite the enduring significance and pain of this memory, Ann tries to minimize it when examined against the net effect of her husband's support. Ann notes that other members of the family have been somewhat supportive, but not overwhelmingly so. In contrast, Ann speaks with appreciation about the support she received from the doctors and nurses at the hospital.

Huh (pause). Well, my husband was my big support. He was, you know, there for everything. And he, he was glad that I was off work when I started having the bleeding problems and stuff, so he was supportive of that, very supportive. And he was there as soon as he could when I went into, you know, labor. The only thing...I was disappointed with was when I was in the hospital he didn't come see me as much because he works here. He, he just felt that coming was being at work. ...[A]nd I told him that since, you know, that it really hurt me that he didn't come spend some time with me while I was in. He'd come maybe like a half hour before he started working, that was when I got to see him. That was a big (pause) big thing that had bothered me...but, other than that, he was great. And my, you know, my family...they were all there...for the labor, you know, they all wanted to be there. They were, they were, they supported me though, you know, and um. And as for the doctors and stuff, they were all great. They all, and the nurses, some of the nurses when I was in the hospital, they were the best. They'd do anyth--, you know, anything they could for you...most of the time I just left them alone because I work here, I know how busy they are and stuff, you know. They, they used to say...to me, that they wished they had more patients like me. Um (pause) I don't know, and since every--, you know, his mom is big, a big help, she helps when she can, baby-sits and stuff like that. Because it's hard, you know...when we...work double shif--, you know, the opposite shifts and stuff. That was a choice, we couldn't afford day-care, so.

When asked if her daughter's pediatrician or the nurses in that office inquire about her well-being, as her daughter's mother, Ann indicated they do not. She indicates that it is possible that they displayed that kind of interest in her during the earliest period in her daughter's life, but because she does not recall all the many visits to that office, she cannot be certain.

Not that I remember, no; maybe right at the very beginning, when she was really little, but not, not lately. I don't remember all the visits because we used to go quite often

because of her being early when she was little. ...[W]e actually had a, an argument over the, the shots they gave her for her lungs that first winter. Because they were very expensive and we didn't have the money, but they wanted her to have them and it's like, well, you can't get blood from a stone, you know. But then they finally put it into like a, a program that would pay for it and then they, and she got them. But that was [the only problem].... Yeah, I really like her pediatrician, she's really good with her.

Ann denies having any particular concerns regarding her daughter's eventual entry into school. In contrast to her general state of worry about her daughter's developmental status, she finds comfort in the encouragement of friends and family that her daughter is doing fine, doing things normal 2 year olds do. Ann's sense of responsibility as a parent is evident, as she voices hope that she can identify and correct elements in her parenting style that will shape her daughter's behavior more positively, improving her chances for success at school.

I just worry...like I said right now that, I mean, maybe she's not, maybe she's, everybody in my families...think she's fine, you know, and I mean, my friends and stuff, they all say, you know, she's 2, you know. 'Cause right now I'm trying to, trying to start the potty-training thing, too. And she just, she'll sit on it but when she actually has to, she'll let you know that she has to go. 'Cause I let her run around sometimes without her diaper. And she's like, "Ooh, pee." And I'm like, "Would you want to sit on your potty?" "No." "Would you want your diaper back on?" "No." I'm like, "Well, we got to do one or the other!" ...Then you worry about the tantrums and, you know, is it something we're doing wrong? I said to my husband the other day...the one day we, me and her were going at it pretty tough, head to head. It seemed like we were fighting all day. And I said, "Is it just me? Am I letting her get at, get to me?" 'Cause I'm with her all the time. And he shook his head. So I often wonder if there's things I could do better, you know, not, not get mad at the drop of a hat....

...[W]hen we go to the doctor, she always asks about her, you know, her learning and her talking and you know, and all this stuff, and. ...[Other people have] said...if the doctor would think something's wrong they would say something. So, I guess she's where she needs to be. I just, I just worry because I have friends that have 4 year olds, you know, and I ask them you know, "What, at this age was she doing this...?" You know, like, "Is she, is she ok?" ...'Cause I have one friend, she didn't get her daughter potty-trained 'til she was almost 3 ½. And I've had family, you know, says, I wouldn't even start trying 'til she's 2 ½. And I'm like, well, I'm not really pushing it, it's just there, she plays with it, she sits on it occasionally. I'm not pushing all that hard, I just, you know, let her run around every once and awhile and if she want to sit, you know. You know, she'll do it I guess in her own time. So everybody says every kid's different.

When asked if there is a particular word or phrase that describes her experience being the mother of her daughter, a former preterm infant now at preschool age, Ann took her time before responding.

(Long pause) ...I think it's the best thing in the world being a mom. It's, it's been a, a great experience....

Ann did not have anything in particular to share that she felt would better inform others regarding mothers who have had a preterm birth. However, she did indicate that she sees differences between mothers' full-term versus preterm birth experiences. According to Ann, a preterm birth experience is characterized by persistent worry about potential health problems for the child and their overall development. The discrepancy between how her daughter appears and her preterm birth history has made Ann's experience additionally complex. On one hand her daughter *looks* like a child who was born full-term, yet, Ann fears that heretofore hidden effects of her daughter's preterm birth may surface at any time, particularly with regard to her

development. Meanwhile, Ann is vigilant, alert to anything that may suggest developmental delay in her daughter.

[A preterm birth is]...probably more stressing, obviously, because the baby is early and you're worrying about complications.... I mean, there's always complications with any baby I guess, but, when they're early you got to worry about their development...

...[T]hat was the big worry...they were worried about her lungs, making sure...that she was ok.... And you got to worry afterwards because they were, you know, like, like I said, they were worried about her getting colds and, you know that, giving her those shots, making sure, and that was because of her lungs and stuff, they were worried about her lungs that first winter. (Pause) I guess that that's the, the biggest thing...(pause). And you know, I'm, I'm, like I said, I'm just worried about her, her learning and stuff like that, development. She seems to be doing good.... ...[I]n a way she was preterm but she's almost, she's normal, you know, she's not like, like some kids who are really little and stuff like that you know, for years it takes them a long time to catch up. ...[S]he seems like a normal kid to me. ...[M]y husband's sister has temporary custody of her grand-daughter...she's a year older, she's 3 and our daughter is as tall as her. Yeah, the, the 3 year old is very little, you know, compared.... And I don't think she was, you know, preterm or anything like that....

...[W]hen you sent me the, the, the invitation to come down here, [my husband] said, "Yeah," he said, "I think you ought to let, you know, let them know that, you know, we haven't had a lot of trouble with her." ...[E]verybody, you know, thinks preterm babies are, you know, that you're going to have a lot of prob-- you know, and she's, she just seems like a normal, like if I would have went full-term. Maybe they had my due date wrong or something! I don't know!

When given the opportunity to add anything else about her experience, Ann reiterated her positive feelings about being her daughter's mother. Ann also expressed the hope that sharing her story had been helpful. That in turn led to a conversation about the uniqueness of every mother and every mother's experience with having a child born preterm, the chief care-giving responsibilities those mothers face, and the value of support extended to them.

Yeah, I, I've often wondered because I've had such, I think it was, compared to I guess to what it could have been, it was such an easy thing, you know, experience for her being pre--, you know. And often I just don't know what it would have been. ...I guess what I'm trying to say I, I don't know how mothers that have to really, you know, have babies that just fit in your hand, you know, how do they, I just can't comprehend how they, you know, how it must be to, troubles they have to, you know, all they have to go through. Because we really had it easy.... Yes, she was early, but she's very, a very normal little girl.

In the midst of this dialogue, Ann spontaneously re-visited the issue of support in her experience, specifically with regard to her husband and her family. With openness and candor she voices frustration and disappointment in how comparatively little her husband participates in caring for their daughter. Despite seeing effort on his part, it falls short of what Ann really needs; under the circumstances Ann resigns herself to the likelihood that she cannot expect any more from him at this time. Her father and his significant-other pose a different kind of dilemma for Ann. Up until the time of her work injury they provided marginal support at best; since then and despite being more available to her in helping to care for their granddaughter, Ann indicates she has misgivings about the sincerity and duration of their support. Unpleasant childhood memories of the relationship with *her* grandparents have informed her sense of doubt. Overall, Ann concludes that the support she does get, regardless of the source, is unreliable. She begins by

responding to the observation that mothers of former preterm infants now at preschool age appear to shoulder most of the childcare responsibilities.

Yeah, I've taken notice of that over the past year with me being home but even, even before that, before I had my injury and I was, you know, we were both working that it was, a lot of it was, it's a lot, you know, laid on me. I guess, I guess then when I think about it then, you know, [my husband], he, he always is there to support but there are times I wish he could just give me a half hour break and you take her.... And it's hard. Because actually with his work schedule, he gets home at 2:30 in the morning; 'til he falls asleep it's 4, maybe 5 o'clock. He doesn't get up 'til noon. Until 3, 3:30, well 'til 3:30 he leaves. So, you know, say fo--, say an hour before that he's getting ready for work and stuff like that.... Plus she goes down for a nap between 1[p]. So how much time does he actually see her? He, he only...gets to see her maybe an hour and half out of the day and then on the weekends. It's his, it's that shift I guess. Maybe if he had a different shift it would be different? And maybe if he worked day-shift? I don't know, it's hard. 'Cause I feel bad for him too sometimes, you know? 'Cause the one day...he was home. ...[H]e was saying that he got very, you know, he spent the whole, you know, with being home he spent the whole day with her and he was like very frustrated with her. He said, he said, "I don't know how you do it all the time" he said. And I'm like, I said, "Well," I said, I said, "Now you see why I get so upset," you know and 'cause she seems not to want to listen...she's pushing the envelope seeing what she can get away with....

And he does, you know, he does, he tries...and I try not to ask too much of him because he does, with my having this back injury and stuff, he does so much for me...because there's not a whole lot I can do. (Long pause). ...[E]very once in a while I get frustrated with my parents. They come every night to put her to bed. But there for a

while...before...I hurt myself, I used to, whenever I'd asked them to baby-sit, I'd get told, "No," that they always had other stuff to do.... Because it, it's actually, I keep saying my parents, she's...not even my step-mom, she's my dad's girlfriend. My mom is actually gone; she's been gone 13 years.... I often wonder if because she's not actually her real grand--, you know, blood grandchild if she is treating her different. Because my dad...he would do what he can for her. He's a little nervous, because she's, I don't know, its been years since he had kids...I think once she gets potty trained he'd be a lot better. It's the, the, the worrying about the diaper and that kind of stuff.... When it came down to like, bringing my husband to the emergency room and stuff the other night, you know, they obviously, they took her, you know.... But for a while when, you know, even if it was just for us to go out for dinner you know, it would just be like, I always got told, "No." She baby-sits a couple days a week...for her son, but whenever I would ask, you know. 'Cause we've been trying to, we've been talking about trying to get both of us on the same shift but we can't really afford day-care, so we had his mom said she'd baby-sit one day. And when, you know how it is when you work down here, if you work in our department you work every other weekend day-shift. So then you have a day off every week. So we would each have a day off during the week unless it fell on the same day so there'd be 3 days covered. If we could get her to cover one, we'd maybe only have to stick her in day care one day.... So, to get her, to get them to commit. But I understand too their lives are busy too, 'cause they take care of her aunt...and...his uncle, and taking them to doctors, plus going to their own doctor but you know, to all that kind of running around.... I try not to get frustrated but, I just, there for a while I just always felt, and it, it goes back to when *I* was a kid. My grandparents took the other 2 grand-kids but they never wanted me. ...And that was a step-grandmother, you know? So, I always felt left out on that side you know, so, and then there was 2 grandkids younger than me that got

treated the same way. ...So I guess in the back of my mind maybe that's what I'm feeling [with] my parents.... (Pause) But other than that I, but I can't co--, I don't complain, I try not to complain because...they're very supportive...they come up every night and put her to bed for me, so, I guess I can't. 'Cause there for a while they were like, "Bring her, you know, stop in, bring her, we don't get to see her." And I'm like, "It's because when I ask you take her you don't and then when I stop in after work you...aren't there".... You know, I try to stop in and let them see her, but. Then she got funny towards them, you know, because she didn't know them. Oh, not no more, she sees them every night....(Pause)...I have friends...that are always asking us, "Let's get together, go out one weekend or, or during the week" and stuff like that and they want to go..."Try to, try to get a sitter for Thursday night" and I'm like, "You don't understand, it, it, we don't have [that]." ...[My husband's]...mom...lives an hour away from us. ...[S]he works too, you know. So it's like [my friend] counts on her mom all the time and I'm like, "You know, I don't, I don't have that, I can't."

Ann was again given the opportunity to share anything else regarding her experience.

With a chuckle in her voice, Ann stated she did not have anything else to share stating, "No, I don't think so. I feel like I complained enough."

"Affirming My Worth"

The message that surfaces as Ann's narrative unfolds is "affirming my worth."

Throughout her narrative Ann recalls events that suggest how significant others in her personal life and the healthcare providers she has encountered display words and actions that reflect their appraisal of her worth as a person. Her sense of worth is closely tied to her needs and the willingness of others to meet those needs. Ann introduces this message early in her narrative as

she describes the night of her daughter's homecoming. For Ann, that experience "was very unnerving...I...was in total panic." Instead of wanting to share that experience with her and being willing to address her clear need of support, Ann's husband had evidently made plans to leave her alone with their baby. She had to compel him to remain with her; she "had to make [him] stay home." Later in her narrative, as Ann reflects on her prenatal hospitalization, she suggests she needed her husband's presence as an affirmation of her importance and value to him as his wife but that did not materialize. Sadly this occurred at a time when both her and her unborn child's health was precarious at best: "...he didn't come see me as much.... ...[I]t really hurt me that he didn't come spend some time with me while I was in...That was a big (pause) big thing that had bothered me."

Ann's needs and her inherent worth extend beyond her role as wife and mother. Her worth as a person and her ability to meet her personal needs could be enhanced if she could be relieved of childcare responsibilities once in a while, particularly by her husband. "[H]e always is there to support but there are times I wish he could just give me a half hour break." Despite having firsthand knowledge of how stressful caring for their daughter can be ("I don't know how you do it all the time") he does not offer to relieve her of providing that care. His apparent insensitivity to Ann's need for free time is compounded by the relatively short amount of time her husband spends with their daughter ("So how much time does he actually see her? He, he only...gets to see her maybe an hour and half out of the day and then on the weekends").

In an effort to meet her emotional and social needs, either with her husband or with friends, Ann has attempted without success to secure support from her father and his girlfriend. In comparison to one of her friends who can consistently rely on her mother for support, Ann confesses, "I don't, I don't have that..." Instead, with regard to her father and his girlfriend, "[W]henever I'd asked them to baby-sit, I'd get told, 'No,' that they always had other stuff to do." Ann wonders if the girlfriend's response is because her daughter is not her "real...blood

grandchild.” This lack of support is informed by a lingering, unhappy memory from her childhood when her grandparents discounted her worth: “My grandparents...never wanted me. ...And that was a step-grandmother.... ...So I guess in the back of my mind maybe that’s what I’m feeling”.

In order to retain as much affirming support as she can, Ann diminishes issues of importance to her, particularly if they represent potential problems. For instance, Ann minimizes the threat her genetic disorder posed to her life at the time of the placental abruption and how it has altered her child-bearing hopes for the future. Despite genuine worries regarding her daughter’s well-being and development in association with her preterm birth history, Ann downplays her daughter’s medical history and any suggestion that she is anything other than normal. In addition, instead of freely voicing legitimate complaints or needs, Ann dismisses the true value of her feelings and seeks ways to justify the actions of those who do not provide the support she seeks:

That was a big (pause) big thing that had bothered me...but, other than that, he was great. ...It’s his, it’s that shift I guess. Maybe if he had a different shift it would be different? ...[H]e tries...and I try not to ask too much of him because he does, with my having this back injury and stuff, he does so much for me....

But I understand too their lives are busy too....

I can’t co--, I don’t complain, I try not to complain because...they’re very supportive...they come up every night and put her to bed for me, so, I guess I can’t.

I feel like I complained enough.

In contrast to the attitudes and behavior of her family members, Ann finds consistent affirmation of her worth in the support she received from the healthcare providers throughout her experience: “[T]he doctors...were all great. ...[S]ome of the nurses when I was in the hospital, they were the best. They’d do...anything they could for you.... They, they used to say...that they

wished they had more patients like me.” Her physicians spent time with Ann to convey their concerns and her options regarding the pursuit of future pregnancies. They also relieved her mind of her feelings of guilt related to what could have caused her placental abruption. Even though she had argued with her daughter’s pediatrician regarding the cost of medication, her view and her needs were respected, contributing to a good outcome: “[W]e didn’t have the money [for her shots]...they finally put it into like a, a program that would pay for it...and she got them.”

Jennifer

“Protect at All Costs”

Jennifer is a 26 year old, married mother who has given birth to two preterm children. Her first child, a son born in 2006, died within hours of birth. Her second child, also a son, was born in 2007. Jennifer is employed in the insurance industry. Assertive and articulate, Jennifer presented her narrative with passion.

Jennifer began her narrative by providing an overview of some of the facts informing her experience of being a mother of a preterm infant now at preschool age, from her son’s time in the NICU to present day.

Uh, first of all, he is my first child. So, I can’t really compare it to anything else only because he is my first, so, pretty much what we’ve had to deal with is, obviously he was preterm. It was very difficult to deal with that, watching him in the NICU for the time he was there. ...[O]verall he seemed to do pretty well. ...[T]he size was fine. He was just a little underdeveloped as far as learning to eat. So, we had to try and coax him the right direction for that. ...After we got him home, there was nothing wrong really. I mean, he seemed like he was a perfect child and just growing up the way he is. ...I’m not sure,

right now, he's 2 ½ years old, so, I mean obviously he's getting close to being ready to go to preschool. And we're considering doing that. ...[R]ight now he's staying with his...great-grandmother...during the day. ...[H]e seems to do pretty well with that. One thing I've noticed and I don't know if it's because of being preterm or not, is just he listens to everyone else better than us. But that pretty much also sounds like just a 2 year old in general. ...[S]o I'm not really sure what is different about him being preterm than not, because I don't have anything to compare it to.

When Jennifer was asked to recount the events surrounding her second son's delivery, she reveals her high-risk status and introduces elements of her first pregnancy into her narrative. Several weeks before her second son's due date, she began leaking amniotic fluid and was subsequently admitted to the hospital, staying there until she delivered. Jennifer's displeasure regarding how she was managed during this period is evident.

...I was high-risk anyway 'cause we had lost a child before. ...[M]y body just was not good enough to carry at that point so I needed to have stitches put in. It was a very high-risk pregnancy with him. Um, the one prior, we lost him because I just dilated and had no warning. All of a sudden just woke up in the middle of the night, blood everywhere. It was too late to do anything and he was too young to be able to do anything with.

...[T]hen going into *this* one, *this* pregnancy, I was with...high-risk doctors throughout the whole thing. So there, there were stitches that were put into my cervix to make sure that it wouldn't open up prematurely.... Went to doctor's appointments regularly; *everything*. ...I would say, it was 2 to 3 weeks prior to when I went to the hospital, I noticed I was having contractions. So I went to the hospital, they gave me the steroid shot...'cause they knew that's what it was, and they called it "Braxton Hicks." Fine. Sent me home, no big deal. About a week later...I was leaking and I called my doctor, he said, you know, "Don't worry about it, it's probably the baby pushing on your bladder." Ok,

fine. So, it continued to leak until to the point where I'm wearing...heavy pads now, like something's not right. I call them again. Well, they don't...really have an explanation. I was not really thrilled with the way they handled the situation 'cause I even had a doctor's appointment with my high-risk doctor in the middle of all this and it was about 2 weeks or so that I was going and here it was my amniotic fluid. So, I wasn't very happy. I got admitted to the hospital, obviously, 'cause I made them check me. ...[A]t that point they cut my stitches and they expected me pretty much to just open up and it was going to be no problem, I was going to have baby that day. That's not really how it happened. I ended up being in the hospital, had...antibiotics for about a week; they held me off for a week and then they actually induced me. So at that point he was 6 weeks early.... So that was leading up to him being born. ...My veins aren't very good anyway, so, they had to constantly go to a different arm or a different vein everyday to continue the antibiotics. So, it was interesting.

Although Jennifer knew she was considered high-risk and would likely experience another preterm birth, she tread softly, not quite sure what to expect. She made every effort to safeguard her pregnancy, keeping her appointments, following doctor's orders, and being vigilant regarding any unusual symptoms. Despite being prepared for a preterm birth, Jennifer admits that initially she did not understand why her son had to be in the NICU.

Right, we weren't sure what was going to happen. We knew there were precautions that we could take in order to prevent going early again. But we were pretty much guaranteed I was going to go early again, which was fine. We, we were ok with that. ...[B]ut we were taking every precaution possible that we wouldn't go too early. And that's why the stitches happened and then I was on bed-rest for a while. My doctor didn't want me to go back to work but...I was itching. I had to do something. So, I was allowed to go back to work, but...I couldn't move, basically. I had to sit there. You can't lift anything...I

followed the doctor's rules. ...I followed everything he wanted me to do. Everything was fine until all of a sudden I...started having contractions. And like ok, I know what this is, went to the hospital. ...[W]hen things happened, I was on the phone or I went to the hospital. They probably got annoyed with me, but that's ok. I wanted to make sure what was happening. ...I had a doctor's appointment at least every week for probably a good 2 months...because they were just measuring my cervix. And that's when we had the stitches put in after we saw it was opening up. ...[O]ther than that...it was pretty much like every 2 weeks I was going to the hospital until...I...was admitted. But I wasn't very happy with my doctor...when I told him the story of the fact that I'm leaking and I've called and this is what they're telling me, he just feels my stomach, says, "Oh, there's plenty of fluid in there." How can you really know without checking? How? I know doctors might be good 'cause they do it everyday. My baby was big, he was 6 pounds, 2 ounces, for 6 weeks early. So most everything that he was feeling was my baby. ...[T]hat was another reason why I didn't quite understand why he had to go to the NICU, 'cause he was so big. But it was just because of not being able to eat properly, he didn't quite understand that, which was fine...I understood. ...[T]hey wanted to make sure he ate enough to gain weight...but...being where he was, kind of pushed him back instead of just coming home. Because as soon as he came home...it was just like that...quick turn-around, he knew what he needed to do. ...I had that steroid shot about 2 weeks prior to that...[so his lungs were ok]....

When asked what her experience being in the NICU was like, from a mother's perspective, Jennifer describes how emotionally challenging it was. Recalling what she witnessed of the high-tech atmosphere of the NICU with its life-saving equipment reminds her of the unhappy circumstances of her first son's birth and subsequent death. She voices anger and dismay that despite his gestational age nothing was attempted to prolong his life. Even though she

eventually revised her perspective of the NICU, appreciating the care available to children there, Jennifer was a strong advocate for her second son's earliest possible discharge from that environment. She credits his ability to eat well and gain weight to not only her presence in the NICU but his being at home, away from the unappealing hospital atmosphere.

...[I]t was difficult. Emotionally, it was very difficult. Um, knowing you can't take your child home was extremely difficult, seeing the other children there. ...I know there was one child there who was there for probably, I think 6 months...and it was just, it's heartbreaking...seeing that kind of stuff. But at least there are tools or machines that you can use to be able to help babies like that. ...[O]ne thing that I was hoping would happen with my first pregnancy was that something could have been helped with him. But he was under the, I guess it was 24 weeks is what it is when they actually *try* to do something. But he was born and he was breathing on his own and everything. I don't understand why they couldn't have tried. Even though he was under the 24 weeks, why couldn't you have tried? That's something that, it hurts. It still hurts to this day and probably always will. But I'm never, probably never going to get real good answers on the way I want anyway...it's just something you deal with. ...[I]t's definitely...heartbreaking to see the children, you know, go through that kind of stuff especially with the tubes down their noses, or whatever. But knowing it's to help them, it's kind of, I don't know, it, I guess it would even itself out. You know it's a good thing but yet you just don't like seeing that, especially for little helpless children that can't do anything. ...[W]e got lucky. ...[Our second son] was there for 2 weeks. So, hopefully, that worked out well, I mean, he probably could have been there longer but they said pretty much 2 weeks was going to be what it was. But I pushed to get him to come home, too. I was there every day for hours and hours. And I tried, 'cause I was trying to breastfeed. And I got him to eat more from me than the bottle. So I ended up spending the night with him to show them that he

would gain enough weight to come home. And that's how I got him to come home, because I pushed. Otherwise...he would have...been there for probably another week or so, I'm thinking. ...I don't know if it's just family oriented with him, with, with my son or the atmosphere of being in a hospital. 'Cause you know sometimes you just don't want to eat 'cause you're in a hospital. It's the atmosphere, what you're around. ...[I]f you make it a little more homey I think it might make a difference. That's my opinion because as soon as he came home or as soon as I did that nightly stay with him he ate fine...there was no problem. It's amazing what atmosphere actually really does to kids and people. ...[I]t's something to think about. Because maybe you wouldn't have as long a stays for certain people...because atmosphere does everything. How many people really want to be in the hospital? ...They want to be home.

Jennifer's future plans for her son include enrolling him in daycare. She reveals the most important consideration regarding her son attending preschool is how it will affect his health. Based on his history in daycare, she fears he will become ill and often. Despite this concern, Jennifer voices willingness and a determination to expose her son to experiences that will better prepare him for kindergarten, particularly those that will increase his verbal proficiency. Since her son is friendly and loving, she does not anticipate he will have any trouble developing social relationships.

Right now, I think the only reservation I have is...sickness. I'm afraid of, of the sickness...especially the...swine flu right now.... I know he's going to get sick, he has already. We've, we had him in daycare when we lived in [another town] and he was constantly sick. That is what I think my biggest fear is by putting him back into the public, is that. ...I know he nee--, his body needs to become immune to things, and...go through that...I understand that. I just don't want him to suffer. ...I don't want him to have to really be sick all the time but I know it's going to happen at some point. I know I

have to do it; I'm just trying to protect my little one. ...[W]e've gotten lucky...we've been trying to find home baby-sitters at this point. And right now he's with his great grandma, so that's a really good home. ...[W]e do want him to interact with the public, we want him to be with the other kids and make friends and go through everything. ...[E]verything that his father and I went through we want him to go through, too. I think he will do fine. He makes friends everywhere he goes. He's a very loving and happy boy. ...I don't see him having a problem. The only thing that I think, I don't know if it's where he's at now or if it's because of being premature, is the verbal-ness, you know. He doesn't say as much as I think he should be saying right now. ...[W]e even bought the "My Baby-Can-Read" program thinking that would help...get him to vocalize. He actually seems bored with it. But yet, he's not saying the things. I mean, he says things...he knows words, he knows what things are. He knows what's going on, he's smart in that aspect; but he's just not vocalizing it. And I don't know why. And I can't figure out how to get him to do that either. And that's another reason I was thinking of going into preschool. Maybe they have a different way of approaching it, to get him to start vocalizing...what's all up here in his head. ...I don't know. We're, we're contemplating that for, for [when he is] 3 [years old]. We think, you know, next year we want to put him into preschool and see what he does. ...[T]o try and get him ready for kindergarten. 'Cause we want him to have every opportunity possible. So we're trying.

As Jennifer's narrative unfolds it becomes increasingly clear how much her current mothering experience has been influenced by the loss of her first son. This is evident as Jennifer considers a word or phrase that describes her experience of being the mother of a former preterm infant now at preschool age. What she identifies as a fierce sense of protection for her son reflects the lingering power her previous birth experience has had in her life.

I think the only thing that I can think of is, “protect my son at all costs.” I mean...he’s my world. He’s magical to me because I was able to actually have a son. And that’s one thing I wasn’t sure at, well, a baby in general, I wasn’t sure if it would actually happen for me...especially after the first time. And, and then knowing what I was in for the second time around was just, it was heartbreaking ‘cause we didn’t want to tell anybody. Even though we were trying, we didn’t want to tell anybody that we were pregnant because we didn’t know what was going to happen. We didn’t know if it would work. ...[I]t hurt everyone, not just us; it hurt everyone to know what we went through. ...[S]o, definitely “protect him, regardless.” Any situation, I will be there to protect him no matter what because I am not about to lose him, not one bit.

Jennifer suggests that the intensity of her protectiveness over her second son is most likely attributable to the loss of her first son, and not because of his preterm status. She indicates she would likely have the same sense of protectiveness whether he had been born preterm or not.

[I would] probably [have that same sense]...because of what we went through prior. I mean, not that I wouldn’t feel the same if we didn’t lose the one prior. ...I just don’t think it would be as strong. ...[I]t’s a different feeling when you actually lose something that you couldn’t help. You know, you lost something...it was taken from you, basically. You can’t help that, so you have a stronger feeling of protectiveness...for the one that you have now. That’s, that’s my opinion. I mean I can’t really tell you for *sure* ‘cause I don’t know, I’m in one situation...I’m not in the other. ...[B]ut that’s what I would...assume....

While Jennifer indicates that she would love to have more children, given the level of stress and uncertainty she experienced with her pregnancies, she and her husband would likely consider adoption if they wanted another child.

I would love to try. ...[A]ctually at the time I had my son I got my tubes tied. ...I would love to try again; I just don't think it's very practical for us because of what we went through. It's too nerve-wracking, it's too stressful to try and go through that and not know what the outcome's going to be like. ...[W]e have talked about adopting because there are many children out there that could use a good home. But...I don't know, I mean, I loved being pregnant. ...[T]he whole experience for me was just great and I loved it, even though it was very stressful and...not knowing what was happening. I still enjoyed being pregnant and...the experience. ...[S]o...we probably won't have another that way, but if...anything, we'll adopt...a child. That's what I think, we might, but I don't know yet. I want another one that's...for sure, but...my husband's not quite at the...same place I am.

Jennifer's primary source of support in the course of her experience has been her husband. While she acknowledges having received some support from others during her son's earliest days, she admits she cannot remember much of those details; her attention was focused on being in the NICU with her son.

...[F]irst and foremost, my husband. I mean, he was right along there with me willing to do everything that needed to be done. He supported me...getting up at night...just having a baby in general. And...he was at the hospital when he was in the NICU, you know, everything. Even though he had to go back to work, I understood that. He couldn't be there as much as I was, but he was there to help me through it emotionally...by supporting me with what was happening. ...[H]onestly, I don't remember much of anything outside of the NICU only because I was there all the time. ...I had to go home obviously, I had a dog at home, we had to take care of her and, and things like that, and there was just things at home you have to take care of.... ...[T]hat period of time I don't really remember a whole lot other than being there with my son. So I can't really tell you

what kind of support I had. I'm sure I had some, but I don't really remember that. After we brought him home, um, we had people help us...bringing us some food...and just trying to get us stocked up so, you know, we didn't have to worry about other things other than just trying to take care of him and adjusting to the new baby in the home and...what was happening. ...[S]o we had that.

In terms of support she has *not* received during the course of her experience, Jennifer wishes others would have been available to help care for her son. She indicates she and her husband rarely have time alone and she almost never has opportunities for personal time. She voices how important having some time away from her son is to her, that it restores her sense of self and is rejuvenating.

I think the one thing I was really hoping for as he got older, hoping that somebody would kind of help us so my husband and I could have some time by ourselves. You know, even if it was one night a month, you know, something very minimal, that it wasn't a big deal. And we didn't have that a whole lot and we still don't. I got lucky today that my brother was willing to take my son for the day so I could go, you know, get my eyes done and, and then come here and do this, and kind of just have a day to myself. This is the first day to myself that I've had...probably since before my son. ...I don't get time by myself. My husband and I, we get a day here and a day there *maybe* throughout a year, but we don't get...a whole lot of time. ...[I]f I could ask for any kind of support, it would be that, just to kind of give us a break every now and then. You know, going to work is not a break. You go to work, you don't have your son, it's a different kind of thing, you're working, it's not fun most of the time anyway. ...[S]o...I would say the support that I would want would be that right now...if I could get it once a month...one evening a month or...one overnight a month I think would be very nice. 'Cause you need that adult time. You need to feel like an adult, a person, not just...somebody who has to take care of somebody all

the time. ...I know it's probably going to sound awful, but it's getting old. I mean, I love my son to pieces, but I need a break, I just do. 'Cause after 2 ½ years straight, it, it's hard, you know, especially...the sleepless nights, the nights that you try to get sleep but are really not getting much sleep 'cause you're constantly getting up. Right now we're in the potty-training phase so he's been getting up a lot. Actually 3 nights in a row...he slept through the night. For...probably the past 2 months, he hasn't been sleeping through the night. And...I haven't figured out why. ...[I]t could be part of growth...growing pains...he might be dreaming now...potty-training, I mean it could be a couple different things. There's nothing majorly wrong with him, we know that. But...it's hard, especially when you work full-time and then you take care of everything at the house, I mean...it's like my job never ends. I have more than one, that's for sure. I think I have like 3 full-time jobs right now, that's the way I feel. ...I work for my employer, I'm a mother, and then I'm also a wife and a...homemaker.

Although Jennifer's husband has been supportive emotionally, she reveals that she needs him to offer more hands-on help in order to keep their household running smoothly. She perceives the housework is all on her. While Jennifer admits she likely contributed to her husband's lack of participation in completing housework, she realizes now that she cannot do it all; she needs him to get more involved.

...I think the other support I would want is just my husband to understand a little bit more. He has a physical job and get--, he's tired. I understand that. But, my job is very strenuous, too. I'm working a lot of hours for my job, my...actual job. And then when I get home, it just switches. Now I have to make sure dishes are done, cook--, food is on the table, food's in our bellies, and clean-up afterwards, and you know, make sure the laundry's done, and this and that and—why can't *he* do something? You know, and that could have been my fault from the beginning, saying, you know, "I'm, I'm more than

willing to take care of it.” ‘Cause I wanted to be a stay at home mom. And I did that...and it just didn't work. I got bored. But, now I don't think I would, with my son being the age he is...I wouldn't get bored now 'cause he's fun. The first 4 months of his life were eat, sleep and poop; what else do you do? That's pretty much what he did. So now I wonder I got bored. I'm...not that kind of person; I have to do things. I have to be challenged a little bit. ...[B]ut, financially that's not how it works either. That's the other aspect.

Jennifer voices regret that both sides of the family seem reluctant to offer more meaningful support to her. Her proposed solution of rotating baby-sitting services seems, from her perspective, to be a do-able and practical means of help, not only for her and her husband, but to other couples in the family with small children. She indicates that her solution, as reasonable as it appears, is unfortunately, unlikely to work due to untoward family dynamics.

...We get support. We do, I mean, we get support from his family as well as my family. ...I don't think it's...as much as what I would like. And I'm sure probably a lot of people say that. ...I'm not looking for it all the time, it's just, even if we could rotate it, if I could even just have it work out that...my mom does it this month...then his mom does it next month...and rotate it throughout the family...you'd be doing it once every 3 to 4 months. I wouldn't think that would be difficult. And we're more than willing to do the same for my brother and...my husband's sister.... We're more than willing to do the same for everyone else. I don't know, sometimes we just feel like an outcast. But, I don't know if it's just family issues in general or what it is. I'm sure it's not just...having a preterm baby though. It's just family issues.

Jennifer praises their family doctor, not only for his care for all of them but also for being a reliable and friendly source of support. She is grateful for the relationship they have built with their doctor and indicates that he has often inquired about her and other family members' welfare.

See, the doctor that I take my son to is actually our family doctor. We all see him...that's one thing that I really wanted to keep. I wanted a family doctor that all, our whole family sees him, not just take our son to a pediatrician that you're only going to see the kids. ...[T]o me a family doctor is worth more than a pediatrician. Not saying that if there was an issue, I mean, he certainly sent us out when we needed to. If...he can't answer the questions or, or what's happening, he sends us to somebody who can take care of it. So he's good in that aspect. He's always asked how we are. ...[H]e's more like a friend, too, not just a doctor, which is another nice thing about him. ...[W]e actually followed him from doctors' offices because we wanted to keep him as our family doctor. We just really, we created...a rapport with him that we wanted to keep. It's one of those, that you just want to see him and that's it. ...Now the nurses, well, we don't know them as well. The doctor, yes...he always asks how we are doing.... You know, it just, like a friendship, it's not just a doctor-patient relationship, which is nice. ...And you can ask him things outside of, you know, "doctor things," too. Or if we're there just to see for my son, his check-up, and I have a question for me or my husband, I can ask him at the same appointment and he's more than willing to help me out with that. ...I'm glad we have that.

Jennifer was asked to imagine she would be speaking to a group of nursing students about her experience. I asked her to envision, as a woman who has had a child born preterm who is now at preschool age, what she would want nursing students to know so they could understand such an experience on a deeper level.

I would think just knowing in general that somebody went through this is a very powerful thing just to know and they should be definitely be...I wouldn't say be...careful in what they say, but sometimes certain things...that would be said might be taken the wrong the way for somebody who has had a preterm baby. ...[W]hen you see forms that you fill

out at the doctor's office, you see about the miscarriages...still-birth is another one that is on there and the actual birth; preterm was not on there for a very long time. And I haven't seen many forms like that recently anyway because I don't go the doctor that often, but, um, that's one thing, [preterm is] definitely different than a miscarriage. And a lot of people mix that up. They mix up preterm and miscarriage a lot. ...[B]ecause my first son was a preterm also. He was not a miscarriage even though he did not survive. He was born alive. And that's something that a lot of people don't understand, they don't understand the feeling of that, nothing. So that would be certainly something to know. Make sure if it's a preterm, you still ask the question, "Are they alive or not?" Because it could be two different ways. That's what I would suggest. ...[P]eople just don't take it all the same way. ...[A] baby could have been born...full-term, lived for couple months, and then passed. ...[T]here's so many different reasons for things happening. I definitely think on questionnaires that they would do for people if they're asking something about how many children you have, how many children have you had and if they're living or not. You know, ask both questions because they might not be any more, 'cause obviously, if they're not, you [as a nurse] want to read that sheet. And you don't want to...make general conversation, "How's, how's your, your child?" And they're not living. How would that affect the person there? That would be a, a *traumatic* experience. I know I would not be very thrilled, if I'd stay!

Reflecting on Jennifer's comments, I made the observation that the influence of the birth of a child who did not survive lingers with their mother. In response to this observation, she voices, as one who knows first-hand, how important it is for healthcare providers to recognize the potential for that influence, to avoid assumptions, and to have accurate information about the context of their patients' childbearing experiences.

That's what I'm dealing with right now, because we had one prior to this one.

Unfortunately he didn't make it, but I'll never forget it. He's always with me, regardless.

And it's just something, you know, people should be cognizant of the fact things happen and you can't just assume. You have to know facts, especially in the field of nursing or being a doctor, you need to know the facts before you open your mouth. So...when you go to see a doctor maybe there should just be a few more questions to ask, especially for women in that area. I mean I think it would be good for...the men... 'cause it affects men too, it's not just women. It...tends to affect women more. In my husband's case, he just doesn't talk about it. He doesn't want to...bring it up. That's his way of dealing with it. Ok. Everyone deals with it differently. But it never goes away.

Jennifer reveals more detail about the life and death of her first son and in the process, indicates that there has been no escaping the influence of her first pregnancy on her second one. In light of those details, she reiterates the importance of healthcare providers getting their patients' historical facts straight so that appropriate care can be given to them.

No [escape], not at all. 'Cause, I mean, we knew what was happening the first time around. ...[T]here was nothing we could do to prevent it from happening. We didn't know what was happening so it was just a...regular pregnancy. Nobody knew anything. I mean, I was just in-between doctor's appointments, and at that point regular doctor's appointments are few and far between sometimes. ...I got to um, 20 weeks with him. So I think I was just getting ready to go for another doctor's appointment. Out of nowhere, it just happens. It just happens to people. Some bodies just don't do very well with pregnancy. And that seems to be the way my body is. And I understand that. And I know that now. But how do you know? ...You don't know anything. So...we had a very long talk, my husband and myself, whether we wanted to try it again 'cause we weren't sure what was going to happen. And I...wanted a baby of my own and it was something we

were going to try, see what happens. ...God forbid if it would have happened again, we would not have tried again. We were not going...“three times the charm” thing, no. ...I can’t deal with that; mentally that is not something that you take a chance on. We did the second time and fortunately it worked. ...[O]riginally my doctors just wanted me to go with a regular doctor; I said no; I pushed. They said you had to lose more than two before you go to see a high-risk doctor. That was the other thing I was not thrilled with. But I pushed. I pushed because of just everything that happened. But they were look, there again, it was “miscarriages.” Mine was not a miscarriage. It was a preterm birth...my son died, ‘cause nobody would help him. That’s why they need to ask the questions.... ...So, hopefully, with certain things that have happened in the past...couple years...I’m sure there’s other women that go through something similar...they might change a little bit of the way they do certain procedures. You know, just ask...a few more questions, that’s all. ...[F]ind out a little bit more about somebody’s past before you just automatically assume or push in...one direction.

Jennifer indicates that the loss of her first son triggered significant personal transformation. Part of Jennifer’s transformation is reflected in the central place her second son has in her life.

...[L]osing that first one, changed me forever. And, and it would for anybody. ...I don’t know how...to describe it to anyone. It’s just not something I would want anyone to go through, not at all. But...it definitely changed me as a person and I am all about my son. Don’t get me wrong, he frustrates me...that’s part of being a kid, you know, a mom and a son. You know, a mom and a kid period, you get on each other’s nerves, especially...when he’s like me when it comes to having the attitude, ok? You know? That’s just, it’s a given. But, anybody comes between me and him? I’ll kill for him; just because...he’s my whole world. ...[M]y husband was my whole world until he came

along. Now my son is. ...[I]t might sound bad, but he means more to me than my husband. But I love my husband! But that's just what happened.

Jennifer acknowledges that while perhaps unconventional her appraisal of the current dynamic with her son and with her husband is her reality. The meaning that Jennifer attributes to her first pregnancy comes into sharper focus as she explains the healing effect it had on a cancerous condition discovered before she became pregnant. Although her first pregnancy ended tragically, it ushered in not only her physical healing but also the possibility for a second pregnancy.

[That's my reality], it really is. You know, [my second son]...was a very important part of me. And my first son was a very important part of me too. I will never...forget him at all because I actually had...issues with abnormal cells that became cancerous and with having him, it all went away. ...And they did tell me by having a baby it could possibly take it all away. ...And it did! Because I was dealing with that for years. I even went and had a LEEP [loop electrosurgical excision procedure] done and you know, everything! And by having him, it went away. And I've been cleared since. ...I mean...if someone really listens to the whole story...beginning with my first son...you'd be amazed at...[the] outcome. ...I thank God everyday for my life. And if it wasn't for my first son, I don't know where I'd be. I don't know what I'd be going through. I probably wouldn't have my second son, for sure. And he was a mistake, you know, my first one. We didn't plan it...but it's good it happened when it did, too. Because I'd just gone through my LEEP and then everything came back again. And it came back full-force. So what do you do? You just do what you can and hopefully everything works out for the best and luckily it did.

In contrast to her earlier comments, Jennifer concedes that it was best that her first son did not survive after all. She admits that knowing the facts (including the results of her son's

autopsy), having the benefit of reflection over time, and being able to talk with her husband about her experience has enabled her to make sense of it, to frame it from a different perspective.

...[W]e had an autopsy done on my first son and his cerebellum wasn't forming, which was another good thing that he didn't survive because of that. So...it was a lot, you had to really put all the pieces together to come to terms with things. It took me a while for that. But once I found out everything, it's like...it happened for a reason and it's a good reason it did. But it's hard to come to terms with that, especially when you're in the situation, it's happening to you right then. I was mad with doctors for a while, for not trying. Nobody was even in the room when it happened.... It was just all of a sudden. ...[M]y water broke one minute and next thing you know, I started dry-heaving and it, out he pops. ...So...between the two situations, I've been through enough for my age. And I'm young. ...Most people don't deal with this in their whole lifetime. ...So, I'd prefer if the rest of my life goes clean-sailing. ...[L]ooking at me now, a lot of people would never know that I've been through what I've been through. But I've had a lot of time...to think. And my husband and I talked a lot and he's like my therapist....

As Jennifer reflects on the timing of the events in her experience she sees how far she and her husband have come and the good things ahead for them and their son. She is happy to see their son grow but admits she is not ready for the eventual bumps and bruises active boys sustain. The fear of losing her second son, rooted in the loss of her first, is always at hand, informing her parenting style. Despite admonitions from her husband to let go and allow their son to learn some things on his own, she lives in dread that a permissive decision on her part might lead to his being injured or worse yet, his death; there is too much at stake for her emotionally to let go quite yet.

...You know, we're just starting out life and, and all this happens to us. ...[W]e didn't even have our own house yet, we were living with his parents. ...I'm glad it's all over and done with now. ...[W]e bought a house and...we're finally starting to settle

down...things actually seem to be fitting into place now. ...[T]hat's the way I want it...to be...with our son now growing up and watching him, it, it's just a blessing to see him grow up as healthy as he is. And he's all-boy. And I'm just afraid to let go of certain things, you know? Daddy says, "Well, come on, you got to let go and you got to let him learn for his own." Yeah, I'm not ready for that yet; I'm not. You know, he wants to be a boy and he's a tough boy and I know that, but, I'm just not ready to see things happen. You know, he's already had a black and blue eye...he ended up hitting his...metal bed rail.... ...[W]e thought we were going to have to come to the hospital for that. And then he ran into a dresser, and fell down the stairs.... ...I know he's a boy, I know he's going to get hurt. But, I just don't want the stitches yet or the broken bones yet. I don't want to go to the hospital yet. I'm not ready for that; he's only 2. ...I know I have to, that's one of my fears I guess with him at the moment.... And that's another part of protecting at all costs. ...I don't want to shelter him but I don't want to see...anything happen to him. I'm just afraid. I'm afraid of losing him because I've already lost one, I don't want to lose another, especially now that I've had 2 ½ years with him. I've seen people go through that and I don't know if I could. I don't know how I could do that. That would be something I...couldn't get over. ...I never got over my first one let alone if something would happen to him. I'd never forgive myself if it was something from me that I...let him do something all of a sudden. I'd never forgive myself. So...I can't do that. I'm not ready to let go yet. Maybe not let go completely but not let go of how I am with him. ...And I'm sure it has a lot to do with our, because of our first one.

Jennifer was asked to elaborate on the transformation that took place in relation to her first son, how she is a different person now compared to what she was before. Providing details of the surreal events surrounding his delivery, Jennifer makes clear that experience changed her forever.

It made me grow up fast. ...I guess 24, 23 when I had him. ...[W]e found out we were pregnant. ...[W]e were going to have him...do whatever we can, you know, we were scared obviously.... ...And...so thrilled...we were happy we were having a baby, especially me because I wasn't sure what was going to happen with me...dealing with all the issues...with the abnormal cells. And, and then waking up at 3 o'clock in the morning to all this blood was just terrifying. I was terrified. I didn't know what to do about that. ...I got my husband up and we went to the hospital...told me that I was 10 cm dilated. ...What am I supposed to do? I'm only 20 weeks pregnant. ...I didn't cry at that point. I didn't know what to do, I didn't know what I was feeling. ...[T]hey said there's a possibility it could have been something with the placenta or...something that was making me bleed. And then they found out that I was 10 cm...it just kind of like hit me that I'm losing this kid. You know, what am I going to do? ...[T]hat day changed me forever. ...[J]ust being there and then having him and seeing how small and fragile he was and then watching him die (pause) (Jennifer crying) that was probably...the hardest part. ...I didn't really know him, but having those months with him inside me, being pregnant with him, it hurt like hell. ...[D]ealing with that was probably one of the worst feelings. I lost people like my grandfather and people around me; nothing compares to that feeling, nothing at all. ...I think after that it just kind of made me strong to the point where I'm not going to let anything like that hurt me like that again, 'cause it still hurts. ...[I]t's been 3 years; actually going on 4 years...it still hurts. I have a plant at home yet from that day and I won't let anything ruin that plant. I give that all my love just like...if he would be here. ...[M]y son now, I don't love him any less, not at all, and he's not a replacement, not whatsoever. ...[T]hat was one thing I was afraid of feeling, that I wanted to replace him...not at all. ...I think having this plant...really shows that, because the plant *is* my son. ...[A]nd he's thriving right now. You know, I look at this

plant and I just see it growing and...I see my son. I mean, we named him. We...had him cremated so we have him with us all the time. We have pictures of him. You know, we did everything...we wanted.... But it's difficult, it really is. And...from that day...I changed completely. Because I mean, you don't know...what that feeling's like until you're there, you really don't. ...[S]o that's why it changed me...it made me strong, it made me not want anything to happen to my son because I can't go through that. ...[I]t still hurts...I can only imagine what it would feel like now if something happened to my son; I'd be devastated. ...I was hoping I wouldn't cry. ...I can talk it about it at times and I'll be fine. Like, all of a sudden, I, I was fine up until that point. And that's hard...re-living it. It's difficult. But that's probably why I am the way I am with my son now, 'cause...I'm afraid, plain and simple. [That experience]...changed me as a person, it changed the way I think about things, it changed everything, I mean, just in general. ...[L]ife is so fragile. ...[A]s my husband says...“Live each day as if it's your last.” And it's so true! 'Cause you don't know what's going to happen from day to day. ...I never in my life thought that was going to happen to me, never. You know, be pregnant one day and next, not have your kid. How...could you know that? You don't! ...[T]hat day I didn't have a kid anymore. I was pregnant one minute and a few hours later I wasn't and I also didn't have a son in my arms either. ...I would never want anyone to go through that. We actually had talked to somebody, a nurse...or I think she might have been going to school for a doctor, I don't remember. But she had twins, same thing happened to her. And...I think it was good that they sent somebody in to talk to us about it. But then again...I don't know...it's kind of hard to digest right away. You have to give it some thought. ...[T]hey sent somebody in right away. Yeah, they sent somebody in that day 'cause we were in the hospital 'til about 3 o'clock in the afternoon, so we were in for about 12 hours.... And they...said I could stay as long as I wanted...and keep him

however long I wanted, even though he wasn't living anymore. ...[W]hen I was ready to let go was when they were going to take him. ...I didn't want to stay there anymore, 'cause obviously...everything just happened...and I wanted to try and get on with my life but it was very hard...very hard to leave that hospital...especially without my son [Jennifer crying]. But at least leaving the hospital was the first step. After that I ended up quitting my job. ...[W]e went on vacation. That was one thing they said, "Go make new memories." [That was good advice], yes, it was. ...I wasn't happy with the job I was in anyway. ...I ended up getting a different job when we came back from vacation. ...[I]t was helpful to go make new memories and just was very hard to try and do that. Especially after months of being pregnant...and getting ready for everything. ...[W]e got rid of everything. We didn't want any of it. Even though we said we would probably try again, we were giving ourselves at least 6 months to a year to think about it. We said we weren't going to talk about it for at least 6 months. And when that came up...I said..."I want to do it again, I want to try." And my husband was ok with it, so he kind of let me do what I wanted to do.... ...[W]e didn't buy anything for months 'cause we weren't sure what was going to happen. And I never had a baby shower anyway. ...[T]he Friday before my baby shower was going to be...I ended up being admitted to the hospital.... So everyone came to the hospital that Saturday. They came in spurts 'cause obviously everybody wouldn't fit in the room.

Jennifer reiterates that she needs time to be able to process and reflect on traumatic events. She voices gratitude for her husband and for being able to talk with him about the traumatic birth and death of their first son. She advises others to refuse to settle when it comes to the quality of significant relationships and the decision to have children.

...[E]verybody's different on how they process things. I'm not one that can process things very quickly, especially when something traumatic happens. You have to give it a

second to kind of sink in [and] realize what is actually happening here. ...[I]f I didn't have...my husband, I don't know where I would be. I'm so glad that I had him. ...I think that's good for anybody who has a significant other that they really, truly care about and love. ...[T]here are people that are together and don't really love the other person, which is sad. You know, really go for what you want; don't settle. ...[I]f I could give anybody advice: don't settle. Do what you really want. You know, truly find somebody.

And...same...when it comes to children. ...[D]o what you really want to do. I mean, if you really want to want to try and have a baby just like I did...you'll find a way to do it. There's ways to do it out there. You know, we found a way to be able to have one. And even though he was early, I don't care! ...I didn't care that he was going to be early, I just cared that he was alive. ...I was willing to do anything to get him home, anything at all; and I did! ...I pretty much do anything for him now. That's what I do!

As Jennifer's narrative drew to a close, she identifies the value of maintaining a positive attitude. She admits at times that is challenging and she does not always succeed. But she has found that by attempting to stay positive she can not only glean but learn something good out of otherwise painful circumstances. Ultimately, as a result of her experience, Jennifer indicates she has a deeper appreciation for the work of the Divine in her life. She sees that her first son's life and death were not in vain; on the contrary, he fulfilled a purpose she could not have imagined, affecting her quality of her life in a significant way. Recognizing this gives Jennifer a sense of peace.

And it's very difficult to keep that positive attitude...especially when things are happening. ...I have times when I fall back, I really do, but...you just kind of have to pull yourself out of that patch...and just move on...you grow so much faster and broader if you do it that way, by thinking positive, and just pulling whatever you can out of any situation and learning from it. Because if you don't, then you're losing out, whether you

realize it or not, you're losing out on life or out on something. And I don't want to lose out; I lost enough, I'm not about to lose anything. So that's why, to help me deal with my loss, I had to learn *why* it happened, what was the outcome of it. Me? I'm healthy now. ...I don't have to worry about having abnormal cells and possibly cancer and then have to go through all this crap to try and get rid of it. My...first son I should say, he now is at peace...and if he would have survived, he would have been brain dead. I would never have been able to go back to work. Or if I did we would constantly have nurses. We wouldn't be able to pay for that. ...[H]ow would you really have lived your life? ...I think of it now with our son...a healthy boy and we don't get any time away. We'd *really* get no time away; we'd never have vacations probably, you know, nothing. But you do that for anybody you love. I would have done it, if he would have survived, I would have done it, no if, ands, or buts, I would have. My life would have been different, for sure. But I would have been ok with that. But it's better it happened the way it did, for many reasons. ...I really believe that, otherwise I don't know how I'd deal with it. ...[A]nd to me that's reality. Because...it's facts that truly happened, so why not take that and make it positive? There's no sense in making it negative, because then you're just going to thrive off that negativity and make yourself feel worse. I want to feel better eventually. So, why wouldn't I turn it positive? You know, when I got the phone call from them telling me I was clear of everything...that was like an epiphany to me. It was like right then and there...that kind of told me...what his purpose was in life. ...I do believe, but I'm not a big church go-er so I don't go to church all the time. But there are reasons things happen; just believe in that. ...[M]y husband, he's very kind of anti-God I guess and I said to him, "How do you explain that? You can't. You just have to believe it happens." And he does because of what happened with that. ...He saw everything. He knew everything. He knew all the facts. ...[A]nd then getting the autopsy report...that

was just...the icing on the cake of everything. So if you don't think positive, you're never going to find a good outcome anyway.

“Lessons from Loss”

The overarching message in Jennifer's narrative is “lessons from loss.” Jennifer's experience of being the mother of a former preterm infant now at preschool age is intricately connected to and informed by the death of her first child, also born preterm. That loss initiated significant personal change in Jennifer (“from that day...I changed completely”), the effects of which continue.

In light of her loss, Jennifer has become a strong advocate for her second son's safety and well-being. How she manifests this has the potential to create misunderstanding and tension with others. Perhaps no other phrase from her narrative captures this better than her declaration to “protect my son at all costs.” This stance has created a degree of dissonance between Jennifer and her husband, contrasting their different views on how to manage their growing son's need for physical play. Currently Jennifer is hyper-vigilant regarding his safety, unable to tolerate relatively minor injuries in the course of the normal activity of a 2 ½ year old boy. Her need to protect him from any and all harm may also be contributing to others' reluctance to assist her in caring for her son, even if only for a short period of time, for fear of her reaction should any mishap occur while under their care. As her son invariably encounters a growing variety of people and situations in the upcoming years, Jennifer may face misunderstanding and conflict with others who, without knowledge of her loss, will not know how to interpret her over-protective behavior.

Another, similar effect of Jennifer's loss and subsequent personal change is her perceived need to protect herself from any situation that might pose a risk to her son's health and well-

being. She readily admits she is very afraid for him but suggests she is equally afraid for herself. She does not trust that she could handle seeing him harmed in any way: “I don’t want to see anything happen to him...I’m afraid of losing him...that would be something...I couldn’t get over.” Her experience of loss has also taught her to “push” for the kind of healthcare that will meet her expectations. This behavior may also create negative relationships between Jennifer and unwitting healthcare providers in the future.

Based on her narrative, there is little doubt Jennifer’s experience of loss and the lessons learned from it have deep personal meaning for her, significantly influencing her relationship with her second son. Far from being a static event, Jennifer’s loss and the changes it has inspired have had an evolving quality. Over time, she has gained an appreciation for what she sees as the underlying purpose of her first son’s life and death. Although the full extent of the effects of her loss is not yet clear, Jennifer’s determination to keep learning from her experiences and to maintain a positive outlook suggest she is willing to undergo additional change in the course of her life, both personally and as a mother. Jennifer has learned that this perspective is the path to growth and restoration: “you grow so much faster and broader...by thinking positive...pulling whatever you can out of any situation and learning from it...if you don’t, then you’re losing out...I don’t want to lose out; I lost enough...”.

Chapter Summary

In narrative inquiry studies, a participant’s cohesive narrative is the primary unit of analysis (Mishler, 1995; Riessman, 2008) and as such, is recognized as standing alone, without attempts to reduce it or subsume it with other narratives. This chapter presents the verbatim narrative texts obtained in either audio-recorded, in-person interviews or written narrative regarding the experiences of 6 mothers of former preterm infants now at preschool age. The

interpretation and analysis of each narrative was the result of the hermeneutic process. Re-presenting participants' narratives utilizing the interpretative and analytic results communicates in a cogent manner the meaning each participant attributes to their personal experience (Duffy, 2007; Mishler; Polkinghorne, 2007). To that end, the researcher identified a metaphorical narrative theme that captured the meaning within each narrative. Instead of minimizing the participants' individual voices, it is hoped that this re-presenting of the participants' narratives and their inherent meanings only serves to accentuate them.

Chapter 5

Discussion and Implications

This study explored the personal narratives of mothers of former preterm infants now at preschool age. Each participant's narrative is unique and stands alone. The narratives provide a variety of personal experiences related to the phenomenon under study but more importantly, the narratives reveal the *meaning* each participant attributes to her personal experience. A metaphorical narrative theme, determined by the researcher during the course of narrative data analysis, captures the over-arching message in and meaning attributed to participants' narratives. The participants' pseudonyms selected for this study, the descriptive word or phrase depicting their experience of being the mother of a former preterm infant now at preschool age, and the assigned narrative theme are presented in Table 5-1.

Table 5-1 Descriptive Depictions and Narrative Themes

Participant Pseudonym	Descriptive Depiction of Personal Experience	Metaphorical Narrative Theme
Judy	"A Willing Sacrifice"	"I Matter Too"
Jane	"An Adventure"	"Savor the Moments"
Patty	"It's Amazing"	"Honoring New Paradigms"
Kellie	"Blessed"	"Against All Odds"
Ann	"The Best Thing in the World"	"Affirming My Worth"
Jennifer	"Protect at All Costs"	"Lessons from Loss"

This chapter attempts to integrate the findings of this study with the extant scientific literature presented in Chapters 1 and 2 and is divided into two sections. The first section specifically examines how the content informing each participant's narrative theme is integrated with the literature. The second section presents a broader examination, of the similarities and differences among the narratives, again in light of the current literature. Both sections will examine the respective results in light of both the conceptual literature and theoretical perspective selected for this study. Following these discussions, implications for nursing practice, study limitations, and recommendations for future nursing research and are presented.

Discussion: Participant Narrative Themes

Judy: "I Matter Too"

Judy's narrative clearly expresses her long-standing, pervasive self-denial in association with what she sees as her role as mother. Judy's self-denial and the lack of support and recognition for it from her husband have created chronic stress for her. She has suppressed her own needs in deference to those of her son for so long that she has lost herself in the intervening years, affecting her well-being and overall quality of life.

In contrast to current literature which suggests sources of stress for mothers of former preterm infants are the preterm birth event and the neonatal period, including factors in the NICU environment (Affleck et al., 1991; Beck, 2006; Fenwick et al., 2001; Holditch-Davis, Bartlett, et al., 2003; Jackson et al., 2003; Miles et al., 2002), the source of Judy's stress is rooted in her personal context. Judy barely mentions circumstances surrounding her son's preterm birth, his stay in the NICU, the NICU environment, or the staff members there. Instead, her envisioned

standard of motherhood, persistent guilt and over-compensating for having had post-partum depression, the dynamics in her relationship to her husband, her husband's apparent freedom to choose his level of involvement in parenting, her tendency toward perfectionism, and the associated demands she places on herself are the contextual elements revealed in her narrative that contribute to her chronic stress. This supports literature suggesting personal contextual features influence not only the experiences of mothers of former preterm infants (Libera et al., 2007) but also a mother's appraisal of the kind of support she receives after giving birth (Cigoli et al., 2006), and how a mother deals with stress (Miles et al., 1999). It also supports what Wijma and colleagues discovered, that is, multiple factors in a mother's personal context, not just an isolated birth event, are at play in her life (Wijma et al., 1997).

Compounding Judy's pattern of self-denial is her history of post-partum depression.

While she was not diagnosed with post-partum depression until after her second child was born, Judy believes she had post-partum depression after the preterm birth of her son. This is consistent with literature that suggests mothers of preterm infants experience more distressing psychological symptoms than mothers of full-term infants (Hill & Aldag, 2007; Muller-Nix et al., 2004; Singer et al., 2003) such as depression (Davis et al., 2003; Libera et al., 2007; Singer et al., 1999).

Witnessing the detrimental consequences of untreated post-partum depression serves to fuel Judy's self-denial as she over-compensates, in an effort to make up for lost quality time with her children. While Judy's parenting behavior is similar to what Miles and Holditch-Davis (1995) depict as *compensatory parenting*, that is, over-protection, over-stimulation, and over-attention, the underlying reason for it is different. These researchers identify this parenting style as a means of compensating "children for their neonatal experiences" (p. 246); for Judy, it is due to the negative outcome of her untreated post-partum depression. In addition to her self-denial and post-partum depression, the demands Judy perceives as necessary to care for her son and daughter may have negatively influenced her psychological well-being. This is consistent with Raina and

colleagues' findings, that chronic childcare demands may negatively influence a caregiver's physical and psychological health (Raina et al., 2005).

Judy acknowledges that she understands her health and well-being are integral to her son's well-being and development. This is consistent with substantial evidence in the literature suggesting a mother's contextual features such as thoughts, feelings, and personal characteristics can eventually influence her child's cognitive and physical health (Egeland & Farber, 1984; Feldman et al., 1999; Josefsson et al., 2007; Leckman et al., 2005; Magill-Evans et al., 1999; Mantymaa et al., 2003; Muller-Nix et al., 2004). Despite this knowledge, it appears Judy cannot see her way to initiate the changes in her life that would enhance her own health.

Against the back-drop of the theoretical perspective for this study, Transformative Learning Theory, Judy appears unable to freely engage in critical reflection and to entertain the questions critical reflection entails. It appears that instead of experiencing an abrupt event that created a dilemma for her (Dewey, 1933), she has had a series of chronic challenges leading to the loss of her own identity and well-being. Perhaps having access to a safe environment, such as what is recommended for discourse (Mezirow, 2000), is needed for her to begin the reflection that could lead to her transformation (Belenky & Stanton, 2000) toward renewed health. Although Judy suggests that she experienced a transformation related to her post-partum depression treatment stating, "I'm a different person as a mother now....I identified a problem with me....[W]hen I had my 2nd child, my daughter...I had severe post-partum depression....I was put on medication...I did therapy," the *process* of transformation is different from what is explicated in Transformative Learning Theory. Some may argue that distinguishing between the effects of successful medical treatment versus the process of revising personal perspectives is not important as long as the end result is favorable. However the difference is significant. Transformation as posited by Transformative Learning Theory entails inner work (Dirkx, 2006) and is a manifestation of the emancipatory knowledge born of self-awareness, critical reflection and

critical self-reflection (Cranton, 2002). While the end result of transformation and successful medical treatment may be similar, the latter may hinge more on one's cooperation and compliance with a prescribed plan of treatment versus finding one's way through the often uncharted and unfamiliar territory of revising one's perspectives.

Jane: "Savor the Moments"

Jane's narrative reveals the value she places on each and every moment of being a mother. No detail is insignificant; instead, each detail is seen as an important component of her experience of being a mother of a former preterm infant now at preschool age. Every aspect of Jane's experience is connected to and informed by elements of her personal context, particularly, the fact that she will likely not give birth again.

Jane suffered a crisis during the prenatal and neonatal period surrounding her son's preterm birth. However, in contrast to the evidence in the extant literature suggesting that the preterm birth itself and the subsequent neonatal period is a trauma or crisis (Affleck et al., 1991; Als, 1986; Beck, 2004, 2006; Eriksson & Pehrsson, 2002; Jotzo & Poets, 2005; Kersting, et al., 2004; Libera et al., 2007; Reid, 2000; Roller, 2005; Shaw et al., 2006), Jane's crisis was related to her dashed expectations of herself as a mother. Similarly, Jane's emotions of loss and grief during that period were not related to her son's preterm birth, the *ambiguous loss* as suggested by Golish and Powell (2003); instead Jane's emotions of loss and grief were in response to what would be her limited childbirth experiences. She envisioned herself giving birth to many children, not just one. Jane did all she could to enhance this one mothering experience, for instance, in her desperate attempt to make breast-feeding successful; when that failed, she had to accept that yet another aspect of her mother-self would have to go unrealized. Jane's narrative has been strongly influenced by the dissonance between her birth-reality and her expectations, congruent with other

mothers' experience as reported by Beck (2004) and MacDonald (2007). Lee and colleagues suggest that cultural norms can influence maternal thoughts and feelings (Lee et al., 2005). Jane indicates that within her family, a cultural microcosm, uncomplicated and unrestricted childbirth is the norm, increasing the dissonance even further between her lone childbirth experience and her childbirth hopes and expectations.

Jane's dichotomous interactions with the NICU nurses support what is found in the literature. Jane found what Fenwick and colleagues (Fenwick et al., 2001) and Roller (2005) revealed, that how NICU nurses communicate their expert knowledge can be problematic. For Jane, this kind of communication was not only intimidating as suggested by Feeley (Feeley et al., 2007) and Jackson (Jackson et al., 2003) and their respective colleagues, but insensitive as well, exacting an emotional toll on her and other family members. Jane was the recipient of that same mode of communication in response to her struggle to provide sufficient amounts of breast milk for her son. Instead of the NICU nurses supporting her decision to stop breast pumping, they continued promoting the superior virtues of breastfeeding, with little regard for how frustrating it had become for Jane. On the other hand, as suggested by Jones, Woodhouse, and Rowe (2007), Jane was grateful for the collaborative and educational interactions with the NICU nurses with regard to how she should care for her son.

Literature suggests that mothers of preterm infants experience a range of negative emotions associated with the preterm status of their child and their health (Hill & Aldag, 2007; Libera et al., 2007; Muller-Nix et al., 2004; Singer et al., 2003). In contrast, Jane's negative emotions during the neonatal period were prompted by missed opportunities to be with her son in the NICU. She chided herself for not being in the NICU more often; only later in her narrative did she remember that financial constraints and her own hospitalizations post-partum kept her from being with him. Her poor memory of the details during this period may be related to what

Eidelman, Hoffmann, and Kaitz (1993) identify as mothers' decreased mental concentration during the post-partum period.

While it is not clear if her experience of being the mother of a former preterm infant now at preschool age prompted a transformative experience per se, her apparent self-awareness and reflection, key components of emancipatory knowledge (Cranton, 2002), suggests that she has. During the course of her experience Jane successfully revised her perspectives, habits of mind, and points of view regarding her personal fears as well as her expectations and hopes of motherhood. She explored her options and constructed corresponding plans of action (Mezirow, 2000), ultimately integrating new attitudes and behaviors into her life (Cranton; Mezirow, 1997b).

Patty: "Honoring New Paradigms"

Patty's narrative reveals to what extent the paradigm, or the pattern and direction of her life, has changed as the result of having former preterm infant twin daughters. With their birth she came to see the larger purpose of her life, what her life was meant to be, as well as positive changes in her personal characteristics. This new sense of self and purpose empowered Patty to embrace the responsibility of raising her children with little outside support.

While Patty does not reveal detail regarding the birth of her daughters, she does indicate their births were unexpected, at 32 weeks gestation, and she was unprepared for their arrival. Apart from these details, Patty says nothing about her prenatal course and very little about her daughters' time in the NICU except that being there "wasn't'...a happy time." Patty makes clear that she does not revisit that period in her daughters' lives, that she makes every effort to avoid thinking and talking about it. This relative silence regarding the NICU suggests Patty may have viewed her daughters' neonatal period as traumatic. If so, this is in keeping with what the

literature depicts a preterm, neonatal experience to be for mothers, that is, a trauma or crisis (Affleck et al., 1991; Als, 1986; Beck, 2004, 2006; Eriksson & Pehrsson, 2002; Jotzo & Poets, 2005; Kersting, et al., 2004; Libera et al., 2007; Reid, 2000; Roller, 2005; Shaw et al., 2006).

Patty's determination to avoid the NICU memories also suggests the possibility that she is displaying symptoms of post-traumatic stress disorder. If so, this would support the findings of Holditch-Davis and colleagues (2003) who discovered symptoms consistent with post-traumatic stress disorder (including avoidance) among mothers of former preterm infants several months following the birth (Holditch-Davis, Bartlett, et al., 2003). It would also support Kersting and colleagues' (Kersting et al., 2004) findings that post-traumatic stress responses of some mothers of preterm infants may extend beyond the infant's first birthday. Patty's avoidance is also congruent with Beck's (2006) study which revealed post-traumatic stress disorder symptoms following a traumatic birth experience can linger for many years following the birth.

Another interpretation of Patty's avoidance pattern is in contrast with the presumption that she is experiencing the avoidance associated with post-traumatic stress disorder. Her refusal to dwell on the NICU memories may be a manifestation of a second new paradigm, one of hope regarding her daughters' potential. Her avoidance may signal a conscience choice not to see her daughters as vulnerable former preterm infants, based on the objective facts of their health status. If this be the case, her avoidance may be an expression of her personal sense of power and not psychologically dysfunctional. Her new sense of purpose and commitment to view them as "regular, born-on-time" may in fact be a positive contribution to her daughters' health and development. This would be congruent with the substantial evidence in the literature identifying the influence of a mother's thoughts and feelings with what is ultimately a child's cognitive and physical health (Egeland & Farber, 1984; Feldman et al., 1999; Josefsson et al., 2007; Leckman et al., 2005; Magill-Evans et al., 1999; Mantymaa et al., 2003; Muller-Nix et al., 2004). In addition, Patty's refusal to dwell on unhappy neonatal memories and the potential disability that is often

associated with preterm birth may be a way for Patty to relieve psychological stress. Such a strategy supports the findings of Elklit and colleagues (Elklit et al., 2007), that is, a child's enduring status as preterm may reinforce the psychological distress a mother first experiences during the neonatal period. It may also be an expression of Patty's newfound sense of mastery, a characteristic that Miles and colleagues (Miles et al., 1999) found to influence maternal distress.

Within her new paradigm of empowerment Patty is finding her way through the ongoing, stressful conflict of feeling the need to be over-protective regarding her children and at the same time needing relief from childcare demands. The stress that Patty identifies is congruent with what Raina and colleagues (Raina et al., 2005) suggest: chronic childcare demands may negatively influence a caregiver's health and well-being. While Patty's tendency to be over-protective may be evidence of the post-traumatic stress disorder symptom of heightened arousal demonstrated in mothers of children born preterm (Holditch-Davis, Bartlett, et al., 2003), it appears that it is more likely to be an expression of *compensatory parenting* as described by Miles and Holditch-Davis (1995). According to these researchers, *compensatory parenting* includes over-protection and over-attention "in an attempt to compensate the children for their neonatal experiences" (p. 246). This coincides with Patty's desire to focus the attention on her daughters, "I just want people to focus on my kids....they deserve it, for all they went through....all that they still have to go through." It also fits with the unhappy time the NICU represents to Patty since *compensatory parenting* has been associated with negative NICU-related memories and the distress those memories induce (Miles & Holditch-Davis).

Patty's experience of profound life change following the births of her daughters born preterm suggests she has undergone a transformation as per Transformative Learning Theory. Faced with having to care for not only her son but twin preterm daughters too (and that essentially with little help from others) was the dilemma Patty experienced. Taking advantage of whatever support was available to her, be it Early Intervention, or her significant other, was a

means for her to discover outside resources to help resolve this dilemma. But she also discovered inner resources to help work out this dilemma; this discovery and the subsequent perspective revisions revealed a new purpose, a new life meaning, and new strengths in Patty. This is consistent with the effect of change in one's habits of mind and points of view that come about through transformative learning; such change alters one's self-perception (Cranton, 2006). Patty has taken steps to integrate her revised perspectives into her life, implementing plans of action as she sees fit. Patty was able to experience significant personal change despite what appears to be a lack of opportunity for dialogue or discourse. Despite this lack, Patty was able to engage in critical reflection of assumptions (Mezirow, 1998) leading to subsequent transformation (Cranton).

Kellie: "Against All Odds"

Kellie's narrative is set against a series of pre-conception, prenatal, and neonatal challenges. Being pregnant at all was, at the beginning of her in-vitro process, a dim prospect; but being pregnant with twins was too good to be true. Once she learned about her son's intra-uterine growth restriction, she had some time to prepare for the preterm births of her twins including adjusting her expectations of what their births and neonatal period would be. This is in keeping with what is presented in the literature regarding a mother's need to reconcile her perceptions of the birth reality compared to her expectations (Beck, 2004; MacDonald, 2007). Kellie did not depict her children's preterm birth experience as a trauma or crisis, in contrast to much of what is in the literature regarding the preterm birth and neonatal period (Affleck et al., 1991; Als, 1986; Beck, 2004, 2006; Eriksson & Pehrsson, 2002; Jotzo & Poets, 2005; Kersting, et al., 2004; Libera et al., 2007; Reid, 2000; Roller, 2005; Shaw et al., 2006). Nevertheless, the preterm births of her children were fraught with uncertainty, in particular with regard to her son's short- and long-term

health status. Uncertainty has been found to be a common emotion amongst mothers of preterm infants (Affleck et al.; Jackson et al., 2003).

Bonding with her infants in the NICU proved to be another challenge. The public nature of the NICU environment and having to move about the NICU to see them both was not conducive to the kind of interaction she had hoped. Her frustration with the NICU environment is similar to how other mothers depict the NICU environment (Affleck et al., 1991; Siegel et al., 1993). In addition, even though Kellie appreciated the good job the NICU nurses were doing caring for her infants, Kellie resented the intimate knowledge they had about them. She wanted to be the one to take care of her children and to share with others what she was learning about them individually. This too is congruent with how the literature depicts the often conflicting relationship between preterm mothers and NICU nurses. Mothers and nurses alike see the nurses as the experts of infant care in the NICU (Fenwick et al., 2001; Roller, 2005) and mothers are often intimidated by the nurses' level of expertise (Feeley et al., 2007). The NICU nurses play an important role in either impeding or facilitating a new mother's attainment of the maternal role (MacDonald, 2007; Shin & White-Traut, 2007).

Although her son faces challenges to gain ground developmentally, Kellie's overall optimism, hope, and commitment to do all she can to help him is clear. This is in keeping with several sources in the literature suggesting that the influence of a mother's thoughts, feelings, and personal characteristic ultimately have a positive effect on the cognitive and physical health outcomes of her child (Egeland & Farber, 1984; Feldman et al., 1999; Josefsson et al., 2007; Leckman et al., 2005; Magill-Evans et al., 1999; Mantymaa et al., 2003; Muller-Nix et al., 2004).

Kellie indicates that her experience of being the mother of former preterm infants now at preschool age has made her a better person, that she has seen change and growth in herself. She also indicates that despite the difficulties encountered in the NICU, she has revised her perspectives. She now views the nurses in a positive light and acknowledges the value of having

had her infants in that environment. These elements of life experience, interpreting one's experience, and new or revised meaning derived from one's experience suggest that a degree of transformation has taken place in her life (Mezirow, 2000). Her revised perspectives regarding the NICU nurses and Kellie's consistent acknowledgement of the Divine at work in her life in the course of her experience, reveals the effect of her transformation on relationships and the effect of the spiritual domain at work in fostering her transformation (Dirkx, 2006; Dirkx, Mezirow, & Cranton, 2006).

Ann: "Affirming My Worth"

Ann's narrative is interwoven with references to how others, over the course of her experience, appraise her worth and as a result, to what degree they address or neglect her needs. Ann notes the type and degree of support provided or withheld, from both significant others in her personal life and healthcare providers. Her need for and sensitivity to support in association with her pregnancy and becoming a mother are congruent with the kinds of maternal support identified by Cigoli and fellow researchers (Cigoli et al., 2006), including "trustful support" (p. 96) from a woman's partner and mother. Since Ann's mother died many years before giving birth to her son, her need for what Cigoli and colleagues term "emotional sharing" (p. 96) of her experience with her husband was even more significant. In light of this, it is understandable why Ann includes in her narrative her husband's lack of support not only during her prenatal hospitalization, but also on the day of their daughter's homecoming, and in the sharing of the childcare responsibilities since. Ann's well-being during the course of her experience appears to be related to the support she received from healthcare providers; this too is fitting with Cigoli and colleagues' findings suggesting a mother's perceptions of high levels of support from healthcare personnel is stress reducing. Ann expresses a need for ongoing support from family members but

reveals that those sources of support are unreliable. Eriksson and Pehrsson (2002) found that many parents of former preterm infants aged 2 to 8 years benefit from long-term psychological support well beyond the neonatal period; it appears that Ann would also benefit from such formal support, especially since her informal support network is not dependable.

While Ann indicates she has undergone a measure of change as a result of having her daughter, it does not appear to be change that could be characterized as transformative. This may be due, in part, to the lack of opportunities for her to safely engage in respectful dialogue with those who take her experience and needs seriously, opportunities that could help her toward resolving conflicts and dilemmas (Gilligan, 1993; Mezirow, 2000). Her chronic lack of meaningful support from family members, despite her repeated requests for it, has compounded this, effectively rendering her “voiceless” (Belenky & Stanton, 2000). Women who see themselves this way find it hard to express what they know (Belenky & Stanton). At several points in her interview Ann gave evidence of this as she seemed to struggle to know what to say. However, toward the end of the interview Ann spontaneously expressed deeper aspects of her experience; this suggests that given a safe environment in which to express her thoughts, she will participate in dialogue, sharing her reflective insights (Belenky & Stanton; Mezirow, 1997b).

Jennifer: “Lessons from Loss”

Jennifer has given birth to two children, both sons born preterm. Her first son died within hours of birth; that loss has significantly influenced her relationship to and interaction with her second son, now preschool age. This history and the contextual features embedded within it is a clear example of what Wijma and colleagues (Wijma et al., 1997) suggest: a birth is not an event in isolation, but rather, is informed by multiple contextual factors contributing to a mother’s appraisal of it.

One of the lessons Jennifer learned through her loss was to protect her second son “at all costs.” This over-protectiveness and hyper-vigilance regarding his well-being is akin to the post-traumatic stress disorder symptom, heightened arousal. This symptom has been noted in other mothers of preterm infants according to Holditch-Davis and colleagues (Holditch-Davis, Bartlett, et al., 2003). Post-traumatic stress disorder symptoms have been known to be more common among mothers of preterm infants as compared to mothers of full term infants (Kersting et al., 2004). Jennifer’s over-protectiveness is also indicative of maternal behavior seen with the Vulnerable Child Syndrome (Lamb, 2002). A child’s preterm status was found to be the strongest predictor of this syndrome in a study conducted by Culley and colleagues (Culley et al., 1989). Jennifer’s over-protective behavior is congruent with this finding, compounded by her history of having not just one, but two children born preterm. Even though she admits she needs practical support from others in the form of relief of childcare demands, her hyper-vigilance and over-protectiveness may be the very thing that keeps others from offering that support. Jennifer’s perceived need to protect herself from real or perceived threats of loss may also contribute to her hyper-vigilant and over-protective behavior.

Jennifer’s fear of loss taught her to push for the kind of healthcare she expects for her son and herself. She has learned to be an advocate for the standard of care *she* sees as most appropriate for her son, dating back to his days in the NICU. This is in contrast to findings in the literature suggesting mothers are often intimidated by the NICU nurses’ knowledge and expertise (Feeley et al., 2007; Fenwick et al., 2001; Jackson et al., 2003; Roller, 2005). Jennifer’s history of loss taught her to exert her power as mother when power struggles arose with NICU nurses, again in contrast to the frustrated, powerless preterm mother depicted in the literature (Fenwick et al.; Heermann et al., 2005). Jennifer’s sense of mastery helped to reduce her psychological distress while visiting her son in the NICU. This is congruent with the findings of Miles and colleagues

(Miles et al., 1999), that a sense of mastery reduces symptoms of distress in mothers of medically fragile infants.

The loss of Jennifer's first son ushered in significant personal change. From the day her first son died she "changed completely." The characteristics and course of Jennifer's experience of change are similar to what is proposed in Transformative Learning Theory, particularly with regard to the cognitive domain (Mezirow, 2000). Jennifer's loss of her first son was an unexpected event ("...it was just a...regular pregnancy...out of nowhere, it just happens") which proved to be a disorienting dilemma: "...I'm only 20 weeks pregnant. ...I didn't know what to do, I didn't know what I was feeling...it just kind of like hit me that I'm losing this kid. You know, what am I going to do?" This disorienting dilemma triggered reflective thinking in Jennifer and as a result she began to address held assumptions ("I never thought this would happen, never") and to recognize others have had a similar experience ("We actually had talked to somebody...she had twins, same thing happened to her"). In the wake of this dilemma Jennifer started to scrutinize and question what happened in order to come to terms with it all (Cranton, 2002; Dewey, 1933).

Jennifer's narrative gives evidence that over time she engaged in critical reflection and critical self reflection ("I've had...a lot of time to think" and "it's kind of hard to digest right away...you have to give it some thought") (Mezirow, 1998), considered her options ("I wanted a baby of my own" and "we have talked about adopting"), constructed a plan of action ("protect my son at all costs" and "I'm not going to let anything like that hurt me like that again"), and reintegrated new perspectives into her life ("it's better it happened the way it did, for many reasons" and "the phone call...telling me I was clear [of abnormal cells]...told me...what [my first son's] purpose was in life") (Cranton, 2002; Mezirow, 1997b, 2000). Talking with her husband facilitated this reflection (Gilligan, 1993; Mezirow, 2000).

Jennifer's narrative also reveals the role and influence of the affective and spiritual domains in her experience. Jennifer's memories of her experience still evoke strong emotion; nevertheless, indications of her revised perspectives emerged during the course of her narrative as she reviewed the facts surrounding the loss of her son. While evidence of the cognitive domain is strong, Jennifer's narrative provides an example of how a transformative experience may be one which utilizes and finds expression in multiple domains (Cranton & Roy, 2003; Dirkx, 2006; Dirkx, Mezirow, & Cranton, 2006).

Discussion: Narratives' Similarities and Differences

Each of the six narratives included in this study is a unique depiction of a woman's experience of being the mother of a former preterm infant now at preschool age. While each narrative stands alone and like the respective authors, deserves to be acknowledged as distinctive, there were similarities and differences noted among them. This section will examine those similarities and differences. This examination is not intended to reduce narrative data or to explicate cross-case themes. Rather, the aim of comparing and contrasting the narratives is to gain a deeper understanding of the *features* within the respective narratives. Narrative similarities and differences will be integrated with the extant conceptual and theoretical literature that informed this study as found in Chapters 1 and 2.

Similarities among the Narratives

There are four similarities noted among the narratives that include both process and content. First, all the participants tended to have difficulty focusing on themselves, their thoughts and feelings to varying degrees. In contrast, they spoke with ease and often at length about their

respective child(ren). Despite having been instructed that the purpose of the study was to explore their experience and the meaning it holds for them, most of the participants had difficulty making the switch from talking about their child(ren) to talking about themselves. Participants' tendency to focus on their child(ren) versus themselves is an indication of having achieved maternal identity (Mercer, 2004; 2006). According to Mercer (2004), while the timeline for becoming a mother varies with each woman's experience and is influenced by multiple variables, hallmarks of achieving maternal identity are pleasure in and love for one's child (2006). Since it is common behavior to talk about the object of one's love relationships, it is little wonder participants spoke so eagerly about their child(ren).

Second, each participant expressed hope for normal health and a normal life for their child(ren) born preterm. Even participants whose child(ren) faced an uncertain future due to known developmental delay (e.g., Kellie) or a feared delay (e.g., Ann) pursued the theme of normalization. There are conflicting findings in the literature regarding this maternal view. On one hand, literature indicates that mothers of former preterm infants at preschool age focus on their child's real or imagined vulnerability (Culley et al., 1989; Perrin, West, & Culley, 1989). On the other hand, research findings suggest mothers of former preterm infants at preschool age paradoxically see their child as special (or vulnerable) and at the same time normal (Miles & Holditch-Davis, 1995).

Third, all of the participants spoke of their need for and the benefit of outside informal support, in reference to what they had received and/or wished to receive. Cigoli, Gilli, and Saita (2006) identified the value of support from family and friends for women following childbirth. While the women in that study were no more than 6 months post-partum, the point is well taken that support from those in one's informal support network is perceived by mothers as important to their well-being. Mothers whose children are older also benefit from support, as the participants in the current study suggest. This is consistent with the findings from a study exploring the

psychosocial needs of parents of preterm infants aged 2-8 years (Eriksson & Pehrsson, 2002). In that study, nearly a third of the participants indicated the need for psychological support. Other mothers of former preterm infants have described feeling socially isolated and withdrawn within the first year of their child's life, also indicative of the need for psychological support (Garel, Dardennes, & Blondel, 2006).

The fourth similarity among the narratives in this study is participants' personal change in the course of their experience of being the mother of a former preterm infant now at preschool age. All of the participants indicated some degree of personal change within their experience. Some participants, for instance Patty and Jennifer, were explicit about the degree of change they had experienced. Others, such as Judy, Jane, Kellie, and Ann indicated the degree of their personal change was more subtle or due to other influences such as post-partum depression. Some, but not all the participants had what could be depicted as a transformation as a result of their experience. Nevertheless, the tenets of Transformative Learning Theory, when examined along with a participant's narrative, provides a means for understanding where all the participants are in the process of transformation or what is needed to facilitate or support their transformative learning (Belenky & Stanton, 2000; Cranton, 2006; Mezirow, 2003).

Differences among the Narratives

The aspect, more than any other, that is central to appreciating what informs the noted differences among the narratives in this study is the personal context of each participant. Without an understanding of each participant's personal context, information obtained in the exploration of the differences among the narratives is incomplete, misleading, and devoid of meaning. Participants' personal context is deeply embedded and intertwined in their experience of being the mother of a former preterm infant now at preschool age. Judy's strong sense of self-denial

associated with motherhood and her history of post-partum depression inform and shape her experience. Jane's dashed expectations regarding her imagined mother-self influences her attitudes, perceptions, and attention to the details connected with every facet of her mothering experience. Patty's discovery of her life purpose and an appreciation for and reliance on her own inner strengths were not only the result of giving birth to preterm twins but characterize the kind of mother she has become. Kellie's struggles and challenges to conceive in light of posed genetic abnormalities, to maintain her pregnancy as long as possible, and to revise her expectations despite disappointments and frustrations related to her earliest mothering experiences reflect the value she places on motherhood and Divine agency. Ann's family dynamic and the unreliable sources of support available to her shed light on her unfulfilled needs and her capacity to initiate steps toward enhanced personal health and well-being. And Jennifer's history of loss and the personal changes it triggered informs everything related to who she is as a person and mother.

There are seven differences noted among participants' narratives in this study and all concern content: neonatal crisis, degree of stress, NICU memories, vulnerability to healthcare providers, becoming a mother, parenting style, and extent of personal change. First, in contrast to what is consistently suggested in the literature (Affleck et al., 1991; Jotzo & Poets, 2005; Kersting et al., 2004; Libera et al., 2007; Muller-Nix et al., 2004), not every participant depicted their child's neonatal period (including the birth) as traumatic or a crisis. This is consistent with findings that reveal variation in how mothers appraise childbirth (Ayers, 2007; Wijma et al., 1997). In addition, the reasons for interpreting that time as a crisis were different for those depicting it as such. For instance, Jane's crisis in the time surrounding her son's birth was related to her singular mothering experience, not because her son was born preterm. Patty's crisis did not materialize until her twin daughters' homecoming from the hospital, a time she characterizes as when "reality" set in, when she realized how little support she would get in caring for her daughters. Jennifer's crisis during her second son's neonatal period was related to the loss and

grief she experienced with her first son's preterm birth and subsequent death. Despite the many challenges involved in her experience, Kellie did not depict the birth of her twins as traumatic; if anything, it was portrayed as miraculous. Kellie's crisis point was related to her effort to bond with her infants in light of her negative experiences in the NICU.

Secondly, narratives are different with regard to the presence and degree of stress or distress and its *source* as expressed by participants during the course of their experience. Neither Jane nor Kellie indicates that stress or distress is a feature of their respective experiences. The degree of stress or distress for any one participant appears to be associated with how well extant problems are being resolved or off-set by other events. For instance, Judy's history of post-partum depression created significant distress for her, distress that was ameliorated with successful medical treatment and therapy. In addition, Judy's distress regarding having so little time to pursue her own interests is attenuated by the opportunities to spend time with her husband, via the childcare support she enjoys from her parents. Patty admits that the ongoing conflict between needing to spend time alone or with her significant other with her strong desire to be with her children is a chronic source of stress. She expresses hope that as she reduces her over-protective behavior, she will feel more comfortable with accepting support from those who could assist her in caring for her daughters. Ann's distress regarding her chronic lack of personal time and the paucity of reliable support from family members shows no sign of improvement. Jennifer's distress as evidenced by her hyper-vigilance regarding her son's safety, may improve as she continues to evolve in her process of personal transformation. These differences are in contrast to findings in the literature suggesting stress or distress of mothers of former preterm infants aged 6 months to 3 ½ years (Elklit et al., 2007), from birth to 3 years (Singer et al., 1999), or at 6 months and 18 months (Muller-Nix et al., 2004) are related directly to some facet of their child's health and well-being. These narrative differences offer partial support for research findings indicating a preterm mothers' quality of life is adversely affected by perceived life

control, happiness, peace, life worries, and perceived infant health (Hill & Aldag, 2007; Ferrans & Powers, 1985).

A third difference is the degree of attention to NICU memories. Judy and Patty give little attention in their narratives to the NICU environment, the time spent there, or the NICU healthcare staff. Patty's narrative supplies only a glimpse into her appraisal of the unhappy time spent in the NICU but reveals nothing about her interactions with the NICU staff. Ann mentions the NICU environment only with regard to how shocking it was to see her newborn amidst the hoses and equipment and Kellie notes her frustration with the lack of privacy and mother-friendly unit practices within the NICU. Jennifer's only reference to the NICU reflects her determination to accelerate her son's discharge from what she saw as an unpleasant environment, one not conducive to his well-being. Ann's, Kellie's, and Jennifer's experiences fit with how the NICU is depicted in the literature, as being public, hostile, unfamiliar, frightening, and stressful for preterm mothers (Affleck et al., 1991; Siegel et al., 1993; Miles et al., 2002). Jane's narrative highlights various interactions with the NICU nurses; sometimes distressing and disappointing, sometimes empowering and encouraging. Kellie's narrative also includes how the difficult it was for her to deal with the NICU nurses; she resented what was perceived as their exclusive care for and knowledge of *her* children. Ultimately Kellie's perceptions of and relationships with the NICU nurses improved. These testimonies of problematic and often conflicting interactions with NICU nurses are consistent with other preterm mothers' experience as depicted in the literature (Feeley et al., 2007; Fenwick et al., 2001; Heermann et al., 2005; Jackson et al., 2003; Jones et al., 2007; Roller, 2005).

A fourth difference among the narratives in this study is vulnerability to healthcare providers. This overlaps somewhat with what is noted above regarding the influence of NICU nursing staff, but also includes participants' vulnerability to other healthcare providers. Judy notes that were it not for her obstetrician, her post-partum depression may have never been

detected. Jane includes several incidents of the potential for either goodwill or ill-feelings springing from the words and actions of her son's healthcare providers. Ann indicates how she has been affected by what physicians and nurses communicate as well as what her daughter's doctor does *not* say when considering her risk for developmental delay. Jennifer enjoys a valued relationship with her family doctor, one who knows her history and whom she trusts with not only her health, but the health of her son. Four of the participants noted that their child(ren)'s pediatrician and their office staff rarely if ever inquire about their well-being as the child(ren)'s mother. Apart from healthcare providers' interactions with mothers of former preterm infants in the neonatal hospitalization period (MacDonald, 2007; Van Riper, 2001), extant literature offers little that addresses the quality of the relationships between these mothers and healthcare providers or the mothers' vulnerability to the providers' words and behaviors (Beck, 2006; Sankey & Brennan, 2001).

A fifth difference noted among the narratives is how the participants depict the quality of interaction and attachment with their child(ren). Judy acknowledges that attachment to her son was delayed, most likely due to what she believes was undetected post-partum depression. This is consistent with findings from several studies indicating how post-partum depression can adversely influence the maternal-child relationship and a mother's engagement in attachment behaviors (Davis, et al., 2003; Feldman et al., 1999; Miles et al., 2007; Poehlmann & Fiese, 2001). Jane indicates that although she was not able to see her son immediately after his birth, she did hear him cry; that plus a Polaroid photograph of him taken moments after his birth, provided her with the means to initiate the attachment process. Jane's experience is congruent with findings in the literature that indicate the immediate survival needs of the preterm infant take priority and may postpone attachment opportunities (D'Harlingue & Durand, 2001). None of the other participants explicitly note their engagement in maternal-infant attachment. However, the

positive manner in which they depict their child(ren) and their relationship to them provide implicit evidence to suggest attachment has occurred.

Sixth, parenting style is a noted difference among the participants' narratives. Despite Judy's struggle not to see her son as a former preterm infant, she tends to over-stimulate her son in an effort to expose and challenge him to engage in normal boyhood activities. Patty and Jennifer are admittedly over-protective and hyper-vigilant in their parenting styles. Ann indicates hers is a relaxed parenting style but perhaps one that is too lenient in setting limits given the frequent bouts of strife with her 2+ year old daughter. These participants give evidence of *compensatory parenting* as described by Miles & Holditch-Davis (1995). This style of parenting involves the provision of "special experiences and avoided other experiences in an attempt to compensate the children for their neonatal experiences" (Miles & Holditch-Davis, p. 246). These researchers also reveal that *compensatory parenting* includes over-protection, over-stimulation, over-attention, and a lack of limit setting. In contrast, Jane is relaxed in her parenting style as she tries to strike a balance between presenting her son with challenges that are realistically within his reach. Kellie does not include features of her parenting style in her narrative.

The last point of difference among the narratives in this study is like the last point of similarity: the extent of personal change participants reveal during the course of their experience. Of all the participants, two give evidence to having had a personal change that can be characterized as *transformative*: Patty and Jennifer. Before Patty's preterm twin girls were born, her life seemed somewhat aimless. Although she had a son and was working, she indicates her life lacked happiness and fulfillment. Bringing her daughters home and realizing that for the most part, she would be their caregiver almost exclusively, revolutionized her thinking, her speech, and her behavior. Her life took on a level of meaning and purpose she had never known before. Despite the heavy and unrelenting responsibility, her life finally made sense; she knew caring for her children was what she was supposed to do. Patty's transformation is an example of the

positive effects that can occur with revised frames of reference (Mezirow, 2003) and the subsequent extent of the change that can take place in a person's life (Cranton, 2006).

Jennifer's transformation is in many ways still in process. Her transformation was triggered by the unexpected preterm birth and immediate death of her first son. Those events took place in a single day; Jennifer notes that from that day, she was forever changed. Jennifer's transformation is characterized by powerful emotions such as loss and grief (Dirkx, 2006; Dirkx, Mezirow, & Cranton, 2006); these emotions pertain to the loss of her son but also the loss of her former self. Her optimism and hope as a young and expectant newlywed was shattered and as yet, has not been restored. Slowly she is revising her perspectives and in the process, is rebuilding her life. As her narrative unfolds her effort to integrate her revised perspectives becomes clear. What once was a perspective of anger and distrust toward healthcare providers is changing to one of recognizing a Divine purpose for her first son's life, one that illuminates the mysteries surrounding his untimely birth and her questions of his supposed viability. While all the manifestations of Jennifer's transformation may not be positive or entirely therapeutic, for example, her perceived need to ferociously protect her son and to protect herself, her narrative suggests openness for ongoing personal change and growth. Jennifer's experience is an example of how arduous the inner work and the process toward transformation can be (Dirkx; Dirkx, Mezirow, & Cranton).

Implications for Nursing Practice

In this age of extraordinary technology and unprecedented access to knowledge, nursing practice has undergone many changes in the delivery of patient care. Electronic databases are gold-mines of information on both quantitative and qualitative research studies, providing evidence for the evidence-based practice now considered a standard element of contemporary,

high quality nursing care (Fineout-Overholt, Nollan, Stephenson, & Sollenberger, 2005). In the midst of what is often a plethora of evidence to potentially influence nursing practice is a rich, relevant source of evidence often over-looked: an individual's personal narrative.

The current study confirms the wealth of information and knowledge obtainable only when a person is given the opportunity to make known their personal narrative. Inviting and witnessing a person's personal narrative provides aesthetic knowledge, one of the essential, fundamental, and valued patterns of knowing in the nursing discipline (Carper, 2004). This pattern of knowing acknowledges an awareness of and appreciation for the experiences of fellow human beings and "the perception of abstracted *particulars* [emphasis mine] as distinguished from the recognition of abstracted universals" (Carper, p. 225).

Participants' narratives in the current study confirm that each participant's personal context is key to understanding what is often a complex, multi-faceted experience of being the mother of a former preterm infant now at preschool age. Evidence-based practice is designed to guide nurses and other healthcare providers in providing the best quality of care possible in meeting their patients' multi-faceted needs. When nurses and other healthcare providers use the best evidence available, including evidence from patients' personal contexts and narratives, and when their patients know they have made every effort to use that evidence, optimal outcomes result (Melnyk & Fineout-Overholt, 2005).

While the formal evidence-based practice movement is designed to influence nursing as a discipline, individual nurses can also benefit from evidence to inform and potentially change their own practice. The current study's findings verify that evidence gleaned from personal narratives provides an opportunity for a nurse to see his/her own practice change in response to that evidence. As a source of aesthetic nursing knowledge, exposure to the personal narrative of a patient entails empathy, engagement, and reflection; reflection has the potential to lead to revisions in the perspectives that inform one's nursing practice (Holloway & Freshwater, 2007;

Johns, 2005). The experience of being exposed to and reflecting on a patient's narrative is an example of what is entailed in *reflective practice*. Reflective practice is a means toward a more mature nursing practice (Johns, 1995), its purpose being "to enable the practitioner to access, understand and learn through, his or her lived experiences and, as a consequence, to take congruent action towards developing increasing effectiveness within the context of what is understood as desirable practice" (Johns, 1995, p. 226). As a result, aesthetic knowledge obtained through a patient's personal narrative has the potential to trigger not only personal but professional transformation in a nurse (Holloway & Freshwater).

Findings from this study also indicate a realm of nursing care that involves promoting transformation in the lives of mothers of former preterm infants. Taking a cue from Adult Education educators, purposefully fostering critical reflection and facilitating opportunities for transformative learning to occur in the lives of their patients is something for nurses to consider. However, such an endeavor is not for those with only a casual appreciation for transformative learning. It involves many elements including recognition of a patient's capacity for engagement in reflection, recognition of where a patient may be along the continuum toward transformation, taking responsibility to create a safe and supportive environment for discourse, and an awareness of the ethical considerations at work in promoting transformation in potentially vulnerable individuals.

Study Limitations

Given the unique characteristics of the participants' personal narratives in this study, findings may not be transferable to other mothers of former preterm infants now at preschool age. However, the attributed meaning of the narratives and the implications of the study's findings may be found meaningful and appropriately applied to a wider population (Powers, 2005). A

second limitation of the study is that the participants' narratives were obtained via a single in-person interview or limited email exchanges. While time constraints made additional interviews impractical in this study, a second interview may have provided opportunity for enhanced participant reflection regarding their personal narrative. Lastly, the researcher's access to potential participants' mailing addresses was found to be limited and several invitation letters were returned due to inaccurate addresses. Other women may have participated had the researcher had access to up-to-date mailing addresses for all the women in the sampling frame. The sampling frame could have also been expanded by recruiting mothers of former preterm infants from local pediatricians' offices.

Recommendations for Future Nursing Research

In considering recommendations for future nursing research, two distinct tracks come to mind. One is to pursue other research studies in the tradition of narrative inquiry, to seek others' personal narratives for the rich contextual meaning they provide. The mothers in the current study have children born preterm who have been relatively healthy from birth. Future studies exploring the personal narratives of mothers whose former preterm infants now at preschool age have had serious, ongoing medical issues related to their preterm birth would be of interest.

Another approach to future research is to design intervention studies aimed at enhancing the stated quality of life of mothers of preterm (or former preterm) infants via their relationships with the nurses they encounter. One such intervention study would entail an intervention delivered by NICU nurses, targeting mothers with preterm neonates. The proposed nursing intervention would be designed to facilitate the process of becoming a mother while the infant is in the NICU. Such nursing interventions are in short supply (Mercer & Walker, 2006). During this period of time new mothers are in/around the second stage of becoming a mother which

includes acquainting herself to her infant (Mercer, 2004). The intervention in this study would involve a purposeful communication strategy aimed at giving a mother the opportunity to identify and discover characteristics and nuances about her infant through direct contact and discovery of her infant's cues and traits versus that information coming to the mothers second-hand, via the nurses. A possible research question for this study would be, "What is the effect of the 'Mom Saw it First' intervention on a mother's acquaintance with her preterm infant in the NICU?"

Another possible intervention study would be one designed to involve nurses in pediatricians' offices, targeting mothers of former preterm infants. The intervention in this study would be designed to enhance nurses' recognition of the mother as an individual and her evolving role identity as well as her general welfare (Steis, Penrod, Adkins, & Hupcey, 2009). Inquiring about a mother in this fashion conveys maternal support and also awareness of her role in the health of her child. A possible research question pertinent to this study would be, "What is the effect of the 'How are You, Mom?' intervention on the perceptions of self for mothers of former preterm infants?"

Conclusions

The exploration of the personal narratives of mothers of former preterm infants now at preschool age has revealed the *unique* and often *complex* experience of women who undergo this phenomenon. Extant literature reveals only in part what informs each participant's experience and the meaning she attributes to it. An examination of the narratives reveals some similarities and differences in terms of the features included. Regarding similarities, all the participants had a measure of difficulty focusing on themselves, expressed hope for normalization regarding their child(ren), acknowledged the need for and benefit from outside support, and went through a degree of personal change as a result of their experience. Seven differences, fueled by the

intricacies of participants' personal contexts were noted among participants' narratives in this study: the neonatal crisis, degree of stress, NICU memories, vulnerability to healthcare providers, becoming a mother, parenting style, and extent of personal change. The use of Transformative Learning Theory provided a lens in which to better understand these participants' experiences as revealed in their narratives. This theory also elucidates what can occur when one encounters another's narrative and its attributed meaning, introducing the potential for knowledge acquisition, deep learning, and potentially, transformation in the reader.

Findings from this study inform implications for nursing practice. Based on the participants' narratives re-presented in this study, it is clear that mothers of former preterm infants do not fit a prescribed mold. Each woman's experience of being the mother of a former preterm infant now at preschool age is distinctive, with very different contextual elements informing her respective experience. Each woman has her own unique constellation of strengths, weaknesses, and resources. It is clear that a mother's experience is often informed by past events (including possible exposure to a NICU) and both intrapersonal and interpersonal dynamics that often pre-date a given pregnancy, leaving indelible marks on her life. It is important for nurses who encounter these women to approach them with the awareness that such is their reality and that there is always more to know, more to understand about each mother and her experience than what is apparent initially.

Generalizations gleaned from research about preterm birth and the mothers who deliver preterm infants are enlightening and informative; a challenge for nurses and others on the healthcare team is to ensure generalizations do not become assumptions directing care. Instead, generalizations should guide care while the healthcare team seeks opportunities for in-depth engagement with and subsequently provide individualized interventions for each mother in light of what is learned about her and her experience of being a mother. Researchers studying the influence of nurses' communication on the process of becoming a mother of an infant in the

NICU setting advocate for such a tailored approach (Heermann et al., 2005; Mercer & Walker, 2006; Wigert, Johansson, Berg, & Hellström, 2006). In order for this to occur the healthcare team must address yet another challenge: time. Discovering the distinctive nuances of each mother and her experience requires not only taking the time to ask but also taking the time to listen.

Findings from this study also inform implications for future nursing research. This study is a first step toward gaining a deeper understanding of not only the experiences of women who are mothers of former preterm infants now at preschool age, but also the kind of support these women need from nurses caring for them and/or their child(ren). Whether following in the tradition of narrative inquiry with another group of mothers of former preterm infants or pursuing intervention studies to implement new communication strategies with nurses for mothers both in the NICU and community setting, many opportunities for nursing research lie ahead. In either case, the evidence found in the personal narratives of women who are mothers of former preterm infants now at preschool age will help determine the best next-steps in this nursing research. In this day of evidence-based practice where the need to identify meaningful research evidence to shape practice within the discipline is critical, nurses would be well-advised to remember the most accessible and most reliable source of patient-centered evidence at their disposal: the patients themselves.

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Appendix A

Participant Invitation Letter - 2004

Dear _____,

Date _____

In 2004 you and your newborn baby participated in a research project with Dr. Kim Kopenhaver Haidet while your baby was in the NICU at Hershey Medical Center. As one of Dr. Kopenhaver Haidet's doctoral students, I am interested in learning about the personal experiences of mothers whose former preterm infants are now preschool age and I would like to invite you to tell me your own story.

If you would be interested in sharing your story with me, I would appreciate the opportunity to meet you and to audio-record your story. So that I will know if this interests you or not, please fill-out, detach, and return the brief form at the bottom of this letter (using the self-addressed, stamped envelope enclosed). Please check "yes" or "no" if you are willing for me to contact you by telephone so that I can give you more information regarding this study. If you check "yes" please include your current telephone number(s).

Thank you!

Cherie Adkins, RN, MS

(Please detach here.)

Please check one of the following responses and return in the envelope provided to:

Cherie Adkins, RN, MS
Penn State University School of Nursing
1300 ASB/A110
600 Centerview Dr.
Hershey, PA 17033

_____ Yes! I am interested in learning more about this new research study and am willing for Cherie to contact me with more information.

My current telephone number(s): _____

_____ No, I am not interested in being contacted regarding this study.

Appendix B

Participant Invitation Letter - 2007

Dear _____,

Date _____

In 2007 your newborn baby(-ies) participated in a research project with Dr. Kim Kopenhaver Haidet while your baby(-ies) was/were in the NICU at Hershey Medical Center. As one of Dr. Kopenhaver Haidet's doctoral students, I am interested in learning about the personal experiences of mothers whose former preterm infants are preschool age and I would like to invite you to tell me your own story.

If you would be interested in sharing your story with me, I would appreciate the opportunity to meet you and to audio-record your story. So that I will know if this interests you or not, please fill-out, detach, and return the brief form at the bottom of this letter (using the self-addressed, stamped envelope enclosed). Please check "yes" or "no" if you are willing for me to contact you by telephone so that I can give you more information regarding this study. If you check "yes" please include your current telephone number(s).

Thank you!

Cherie Adkins, RN, MS

(Please detach here.)

Please check one of the following responses and return in the envelope provided to:

Cherie Adkins, RN, MS
Penn State University School of Nursing
1300 ASB/A110
600 Centerview Dr.
Hershey, PA 17033

____ Yes! I am interested in learning more about this new research study and am willing for Cherie to contact me with more information.

My current telephone number(s): _____

____ No, I am not interested in being contacted regarding this study.

Appendix C

Script for Screening Potential Participants

Potential participants who indicated by return-mail response interest in the proposed study will be telephoned by the PI. The following will be presented during that telephone call to confirm if the potential participant is willing to take part in a face-to-face, audio-recorded interview:

“Thank you for indicating you are interested in learning more about this study. In order for me to learn about your experience being the mother of a child born preterm you and I will need to meet in-person and I will tape record what you tell me. Are you willing to do that?”

Screening Question Data Collection Sheet

Circle the appropriate response per each recruit’s answer to the screening script question:

1. _____ Willing to provide spoken, tape recorded data? **YES NO**
(recruit’s name)
2. _____ Willing to provide spoken, tape recorded data? **YES NO**
(recruit’s name)
3. _____ Willing to provide spoken, tape recorded data? **YES NO**
(recruit’s name)
4. _____ Willing to provide spoken, tape recorded data? **YES NO**
(recruit’s name)
5. _____ Willing to provide spoken, tape recorded data? **YES NO**
(recruit’s name)
6. _____ Willing to provide spoken, tape recorded data? **YES NO**
(recruit’s name)
7. _____ Willing to provide spoken, tape recorded data? **YES NO**
(recruit’s name)
8. _____ Willing to provide spoken, tape recorded data? **YES NO**
(recruit’s name)
9. _____ Willing to provide spoken tape recorded data? **YES NO**
(recruit’s name)
10. _____ Willing to provide spoken tape recorded data? **YES NO**
(recruit’s name)
11. _____ Willing to provide spoken tape recorded data? **YES NO**
(recruit’s name)

Appendix D

Interview Probes and Questions

The in-depth, unstructured interview will begin with the broad question, “Tell me about a time that stands out for you that will help me understand your experience of being the mother of a child who was born preterm and is now preschool age.” Probes and questions will be used during the course of the unstructured interview as needed. What follows does not constitute an exhaustive list but rather represents a sample of the kind of probes or questions that could be potentially posed to study participants as well as non-verbal means of encouraging the participant to continue talking (Patton, 2002). These probes/questions are designed to elicit additional detail, elaboration, and clarification (Patton).

1. Please tell me more about that.
2. I’m not sure I completely understand; would you expand on that please?
3. Uh-huh.
4. Who else was there?
5. What did you think about that?
6. When did that take place?
7. Gentle head nodding.

Appendix E

Demographic and Obstetric History Questionnaire

Pseudonym: _____

Date: _____

Please answer the following questions in the space provided.

1. Please indicate which year your former preterm infant(s) who is/are now aged 2-5 years was/were in the NICU at Hershey Medical Center immediately following their birth(s):
 2004
 2007
2. Since delivering your baby(-ies) in the year noted above, have you had any additional pregnancies?
 Yes No
3. If you delivered additional children since the year noted above, were any of those babies born preterm?
 Yes No
4. How many children have you given birth to? _____
5. What are their current ages?

6. What is your current age? _____
7. What is your *current* marital status? (Please check one.)
 Married Single Divorced Widowed
8. Are you employed?
 Yes No
9. If you are employed, what kind of work do you do?

Appendix F

IRB Approval Letter

PENNSSTATE HERSCHEY
 Milton S. Hershey
 Medical Center

PENNSSTATE HERSCHEY
 College of Medicine

DATE: April 02, 2009
 TO: Cherie S. Adkins, RN, Nursing (HMC)
 FROM: Kevin Gleeson, M.D., Executive Chair
 Institutional Review Board
 RE: IRB Protocol No. 30711EP - Exploring the Personal Narratives of Mothers of Former
 Preterm Infants Now at Preschool Age

Thank you for your application to the Institutional Review Board (IRB). The above IRB protocol number was assigned for the research and should be included on all future correspondence and documentation. In accordance with Federal guidelines and institutional policy, the proposed research was determined to qualify for expedited review and was reviewed accordingly.

Official approval: Official approval was granted for this research effective April 2, 2009 through March 31, 2010, at which time IRB reconsideration will be required. This approval includes the following:

- Research Protocol - Protocol summary (received 3/11/2009)
- Total entry - 12 subjects. This research may not involve prisoners. If an individual becomes incarcerated after enrollment contact the IRB to address specific regulatory requirements in order to continue participation.
- Informed Consent - Consent form (version date 3/30/2009). **Use of the attached, stamped form is required.**
- Authorization to use protected health information (PHI) - Included in consent form
- Advertisement - Participant Letter (3/11/2009); • Questionnaires - Interview Probes and Questions (3/11/2009), Demographic and Obstetric History Questionnaire (3/11/2009); • Other - Script for Screening (3/11/2009)
- IRB member exclusions from this review: No investigators for this research serve on the IRB.

Informed consent and Authorization: Only approved investigators may solicit consent for research participation. Subjects or their representatives must receive a copy of the consent form.

- Medical record - For clinical treatment protocols, include a copy of the consent form and the protocol summary in the patient's HMC medical record to inform other medical caregivers about this research.
- Originals - Original consent forms/authorizations should be filed in a secure place and retained after termination of the research for a period of 6 years if the research accesses protected health information (PHI), or 2 years if no PHI is accessed. Other FDA or sponsor requirements may apply.

Clinical Trials Registration: Not required

Required Reports and Modification Requests: To submit reports for this research or requests for modifications, use the instructions and forms available on IRB web site, <http://www.hmc.psu.edu/irb>, under Forms & Instructions, Ongoing Studies.

- Problem Reporting: Investigators are required to promptly report any events that may represent unanticipated problems involving risks to subjects or others. See the web for the IRB policy



April 02, 2009
IRB Protocol No. 30711EP

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“Reporting of Unanticipated Problems Involving Risk to Participants or Others” and the applicable report form and tracking log.

- Proposing Changes: Federal regulations require prompt reporting to the IRB of any proposed changes in a research activity and prior approval before changes are initiated, except where necessary to eliminate apparent immediate hazards to the subject. Submit the ‘Modification Request Form’ to change an existing investigation.
- Continuing Review: A progress report will be required for reapproval of this research. You will receive an e-mail reminder and the necessary form 8 weeks before the current approval expires.

The Institutional Review Board appreciates your efforts to conduct research in compliance with the institutional policies and federal regulations that have been established to ensure the protection of human subjects. Please feel free to communicate any future questions or concerns regarding this research to the IRB via its administrative arm, the Human Subjects Protection Office.

KG\kl

VITA

Cherie Sue Adkins, PhD, RN

EDUCATION:

2010	<u>PhD in Nursing</u> The Pennsylvania State University, University Park, PA
2004	<u>Master of Science, Community Health Nursing</u> The Pennsylvania State University, University Park, PA
1996	<u>Bachelor of Science in Nursing</u> , Magna cum Laude Millersville University, Millersville, PA
1989	<u>Bachelor of Science in Bible</u> Lancaster Bible College, Lancaster, PA
1982	<u>Associate of Science in Nursing</u> , with Distinction Kettering College of Medical Arts, Kettering, OH

PROFESSIONAL EXPERIENCE:

1/2009-present	Nursing Instructor, The Pennsylvania State University SON
8/2007-12/2008	Adjunct Faculty, Widener University, Chester, PA (Harrisburg)
1/2007-12/2008	Graduate Research Assistant, Dr. Kim Kopenhaver Haidet, The Pennsylvania State University SON
2004-2007	Training Coordinator, South Central PA Health Care Quality Unit (Hershey, PA), Geisinger Health System, Danville, PA
2001-2004	Research Assistant/Community-Based Nurse, South Central PA Health Care Quality Unit (Hershey, PA), The Pennsylvania State University SON
1997-2000	Clinical Care Coordinator, Keystone Health Plan Central, Camp Hill, PA
1996-1997	Case Manager, St. Joseph Hospital Home Health Services, Lancaster, PA
1991-1996	Case Manager, Olsten Kimberly Quality Care, Lancaster, PA
1989-1991	Staff Nurse – Labor & Delivery, Community Hospital of Lancaster, Lancaster, PA
1982-1986	Staff Nurse, Kettering Medical Center, Kettering, OH

SCHOLARLY ACTIVITIES

Adkins, C., & Haidet, K. K. (2008). The relationships among environmental stimuli in the neonatal intensive care unit and real-time physiologic responses in premature infants. Invited Paper Presentation, *Eastern Nursing Research Society*. Philadelphia, PA.

Adkins, C. & Haidet, K.K. “Exploring the Personal Narratives of Mothers of Former Preterm Infants Now at Preschool Age.” (2009). Awarded Grant, Beta Sigma Chapter, Sigma Theta Tau International.

Steis, M.R., Penrod, J., Adkins, C.S., & Hupcey, J.E. (2009). Principle-based concept analysis: Recognition in the context of nurse-patient interactions. *Journal of Advanced Nursing*, 65(9), 1965-1975.