

DISTRESS AFTER PRETERM BIRTH: A DISCOURSE ANALYSIS OF PARENTS'
ACCOUNTS AND PHOTOGRAPHS

by

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To the Faculty of Washington State University:

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ABSTRACT

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Preterm birth is a distressing experience for parents. This distress may continue into early childhood, with negative consequences for parents' mental health and child development. The purpose of this study was to take an in-depth look at how parents formed their accounts of premature birth, postpartum distress, and lives as parents and partners. Discourse analysis of semi-structured interviews and photo-elicitation assignments were used to analyze the parents' experiences in the context of the couple relationship. The study population included 8 parents of premature infants born from 24 to 30 weeks gestation, who had experienced significant distress in and out of the hospital. Parents participated in the study when their children were between 15 months and 8 years old. In the initial interview parents described their experience of prematurity, emotional distress, and parenting. Participants returned for a second interview where they further described their distress using photographs they had newly taken or selected. Parents described the preterm birth, hospitalization, and aftermaths as ongoing traumatic events. Discourses of distress included *the perfect child*, *the good mother*, and *the good father*. Parents engaged these discourses in reconciling their loss of idealized birth and parenting and their roles after prematurity. *Social isolation* and *disciplinary power* were discourses that showed how parents struggled with interaction with their social networks and with health care providers and institutions. Photo-elicitation provided additional dimensions to the participants' accounts of

distress. Findings highlighted how parents described their trauma and distress in ways not captured by psychiatric diagnoses such as depression and anxiety. Findings may help nurses be aware of the negative effects of preterm birth and respond to the parents' emotional needs.

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CHAPTER ONE

INTRODUCTION

Statement of problem

Preterm birth is one of the most common and significant complications of pregnancy. In 2010, the rate of premature births fell to 11.99% in the United States, a decline from the peak of 12.8% in 2006 (Hamilton, Martin, & Ventura, 2011). Although this represents encouraging progress, the United States ranks 6th in the world in total number of preterm births (Howson, Kinney, & Lawn, 2012). The rate of premature birth in the United States is more than double the rate in European countries such as Ireland and Finland (MacDorman & Mathews, 2010). While advances in neonatal care have dramatically improved the prognosis for these newborns, premature birth remains the leading cause of neonatal mortality in the United States (*Child Health USA 2011*, 2011). Largely due to this elevated rate of premature birth, the United States ranked 30th in infant mortality in 2005 among developed countries (MacDorman & Mathews, 2010). The rates of prematurity vary by race and ethnicity in the United States, with 17.5% of African-American women, 12.1% of Hispanic women, 13.6% of Native American women, and 11.1% of non-Hispanic White women giving birth preterm (U.S. Department of Health and Human Services, 2010). The Institute of Medicine (2007) estimated the annual economic costs to the United States from prematurity to be \$26.2 billion including direct health care costs, special education, early intervention services, and lost labor and productivity.

Prematurity is the most common indication for a prolonged hospitalization in the Neonatal Intensive Care Unit (NICU). This is particularly true for infants born at less than 32 weeks gestation and weighing less than 1500 grams (Institute of Medicine, 2007). Even when

the newborn survives, the experience of premature birth can have a profound impact on a woman's transition to motherhood and a family's well-being. Neonatal Intensive Care Unit (NICU) nurses and providers focus almost exclusively on the newborn, despite the many known challenges to parents after preterm birth. Some circumstances, both clinical and routine, often make it difficult for families to bond with the infant. The new mother is typically discharged from the hospital a few days after the birth and may not see her health care provider until six weeks later for the routine postpartum visit. This may be a missed opportunity for prenatal providers to care for parents of premature infants during a difficult family transition (Kantrowitz-Gordon, 2012).

The transition to motherhood during the weeks to months in the NICU can be very difficult as policy, newborn condition, or physical barriers such as incubators restrict access to the newborn. With limited privacy and frequent startling interruption of monitors, the NICU environment can be disruptive for both child and mother. Even if facilities support rooming-in or prolonged visitation by parents, many families are divided between responsibilities at home and at the hospital, especially those who live a long distance from the NICU. Families with limited resources due to socio-economic status, language barriers, and limited social support may be the least equipped to handle the stress of prolonged newborn hospitalization (Holditch-Davis et al., 2009). Premature birth can delay or impair maternal-newborn attachment as mothers struggle to make a close connection with their infants (Behee-Semler, 1996; Bialoskurski, Cox, & Hayes, 1999; Fegran, Helseth, & Fagermoen, 2008; Schenk, Kelley, & Schenk, 2005).

Lactation is a key strategy for mothers to build a connection to their premature infants (Sweet, 2008). Due to the fragile condition of the preterm infant and the desire for physical connection, the mother may feel additional pressure to successfully breastfeed. Thus, the mother

of a preterm infant may experience more stress about breastfeeding in order to meet the expectation for being a good mother (Sweet, 2008). Unfortunately, there are many barriers to feeding a preterm newborn exclusively at the breast. Preterm infants have immature neuromuscular development which results in disorganized sucking patterns and decreased motor strength. The ability to fully feed at the breast may not be achieved until a mean corrected gestational age of 35 weeks (Nyqvist, 2008). When the infant is unable to feed at the breast, mothers need to pump or hand-express their milk to be stored and delivered to the NICU. Pumping can lead to discomfort, nipple trauma, and logistical challenges in storage and transport of milk. Because of these barriers only 34 to 45% of mothers who give birth preterm continue to breastfeed at two to three months postpartum (Furman, Minich, & Hack, 2002; Hill, Aldag, Zinaman, & Chatterton, 2007). Thus many preterm infants, who are vulnerable to chronic illness and infection, lose the well-documented health benefits of breast milk (Bertino et al., 2009; American Academy of Pediatrics, 2012). This is compounded by the effects on mothers' well-being and is directly related to attachment and mother-infant bond (Akman et al., 2008; Flacking, Ewald, & Starrin, 2007).

Not surprisingly, there are strong emotional and psychological reactions to the birth and hospitalization, which may be broadly described as *distress*. Mothers may fear for the baby's health and have unresolved grief about the loss of normal pregnancy and birth. The maternal distress after preterm birth has been extensively described using the framework of mental illness as described in diagnostic guidelines (American Psychiatric Association, 2000). Mothers who give birth preterm have been found to have higher rates of postpartum depression, acute stress disorder, and post-traumatic stress disorder than mothers who give birth at term (Lefkowitz, Baxt, & Evans, 2010).

The most common psychological reaction to prematurity is postpartum depression, with up to 40% of mothers symptomatic during the NICU hospitalization (Vigod, Villegas, Dennis, & Ross, 2010). This is significantly higher than the estimated 14% of all mothers who develop postpartum depression in the three months after birth (Gavin et al, 2005). In 26% of families with very low birth-weight infants, mothers continued to have significant depressive symptomatology when the child was in preschool (Silverstein, Feinberg, Young, & Sauder, 2010). This is significant not only for the mental wellbeing of women who deliver premature infants, but also for the cognitive and social development of the premature child. Maternal depression after preterm birth has been correlated with negative maternal perception of the child's social abilities (Silverstein, Feinberg, Young, & Sauder, 2010) and behavioral and emotional problems (Huhtala et al., 2012). In a randomized controlled trial of depression treatment after term birth, mothers treated for depression with interpersonal psychotherapy rated their children 18 months after birth with significantly more behavior problems, attachment difficulties, and negative temperaments than control mothers who did not have depression (Forman et al., 2007). This suggests that it is not enough to treat the mother's depression symptoms without addressing the maternal-infant relationship. It is likely that this applies to families who have experienced preterm birth as well. Therefore, a broader examination of the developing relationships within the preterm family, which includes the mother-infant relationship, is necessary.

Understanding the effects of prematurity on the family includes consideration of the father's experience. Interviews of fathers of hospitalized preterm infants have identified strong emotional reactions similar to mothers' reactions including shock (Sloan, Rowe, & Jones, 2008), anxiety, fear, helplessness, sadness (Casteel, 1990), and a lack of control (Arockiasamy, Holsti,

& Albersheim, 2008). Other studies have described experiences unique to fathers, including feeling distant, outside reality, and excluded after preterm birth (Lundqvist, Westas, & Hallström, 2007). Fathers have also identified how they cope with the stress of premature birth by seeking information, protecting their partner and fragile infant (Lindberg, Axelsson, & Öhrling, 2007) and receiving support from their partners (Sloan, Rowe, & Jones, 2008). Serial interviews of fathers over six months after preterm birth showed that early return to work after preterm birth provided them a sense of control and competence (Pohlman, 2005).

Only a few studies have examined symptoms of depression in fathers after preterm birth. In a small descriptive study of 35 fathers of infants born at less than 30 weeks gestation, 60% of fathers had elevated depression scores at one week (Mackley, Locke, Spear, & Joseph, 2010). This decreased to 39% by three weeks and to 35% by five weeks. In a prospective cohort study of infant and child cognitive development following preterm birth that followed 182 VLBW infants from infancy to school age, 17% of mothers and 13% of fathers had elevated depression scores at the two-year follow-up (Huhtala et al., 2011). Fathers who had depression were four times more likely to have infants with cognitive delay. Depression and parenting stress in either parent at two years was associated with child behavioral problems at age 3 years (Huhtala et al., 2012).

In summary, numerous studies have reported many types of distress as common experiences in mothers and fathers during the NICU hospitalization. Studies that have examined parents' long-term psychological health after prematurity have focused on the prevalence and risk-factors for depressive symptomatology in mothers and fathers. A few studies have correlated parents' ongoing depression to the child behavioral and cognitive outcomes. Yet very little is known about how both parents make sense of their experiences of distress and how this

distress affects the couple and parenting relationships after discharge from the NICU. Qualitative research that focuses on the experiences of both parents can provide a new understanding of these relationships (Peters, Jackson, & Rudge, 2008). Arts-informed data collection methods, such as photo-elicitation, have been used to deepen the inquiry into complex emotional and traumatic phenomena (Creighton, 2011). Therefore it is important that this study use such methodology to broaden our understanding of parents' distress after preterm birth.

Purpose of the study

Parents' distress is an experience that is controlled, in part, by societal norms for emotional and psychological responses to the challenges of preterm birth. Underneath these responses are beliefs that shape how parents understand their roles and experiences. These beliefs, or *discourses*, can influence how parents think, talk, and act after preterm birth. The purpose of this study was to understand how discourses of distress operate in the psychological and social responses of parents at least 6 months after preterm birth.

Specific Aims

This study examined parents' accounts of premature birth, postpartum distress, and lives as parents and partners. The specific aims of this study were 1) to describe and interpret the discourses of distress after preterm birth as told by both members of a couple; and 2) to test the feasibility and benefits of incorporating photo-elicitation methods into a discourse analysis of parent interviews.

Significance of the study

This study may provide new insights into the mental health of these vulnerable families, which is congruent with national health and research priorities. Early child development and parenting is a new focus of national health goals in Healthy People 2020. Achieving an

understanding of the developmental trajectories of mental illness is also a goal of the National Institutes of Health. Through an improved understanding of the parents' experiences of prematurity, distress, and parenting, nurses may be more effective in helping these families negotiate the challenges associated with preterm birth.

CHAPTER TWO

REVIEW OF THE LITERATURE

Definitions

Distress has been defined as “pain or suffering affecting the body, a bodily-part, or the mind” (Merriam-Webster online dictionary). The choice of the word *distress* in conceptualizing this study is appropriate because it does not restrict the investigation to a particular psychological or biomedical approach to the parents’ suffering. This is particularly important because using medical diagnoses such as depression, anxiety, or post-traumatic stress disorder (PTSD) may limit participant recruitment, and bias results towards a medicalized understanding of the phenomena in question. Further it may leave out the suffering of those parents who do not meet the diagnostic criteria or screening cut-offs for various disorders, yet have suffering that is significant and meaningful in their lives.

The clinical diagnosis of *major depressive disorder* (MDD) has been defined by the American Psychiatric Association in its classic text, the Diagnostic and Statistical Manual Fourth Edition (American Psychiatric Association, 2000). The diagnosis of major depressive disorder requires the presence of depressed mood or loss of interest or pleasure in most activities for every day, all day, for at least two consecutive weeks. Additional symptoms include: significant weight loss, insomnia or hypersomnia, psychomotor agitation or retardation, fatigue, feelings of worthlessness or guilt, diminished ability to concentrate, and thoughts of death or suicide. The only diagnostic difference between major depressive disorder and *postpartum depression* (PPD) is that the onset of symptoms in PPD occurs within four weeks after child birth. This distinction has been challenged because many of the common physical symptoms of postpartum women such as fatigue, weight loss, and diminished ability to concentrate may overlap with depressive symptoms (Cox, Holden, & Sagovsky, 1987). Furthermore, the four-week limitation may

exclude many new mothers from the clinical diagnosis of PPD whose onset of symptoms is after the first month. Finally, these diagnostic criteria do not take into account the significant impact PPD has on the parent-child relationship nor do they include the possibility for fathers or non-biological mothers, such as adoptive or lesbian mothers, to be diagnosed and consequently treated for PPD.

Because of the complexity of diagnosing MDD or PPD, simple *screening tests* have been developed to aid clinicians in determining which patients are at higher risk. The screening tests are not diagnostic but suggestive of illness; identification of a patient at high risk is only the first step in the pathway towards diagnosis and treatment. Further evaluation is necessary to rule out competing diagnoses and to distinguish temporary mood changes from significant illness.

Various instruments have been tested and validated in various populations for use in practice and research. The Patient Health Questionnaire 9 (PHQ-9) includes each of the 9 diagnostic criteria from the DSM-IV and may be helpful in determining whether the diagnostic criteria are met as well as severity of symptoms (Kroenke, Spitzer, & Williams, 2001). The Edinburgh Postnatal Depression Screen (EPDS) (Cox et al., 1987) includes ten questions and has been specifically validated in the antepartum and postpartum periods. It asks about the severity and frequency of symptoms in the past week, which may not correlate with the DMS-IV criteria for symptoms present daily for two weeks. Nevertheless, the screening tests allow for a continuum of symptomatology severity and frequency in distinction to the DSM-IV language “most of the day, nearly every day.” Partial or complete screening tests have been used by researchers to estimate the prevalence of PPD, although it has been suggested that this may overestimate the prevalence since not all mothers identified as high risk are diagnosed with mental illness (Matthey, 2010). Distress may include other psychiatric conditions such as *post-traumatic stress disorder* (PTSD)

and *generalized anxiety disorder* (GAD). Similar to PPD and MDD there are diagnostic criteria and screening tests for research and practice.

Maternal distress after preterm birth

The majority of research on distress after preterm birth has focused on assessing mothers with screening tools and identifying risk factors for psychiatric illness. Women who give birth prematurely are at higher risk for postpartum depression when compared to women who give birth at a term gestation. In a systematic review of 26 studies that included 2392 mothers of preterm infants, rates of PPD up to 12 weeks postpartum were as high as 40% (Vigod, Villegas, Dennis, & Ross, 2010). Risk factors for maternal depression that continue to up to one year postpartum included infant factors such as earlier gestational age, lower birth weight, and re-hospitalization of the infant, and maternal factors such as unmarried status, maternal role stress, maternal worry about infant's health, and perceived lack of social support. Women who gave birth at less than 33 weeks or to very low birth weight (VLBW) infants (less than 1500 grams) were at the highest risk for sustained depression through 12 months.

There have been a few studies that examined risks for maternal depression that continues after the infant's first year of life. In a longitudinal study of 102 women (almost half of whom were African-American) who gave birth to VLBW infants, unmarried status, worry about infant health, maternal role stress, and infant re-hospitalization were predictive of elevated depression scores through 27 months corrected gestational age (Miles, Holditch-Davis, Schwartz, & Scher, 2007). In a prospective longitudinal study (Poehlmann, Schwichtenberg, Bolt, & Dilworth-Bart, 2009) of 181 mothers who gave birth at 35 weeks gestation or earlier, depression rates were recorded at five times from infant hospital discharge through twenty-four months corrected age. At the time of the infants' hospital discharge the prevalence of depressive symptoms was 32%.

Over time there was a gradual reduction in depression symptoms; by 24 months corrected age (number of weeks born preterm subtracted from chronological age) 12% of the mothers had persistent symptoms of depression. Persistent depression was correlated with the number and severity of risk factors. These included sociodemographic characteristics such as poverty, teen pregnancy, and unmarried status, as well as increased infant illness severity and decreased family support. Neither study addressed the effects of two additional risk factors, substance use and domestic violence; mothers with known substance use during pregnancy were excluded and domestic violence was not specifically assessed. These studies demonstrate that maternal distress is complex and a concern that may last for years after the birth of the preterm infant in some women.

Maternal psychological reactions to premature birth are not limited to postpartum depression. Post-traumatic stress symptoms and anxiety are more prevalent after premature birth and these symptoms may persist long after newborn discharge. In a sample of 84 women from a NICU in the Northeastern United States, 35% had elevated scores on the acute stress disorder scale within 5 days of birth, and 15% of mothers met criteria for PTSD 30 days after birth based on the PTSD Symptom Checklist (Lefkowitz, Baxt, & Evans, 2010). Personal and social factors, including antenatal depression and concurrent social stressors, were significantly correlated with PTSD one month after the birth. In a pilot study of 21 Canadian mothers six months after preterm birth, 24% had elevated scores on the Perinatal PTSD Questionnaire (Feeley et al., 2011). Fifty women followed for 14 months after preterm birth continued to have significantly elevated PTSD symptoms as compared to women who gave birth at term (Kersting et al., 2004), although by 14 months none met the criteria for a PTSD diagnosis. Antepartum maternal mental health or social support was not examined as a potential confounder in this study. Holditch-

Davis et al. (2009) examined multiple indicators of maternal distress in 177 African-American women who gave birth to VLBW infants. Mothers with preexisting mental health disorders and infants with symptomatic drug withdrawal were excluded from the study. Measured variables included stress related to infant appearance and behavior in the NICU, stress related to maternal role in the NICU, depression, anxiety, post-traumatic stress disorder (PTSD), and stress from daily hassles. Social support and interpersonal violence, however, were not included in the potential risk factors. Mothers who scored high on multiple stress scales during infant hospitalization were at the highest risk of continued distress through 24 months postpartum. Based on these studies it is apparent that there are both multiple sources and indicators of maternal distress for years after preterm birth.

The relationship between preterm birth and postpartum distress is complicated by the presence of distress during pregnancy that may have contributed to the early birth. Potential antenatal risk factors for preterm birth include racism, homelessness, interpersonal violence, anxiety, depression, substance use, and stressful events (Institute of Medicine, 2007). The strength of the association and the establishment of a causal link between these risk factors and preterm birth remain elusive due to methodological challenges, the frequent co-occurrence of risk factors, and the use of multiple definitions and measures. Most of the 26 studies on postpartum depression after preterm birth did not control for antepartum depression or other mental illnesses during pregnancy which may have contributed to the preterm birth (Vigod, Villegas, Dennis, & Ross, 2010). Thus, although studies have examined preterm birth as either a consequence of antepartum distress or a cause of postpartum distress, understandings about the experience itself are incomplete.

The few qualitative studies that have examined long-term distress after preterm birth have focused on psychiatric symptoms. Garel, Dardennes, and Blondel (2007) interviewed French mothers one year after preterm birth. Using thematic content analysis, they found the women had high levels of distress. They described depressive symptoms, post-traumatic symptoms, fatigue, guilt feelings, defensive attitudes, and anxiety. The mothers found re-hospitalization of their infants particularly stressful, and had mixed feelings about their infant's behaviors. In another qualitative study, Holditch-Davis, Bartlett, Blickman, and Miles (2003) performed semi-structured interviews at 6 months in 30 mothers of preterm infants. Interviews focused on the three symptom patterns of PTSD: re-experiencing, arousal, and avoidance. All of the mothers had at least one pattern of PTSD symptoms, and the majority of mothers had all three symptom patterns. In summary, studies have demonstrated the complexity and persistence of postpartum distress after preterm birth in mothers.

Paternal distress after preterm birth

The challenges of prematurity are not limited to mothers. A few studies have examined fathers' experience of parenting in the NICU. In thematic content analysis of 16 interviews with fathers of infants hospitalized for more than thirty days in the NICU, the predominant theme was a lack of control (Arockiasamy, Holsti, & Albersheim, 2008). Other themes that have been identified in fathers include the importance of work life in maintaining a sense of competence and protecting the family (Pohlman, 2005) and holding the infant for the first time as an important step toward becoming a father and making the child real (Lundqvist, Westas, & Hallström, 2007; Sullivan, 1999). In a small study of 8 Swedish fathers it took more time to feel like a real father after premature birth, yet overcoming the challenges of prematurity ultimately strengthened their relationship with mother and child (Lindberg, Axelsson, & Ohrling, 2008).

There is limited research that specifically examined distress in fathers after premature birth. In a small descriptive study of 35 fathers of infants born at less than 30 weeks gestation, 60% of fathers had elevated depression scores at one week (Mackley et al., 2010). This decreased to 39% by three weeks and to 35% by five weeks. In 41 fathers of infants in the NICU, 24% met criteria for Acute Stress Disorder 3 to 5 days after birth, and 8% met criteria for PTSD 30 days after birth (Lefkowitz et al., 2010). In a prospective cohort study (Huhtala et al., 2011) of infant and child cognitive development following preterm birth that followed 182 VLBW infants from infancy to school age, 13% of fathers had elevated depression scores at the two-year follow-up. Only 1.8% of the fathers had reported any history of mental illness when asked upon enrollment in the study. These studies all demonstrate that fathers have increased risk of acute and chronic distress after preterm birth.

Consequences to the family

Evidence from term birth indicates that distress in one parent may impact the other parent. Fathers are affected by their partners' depression in addition to experiencing depression symptoms themselves (Davey, Dziurawiec, & O'Brien-Malone, 2006; Goodman, 2004; Paulson & Bazemore, 2010; Roberts, Bushnell, Collings, & Purdie, 2006; Webster, 2002). In a meta-analysis of 43 studies that included 28,004 participants, approximately 10% of fathers had depression symptoms during the year after term birth and there was a moderate correlation ($r = .308$) between depression in mothers and fathers (Paulson & Bazemore, 2010). Men whose partners had PPD described the effects of the mother's postpartum depression in terms of what they have lost: the partner they used to know, their old relationship, intimacy, and control (Meighan, Davis, Thomas, & Droppleman, 1999). When men suffer from depression, their female partners are also affected. Oliffe et al. (2011) interviewed men with depression and their

female partners. They found that gendered roles within the couple were the focus of their strategies to cope. The couples compensated for the man's depression through the woman supporting the man's traditional role as a worker, or by adopting atypical gender roles. A mismatch between gendered role expectations resulted in tension in the relationship. Chapman, Hobfoll, and Ritter (1997) found that mid-trimester pregnant women with stressful life events had higher rates of depressed mood if their partners were not aware of their stressors. The discrepancy between the couple's appraisal of stress was correlated to the women's distress. This was independent from the level of support provided by the partner. This is further evidence of the importance in assessing the couple relationship when investigating distress or depression. This approach, however, has not been utilized in studying postpartum distress after premature birth.

While little is known about the experience of same-sex couples who experience a preterm birth, one study found that biological and non-biological lesbian mothers may experience postpartum depression after term birth at similar rates as heterosexual couples (Ross, Steele, Goldfinger, & Strike, 2007). The feelings of loss after miscarriage may be compounded by the additional challenges they faced in achieving pregnancy (Wojnar, 2007). Lesbian couples experience additional stressors, including decreased social support from extended families, marginalization by society, and legal and institutional discrimination. Protective factors in lesbian couples include planned pregnancies, and more equitable division of labor within the couple (Ross, Steele, & Sapiro, 2005).

The stress upon the couple relationship after preterm birth may result in dissolution of the couple. In a sample of 6016 women from the population-based National Maternal and Infant Health Survey (Swaminathan, Alexander, & Boulet, 2006), married women who gave birth to a

VLBW infant in 1988 had twice the odds for divorce by 24 months postpartum as women who gave birth to a non-VLBW infant (OR = 2.05; 95% C.I., 1.44 – 2.92). Approximately 10% of the families of VLBW infants were divorced after two years. When the pregnancy was unwanted, they were three times as likely to be divorced by 24 months postpartum, resulting in a divorce rate of 15%. This study did not report on the outcomes for couples who were not married at the time of the birth. Preexisting qualities of the couple relationship and the stress of preterm birth likely contribute to the continuation of the couple postpartum. It is unknown how these families fare beyond two years postpartum.

Parents' distress may also impact the relationship between the parent and child born preterm. Maternal depression after preterm birth has been correlated with negative maternal perception of the child's social abilities (Silverstein et al., 2010), and behavioral and emotional problems (Huhtala et al., 2012). In a prospective cohort study (Huhtala et al., 2011) of infant and child cognitive development following preterm birth that followed 182 VLBW infants from infancy to school age, 17% of mothers and 13% of fathers had elevated depression scores at the two-year follow-up. Fathers who had depression were four times more likely to have infants with cognitive delay (OR = 4.09; 95% C.I., 1.31 – 12.37). Even though depression was more common in the mothers, maternal depression was not associated with the cognitive development of the infant. Depression and parenting stress in both parents at two years was associated with child behavioral problems at age 3 years (Huhtala et al., 2012). These studies demonstrate how parents' mental health may have an impact on children's development during the preschool years.

In a randomized controlled trial of depression treatment after term birth, mothers treated for depression with interpersonal psychotherapy rated their children 18 months after birth with

significantly more behavior problems, attachment difficulties, and negative temperaments than control mothers who did not have depression (Forman et al., 2007). This suggests that it is not enough to treat the mother's depression symptoms without addressing the maternal-infant relationship. It is likely that this applies to families who have experienced preterm birth as well.

The effects on the family include not only the parents but also the other children in the family. The limited research on the impact of premature birth on siblings has focused on sibling visitation in the NICU. The long-term impact of prematurity on older and younger siblings is poorly understood. A phenomenological study (Gaal et al., 2010) of 28 adults who were siblings of extremely low birth weight infants found these individuals still deeply affected by the birth story of the preterm sibling. They perceived their parents as overprotective of the premature child, and they maintained a strong relationship and loyalty to the preterm sibling. This study's retrospective view from adulthood may have presented an overly positive view of the sibling experience. The more extensive literature on siblings' reaction to chronic illness provides additional insight into the plight of siblings after preterm birth. This is particularly relevant to families in which the preterm infant develops chronic illness. In a meta-analysis (Vermaes, van Susante, & van Bakel, 2012) of 52 studies comparing siblings of children with chronic illness to unaffected controls, there was a significant small negative effect ($d = .10$) on the psychological function of siblings. These siblings had more internalized problems such as anxiety and depression, as well as more externalized problems such as behavioral and social difficulties. The authors interpreted that these parents may have been overburdened by the care of the ill child and were perceived by the well child as less available for them.

Parenting the vulnerable child

The parenting transition and role development after premature birth may be impacted by the length of time spent in the NICU. The medically fragile infant is subject to continuous surveillance by heart, oxygen, and apnea monitors. Daily weights and blood tests monitor growth and health status; milk is measured, supplemented, and delivered. Nurturing activities like breastfeeding and skin-to-skin care are monitored for safety and adequacy. In this context parents must learn new skills and assert their expertise under the surveillance of experts in a public medical setting (Fenwick, Barclay, & Schmied, 2008; Flacking et al., 2007). Mothers may become vigilant in guarding the safety of their infants which may place them in conflict with the medical professionals (Hurst, 2001). In particular, the nurse-mother relationship has been identified in qualitative research as an important mediator in the mother's developing confidence (Fenwick, Barclay, & Schmied, 2001).

All this reinforces to parents that their preterm child is vulnerable. This identity as a vulnerable child may be further constructed by follow-up surveillance at high-risk child development clinics. Mothers' low expectations for their preterm child's development were associated with delayed daily-living skill growth from ages 4 to 8 (Dieterich, Hebert, Landry, Swank, & Smith, 2004).

The division of labor among parents may not be equal even among families that intend to share parenting tasks equally (Carmen Knudson-Martin & Mahoney, 2009). In the United States, where prematurity is more likely to occur in poverty and without paid parental leave, fathers may return to work as a coping strategy due to the uncertainty of and unfamiliarity of the NICU environment and in order to support the family. It is unknown how parents change their division of parenting roles after preterm birth as compared to after term birth.

Theoretical framework

Distress, whether it takes forms commonly understood as depression, anxiety, or fear, is a subjective experience that cannot be validated through observation or biochemical diagnostic testing. Postpartum depression remains an enigma due to its complexity, prevalence, and disproportionate impact on women. Multiple explanatory models have been presented to explain the etiology of postpartum depression. These include hormone fluctuations around reproductive events (Payne, Palmer, & Joffe, 2009), cognitive theories, and evolutionary approaches (Hagen, 1999). Models such as the biopsychosocial model (Ross, Sellers, Gilbert Evans, & Romach, 2004), the earthquake assessment model (Driscoll, 2005), and the diathesis-stress model (O'Hara, Schlechte, Lewis, & Varner, 1991) seek to explain depression through a combination of individual susceptibilities and environmental contexts. There is no consensus of opinion or preponderance of scientific evidence to justify one approach over another.

The biomedical and risk-factor approach to understanding depression has been challenged by critical social theorists and feminist researchers (Chonody & Siebert, 2008; Ussher, 2010). They see depression and motherhood as social constructions (Johansson, Bengs, Danielsson, Lehti, & Hammarstrom, 2009) that are influenced by cultural ideals such as femininity (Choi, Henshaw, Baker, & Tree, 2005) and the sexual objectification of women (Fredrickson & Roberts, 1997). The cultural expectations for women to be perfect mothers, caring, and selfless can result in women denying their own emotional health and needs. The consequence of this self-denial can be depression (Jack, 1991). The medicalization of postpartum depression focuses solutions away from addressing the social inequalities in parenting, employment, and gendered roles. The DSM-IV and the practice of diagnosis serve to define *normal* feelings and behavior (Crowe, 2000a) and locate the pathology in the individual

rather than in the social and cultural contexts. Similarly, the construction of men's distress or depression may be impacted by discourses of masculinity and fatherhood that promote an idealized vision for men as virile, productive, and in control (Oliffe et al., 2011).

Brown et al. (2001) found that cognitions of mental illness were correlated with coping strategies, independent of illness severity. Patients' causal explanations for their depression included stress, genetic predisposition, lack of physical self-care, relationship or interpersonal problems, medical illness, and the reaction to medical illness. This suggests that patients' understandings of depression may be an important avenue towards understanding depression and implementing effective coping strategies. Approaching postpartum depression as a medical problem may make it more acceptable for some mothers to discuss their negative experiences of motherhood, while for others it may stigmatize their feelings and further prevent them from seeking help (Armstrong & Small, 2010). The cultural expectations for women to be perfect mothers, caring, and selfless can result in women denying their own emotional health and needs. Second wave feminist scholars noted the lack of language for negative motherhood experiences and how mothers' unhappiness resulted from the conditions of motherhood rather than flawed mothers (Rich, 1976). Women who desire strongly to adhere to cultural expectations of the "good" mother may have a hard time admitting negative emotions and experiences and asking for help. Family, friends, and spouses may offer to help with childcare tasks which may augment the woman's feelings of incompetence. All these serve to increase her feelings of emotional isolation (Knudson-Martin & Silverstein, 2009). Men may also find it difficult to admit to postpartum distress due to the perception that PPD is a woman's disease and the expectation for fathers to be strong and stoic. Those that do seek help may accomplish this by reframing their actions as responsible and self-reliant (Johnson, Oliffe, Kelly, Galdas, &

Ogrodniczuk, 2011). Thus the social construction of postpartum distress must be considered before approaching clinical strategies for helping parents.

The specific aim of this study is informed by theories that share a social constructionist approach. Constructionism is based on the assumption that “meaningful reality is understood as constructed between persons in interaction” (Wertz, 2011, p. 308). The parenthood transition in the NICU, parents’ emotional reactions to the premature birth and hospitalization, and how parents relate to each other are all examples of constructed experiences. Social norms, the environment, and individual perceptions affect each parent’s experience. Michel Foucault (1972) contributed two important concepts to the approach of this study: discourse, and the relationship between knowledge and power. Discourse is “a belief, knowledge or practice that constructs reality and provides a shared way of understanding the world” (McCloskey, 2008), p. 24). Foucault believed that knowledge and truth were inextricably linked to power and shaped by politics and social conditions (O’Farrell, 2005). From this perspective, a dominant discourse is one which provides legitimacy to the existing power structures and social relations (Hall, 2001). For example, the professional staff in the NICU, by virtue of their highly technical expertise in neonatology, may control parenting behavior in the NICU while the parenting identity and role is in development. The methodology used in this study is informed by Foucault’s critical social views, which ground the methods described in chapter three.

Foucault and Confession

Foucault (1990) described the power to produce knowledge through confession. This practice began with Christianity and the confession of sins to the priest in the 13th century. By allowing talk about the sins of sexuality in the constrained context of the confessional, discourses on sexuality were produced by the confessor under the supervision of the authoritarian priest.

Foucault examined the evolution of confession through history using his genealogical approach. By the 19th century confessions of sexuality had expanded beyond the religious context into the domains of parenting, education, and psychiatry. By the end of the 20th century confession further permeated society through television talk-shows, judicial practices, and medical care. According to Foucault (1990)

The confession became one of the West's most highly valued techniques for producing truth. We have since become a singularly confessing society. The confession has spread its effects far and wide. It plays a part in justice, medicine, education, family relationships, and love relations, in the most ordinary affairs of everyday life, and in the most solemn rites; one confesses one's crimes, one's sins, one's thoughts and desires, one's illnesses and troubles; one goes about telling, with the greatest precision, whatever is most difficult to tell. One confesses in public and in private, to one's parents, one's educators, one's doctor, to those one loves; one admits to oneself, in pleasure and in pain, things it would be impossible to tell to anyone else, the things people write books about. One confesses – or is forced to confess. (p. 59)

While the focus of Foucault's analysis was on the discourse on sexuality, confession is a useful construction for understanding other discourses such as depression and mothering.

Foucault's genealogy of confession was limited by his early death in the 1980s before the rapid expansion of computer mediated communication and the internet. By the early 21st century the confession society rapidly expanded with the advent of social media such as Facebook and Twitter. By this time, people had the ability to confess personal information across wide spaces and populations using portable smart-phones. These very public declarations may seem anonymous because the receivers of the information are not necessarily connected in space and

time. This has allowed the expansion of confession by being accessible to the majority of people and by removing the authority figure as the listener to confession. Using Foucault's language, this represents a discontinuity in the genealogy of confession.

Despite the pervasiveness of confession in modern society, there are constraints upon what one may confess. Foucault identified rules of exclusion that define discourses by limiting what can be said and by whom (Foucault, 1972). For example, the *good mother* discourse may restrain a mother from confessing that she doesn't love her baby. Discourses may also limit who is allowed to speak. Because the biomedical discourse characterizes new mothers' distress as an illness, health care providers are privileged to make the diagnosis and legitimize or delegitimize the woman's experiences. Postpartum depression lacks objective signs or biochemical tests and relies on a complex set of symptoms for diagnosis which are different from the available screening tests (American Psychiatric Association, 2000). Finally, discourses control the content of expression by defining the limit between sanity and madness. When a woman's talk breaches the discursive limits of normal mothering, the content of her confession may be silenced as the depression talking. Thus the diagnosis of postpartum depression initially validates a woman's distress, but the labeling with mental illness may marginalize and stigmatize her condition (LaFrance, 2007). Both the confession and the ensuing interaction with the health care provider that may lead to a diagnosis may be seen as social practices that are governed by medical, legal, and social discourses (Crowe, 2000b).

Exploring these social practices may be accomplished through *discourse analysis*, a methodology that examines language through the lenses of social action and social contexts. Discourse analysis is therefore an appropriate methodology for investigating parents' distress after preterm birth which is socially constructed and constrained.

CHAPTER THREE

RESEARCH DESIGN AND METHOD

Research design

This study used critical discourse analysis methods to explore how fathers and mothers construct their experiences and feelings of distress after preterm birth. Participants were recruited as couples, although they participated separately in the research. This facilitated free expression by participants and avoided conflict between partners or the dominance of one parent's account of events and experiences (Olliffe, Kelly, Bottorff, Johnson, & Wong, 2011). This study used two data collection methods: interviews and photo-elicitation. Interviews are a standard approach for collecting qualitative data that focuses on the phenomenon of interest. Yet critical social theory acknowledges that the interview is itself a discursive event, with a power differential between the interviewer and the participant (Mishler, 1986). The interviewer-researcher sets the agenda for the encounter and directs the questioning toward answering the specific aims of the project. The photo-elicitation complemented the interviews by collecting data that was participant driven, reflective, and creative. The inquiry was enhanced by collecting data that was rich in detail, facilitating the expression of abstract, difficult, or sensitive feelings that may have been difficult to express in words, and enabling participants to retain creative control over the representations (Burke & Evans, 2011; Frith & Harcourt, 2007). The data for this study consisted of the transcripts of the interviews as well as the photographs. Analysis of the photographs was conducted by the interviewer and the participants during the second interview, but also as an independent source of data by the research team (Olliffe, Bottorff, Kelly, & Halpin, 2008).

Epistemology and ontology of discourse

According to McCloskey (2008), “Discourse is a belief, knowledge or practice that constructs reality and provides a shared way of understanding the world” (p. 24). The ontology of discourse analysis is constructionist; reality does not exist independently from our beliefs about the world. Foucault believed that knowledge and truth were inextricably linked to power and shaped by politics and social conditions (O'Farrell, 2005). From this perspective, a dominant discourse is one which provides legitimacy to the existing power structures and social relations. These discourses change over time, and alternative discourses can become dominant. Discourses support the power of institutions and are integral to institutional practices. The practices of the institutions then reflexively reinforce the dominant discourses (Willig, 2001). These discourses place individuals in positions that allow them to act in certain ways. People may choose between discourses and position themselves differently depending on the social conditions (Stephens, Carryer, & Budge, 2004).

This epistemological approach to understanding phenomena is through the texts of social interactions such as conversations. Texts may include recorded conversations or interviews, institutional policies and documents, and media such as film, literature, or advertisements. Discourse analysis examines these texts in order to expose the discourses that are operating in those texts and understand how they perform. The analysis of these texts is based on the assumption that language is performative and productive (Potter & Wetherell, 1987). This is unlike the view from cognitive psychology in which language is representational of internal cognition. Examining the discourses in people's accounts and texts uncovers the ways that language is used to support and resist power and inequality (McCloskey, 2008). Discourses can be found operating within texts, as well as between different texts (Talbot, 2005). The use of

different types of texts such as recorded interviews and photographs, as well as linking texts between members of a couple, is amenable to the analytical depth of discourse analysis.

There is no agreed-upon approach or set of analytic steps towards conducting a discourse analysis. Two common approaches are Discursive Psychology and Foucauldian Discourse Analysis. The psychological approach focuses on the individual's utilization of available discursive resources in order to accomplish specific goals through communicative action. The Foucauldian approach examines the institutional and societal discourses and structures that constrain individual action (Willig, 2001). This analysis used an integrated approach that included how individuals utilized available discursive resources and how the social structures constrained them (McMullen, 2011). This opened the analysis to the inclusion of personal agency and contextual factors.

Research in reproductive health contexts has previously identified discourses that impact the experience of depression. One such discourse is the *good woman or mother*, an idealized account of women's and mothers' identities (Choi, Henshaw, Baker, & Tree, 2005; LaFrance & Stoppard, 2006). Another is *maternal blame and guilt*, that the woman is responsible for her own condition and how it affects others (Jackson & Mannix, 2004; Johansson, Bengs, Danielsson, Lehti, & Hammarstrom, 2009). *High risk* is a discourse that identifies some women as being at increased likelihood of developing conditions such as prematurity or depression (Godderis, 2010). *Medical discourses* provide biomedical explanations for women's reproductive experiences such as pregnancy, birth, and menopause that prescribe actions and attitudes that focus on medical treatment of depression rather than underlying social or cultural causes (LaFrance, 2007). In the accounts of women who had recovered from depression, LaFrance and Stoppard (2006) found that women needed to reject feminine discourses in order to

care for themselves. Similarly, men must negotiate masculine discourses such as *manly self-reliance* when seeking help in the context of depression (Johnson, Oliffe, Kelly, Galdas, & Ogrodniczuk, 2011).

Position of the researcher in discourse. The epistemology of discourse analysis places the conduct of research, in addition to the topic of research within social contexts. Thus the interview itself is an interactive performance between researcher and participant, with power differences controlling research questions, conduct of the interview, and dissemination of the data (Powers, 1996). The experiences and meanings of the participants do not exist intact waiting to be discovered and elicited by the researcher. Instead, the interaction between researcher and participant generates the knowledge about the discourses through the performance of the interview (Brinkmann, 2007). The researcher is not a neutral observer, who can bracket out his or her own experiences. Similarly, data analysis is discursive and the interactions among researchers are based on discourses of methodologies, educational and scientific institutions, and the literature. Therefore it is relevant to know that the principal investigator is positioned in this research as a father of a preterm infant who was 8 years old at the time of the research, a practicing nurse-midwife, and a graduate student in a PhD program.

Epistemology and ontology of photo elicitation

Photography has been a method for representing reality since its development and popularization in the 19th century. The portability and accessibility of this medium has greatly increased with the transition from film to digital photography and the inclusion of cameras in mobile phones. While visual media have become a dominant form of communication in Western society, texts and transcribed interviews have continued as the most common form of data in qualitative research. Nevertheless there is an increase in the use of photography in methods such

as Photovoice, Photo Novella, and photo elicitation (Hansen-Ketchum & Myrick, 2008). The use of photo-elicitation, in which participants compose and select photographs to discuss at the interview, is consistent with the constructionist approach. The participants exert control over the images: which photographs to take and to include, how to compose and manipulate the image, and what stories to tell as context for the images. All of these choices may be influenced and constrained by the discourses that govern the topic of study. Photo-elicitation is the literal manifestation of the metaphorical ‘lens’ through which participants see and interpret their worlds. Yet the photos do not stand alone; they are the medium for reflection and reminder at the interview where the photos and words join to generate a richer data set than either component alone.

Methods

Subjects and setting. The target population for this proposal was parents of preterm infants who were at least 6 months old, corrected gestational age. The parents self-identified as experiencing distress related to the preterm birth of a child of less than 32 weeks gestation or less than 1500 grams birth weight. The inclusion criterion of distress was deliberately broad and could have included persistent difficult emotions, feelings, or worries about the child born preterm. The distress was open to the participants’ definition because one of the goals of the study was to elicit the parents’ experience and meaning of distress after preterm birth. Use of medical or psychiatric criteria for mental illness could have constrained participants in unintended ways. To discover participant’s understanding of distress was the focus of this study, rather than to describe or correlate defined illness symptoms with risk factors. Participant inclusion criteria were that the parents were in a committed relationship with each other, living together, English speaking, and willing to participate in two interviews and the photo

assignment. Exclusion criteria were families whose baby had died or had major birth defects, or had not been discharged from the hospital. Recruitment strategies included brochures posted at high risk follow-up clinics, parent support groups, and Internet social media. Recruitment was limited to a large metropolitan area in the Pacific Northwest in order to facilitate data collection. Flyers and electronic messages solicited participation from parents by asking, “Has premature birth caused you or your spouse/partner distress? Has your relationship changed?” A sample flyer for the study is included in Appendix A. Convenience and snowball sampling was utilized in order to maximize recruitment of participants. Participants were asked to invite their partners to participate in a separate interview and photo assignment. Interviews were conducted at a mutually convenient time and location separately for each member of the couple. Participants were compensated for their time with retail gift cards upon completion of their participation.

The recruitment and data collection strategies were tested with the first couple and the resulting four interviews and two sets of photographs were found congruent with the specific aims of the study. Recruitment and data collection then continued and the initial couple’s data were included in the final analysis. Determining appropriate sample sizes in qualitative research is achieved through balancing the need to achieve breadth of findings without collecting an overwhelming amount of qualitative data that cannot be analyzed in such depth that each individual case requires. Further, it is hard to predict in advance how much data is necessary to achieve saturation, as sampling may be iterative and simultaneous with analysis of earlier data (Sandelowski, 1995). Given the emotional nature of the study, the investigator felt an ethical obligation not to oversample so that each participant’s involvement would contribute to the findings in a significant manner. Published discourse analyses of women’s depression have had sample sizes as few as six (McMullen & Herman, 2009) and as many as fifteen (LaFrance &

Stoppard, 2006). Ultimately, eight parents from four couples agreed to participate in the study, which yielded a rich collection of transcripts and photographs for analysis.

Apparatus and instruments. The semi-structured interviews consisted of open-ended questions that explored the participants' experiences and constructions of prematurity, distress, and parenting. An interview guide is included in Appendix E. The Socratic method of interviewing as described by Dinkins (2005) and Brinkmann (2007) was used in order to gently challenge participants' beliefs and actions. This served to further elucidate and explore the discursive constructions of parenting, distress and prematurity. Portable digital audio recording devices were used to record interviews and facilitate transfer to secure data storage.

Digital cameras were used for the photo assignments in order to allow participants to reflect, choose, and control their expression through the photographs. Use of digital media has penetrated society to an extent that digital cameras are familiar and accessible to most parents. Participants who did not own their own digital camera or photo-capable smart phone were lent a compact, inexpensive digital camera for their use during the study.

Procedure. All potential participants who responded to advertisements were contacted by telephone or email, informed of the nature and purpose of the study, and screened for inclusion in the study. The script for screening participants is included in Appendix B. The first parent in a couple to be contacted was asked to invite their partner to participate separately in the study, an effective technique for recruiting couples (Oliffe et al., 2011). At the beginning of the first interview, each participant was informed of their rights verbally and by written informed consent. A brief demographic questionnaire, included in Appendix D, was completed in order to provide descriptive information of the study sample. This included a question on past history of diagnosis and treatment of mental illness because such experiences may influence how

participants viewed distress in the current context. Participants were asked to select a pseudonym that was used in the transcripts to protect their anonymity.

At the completion of the first interview, the photo assignment was explained. Participants were asked to take photographs that represented their experiences or feelings about prematurity, parental identity, or distress. Due to confidentiality issues, they were asked to avoid photos that contained faces or other identifiers. It was explained that photographs may be included in dissemination of study results such as published manuscripts, dissertations, and conference presentations. Any photographs that contained identifiers were modified to obscure the identifying portions before they were disseminated. Participants were asked to not share their photographic choices with their partners until both completed the study. Second interviews were prescheduled at the 1st interview and ideally within two weeks in order to avoid logistical difficulties, drop-out, and failure to return the camera (Creighton, 2011). Participants declined a reminder contact before the second interview. At the second interview, the participant was asked to describe the photos, and to explain how the photo represented their experiences or beliefs about prematurity, distress, or parenting. This was a starting point for further discussions about the discourses relevant to this study. Interview guides for both interviews are provided in Appendix E.

At the conclusion of each interview, participants were debriefed on their experiences of the interviews and photo assignment. A list of local resources for counseling, depression, and social support was available for participants who desired additional support. None requested or were assessed as needing additional support.

Audio recordings and interviewer field notes were transferred to a secure digital storage site at Washington State University. The audio-recording device had its memory erased once the

transfer of the recording was completed. Access to the secure storage of the audio recordings and transcripts was limited to the principal investigator and research team. An experienced research transcriptionist produced the initial interview transcripts, and these were edited for accuracy by the principal investigator through careful listening to the audio recordings. Transcripts and field notes were de-identified by removal of names, locations, and other identifiers in order to protect anonymity of the participants.

Human Subjects Protection. The research protocol was approved by the Washington State University Institutional Review Board. Participants had the right to withdraw from the study at any time, to not answer any question, and to request that the audio-recorder be turned off. Risks of participation in this study, including distress or discomfort from sensitive questions, were explained to the participants. A copy of the approved consent form is included in Appendix C.

Data management and analysis. The audio-recorded interviews were transcribed into Microsoft Word by a professional transcriptionist who was instructed to remove identifying information, including names and places. The principal investigator reviewed the transcripts while listening to the audio recordings in order to verify accuracy and anonymity. The corrected transcripts were securely stored on a server at Washington State University with restricted access. The principal investigator conducted the primary data analysis under consultation with the dissertation chair, Roxanne Vandermause, an experienced qualitative researcher. Additional team members who contributed to the data analysis included Merry Armstrong, a member of the dissertation committee, and Molly Altman, a doctoral student studying qualitative research. Written interpretations of the data along with the notes from research team meetings were

incorporated into the final analysis. Interpretations of the data, field notes, and coding of the data were organized using NVivo 10 (QSR International).

Presenting the analytical steps in qualitative research as a sequential list is misleading because of the iterative and simultaneous approach to analysis. Nevertheless, the steps can appear progressive in the levels of interpretation. As the analysis proceeds, the research team members individually and as a group move back and forth among the different steps of analysis. As interpretations of the discursive constructions develop, the texts are reexamined to validate the conclusions (McCloskey, 2008). As the analysis crystallizes, the researchers select excerpts from the texts to serve as examples and evidence for answers to the original research questions (Wertz, 2011). The data analysis method used in this study was adapted from Parker (1992) and Willig (2001).

After reading through the transcripts to develop familiarity, the focus of the analysis was the examination of the transcripts for discourse, which is “a belief, knowledge or practice that constructs reality and provides a shared way of understanding the world” (McCloskey, 2008, p. 24). Careful reading identified explicit and implicit instances of discourses relevant to the research questions. Throughout the analysis careful attention was given to not only what the participants said, but how they said it. Using the perspective of Foucauldian discourse analysis, the next step was to identify the objects and subjects constructed by the discourse, the capabilities and functions of objects in the text, and what subjects said, felt, or performed, as constrained by the discourse. Using the discursive psychology approach, the analysis examined the interpretive repertoires that participants use in constructing their narratives in different contexts and identified the goals and consequences of using these repertoires. Thus the analysis examined how discourse constructed the participants while allowing participants to choose

among available discourses in order to achieve social objectives. Comparisons and interactions among discourses were explored and dominant and resistant discourses were identified. Finally, institutions and power relations that were supported or subverted by the discourses were investigated. The analysis was open to contradictions and alternative interpretations of the data which is consistent with a methodology that sees language as performative. Participants employ different and seemingly contradictory discursive strategies based on specific goals relevant to the context (Willig, 2001).

While the analytical steps described above were applied to the initial interview and the return interview to discuss the photographs, attention was given toward analyzing the photographs themselves as sources of data. Oliffe, Bottorff, Kelly, & Halpin (2008) presented a four-layered approach for interpreting participant generated photos in an ethnographic study of new fatherhood and smoking. This was adapted for discourse analysis into a three-layered approach. An important change for this study was that the linkage between the photographs and the participants' words was maintained throughout the analysis. Since the second interview was organized around the photographs, it was relatively simple to form direct linkages between segments of the interview and individual photographs. The three steps of analysis were: *preview*, *review*, and *discourses*. These steps took progressively more interpretive stances in analyzing the data. In *preview*, each individual photograph was analyzed based on the participants' descriptions in the interview. This step began during the interview but continued during the data analysis. In *review*, the analysis went beyond the individual photograph to examine the social context, values, and relationships across the participant's collection of photographs. In *discourse*, the analysis of the photographs was linked back to the discourses identified in the first interview or to new discourses for that participant. Photographs were thus used as important

examples of discourses and provided rich detail in the findings, but the connection to the participants' words were maintained. This served to balance the participants' perspective, in spoken word and photography, with the researcher's broader perspective which exists within the discourses being described. This method contrasts with Photo Voice, which was originally developed as a community-based method to give voice to participants in the absence of interpretation (Wang & Pies, 2004).

Evaluation Criteria

Potter and Wetherell (1987) described four criteria for validating the findings of a discourse analysis: *coherence, participants' orientation, new problems, and fruitfulness*.

- Coherence is achieved if the discursive structure appears complete. The discursive model should explain how the discursive objects and subject positions affect each other. The model should describe broad patterns as well as micro-level details. Exceptions to the model should be explored and characteristics that make them exceptional detailed. A proper explanation of the nature of exceptions may strengthen the validity of the discursive model.
- Participants' orientation is demonstrated through reexamination of the transcripts to confirm that the claims of the analysis are evident in the participants' interactions and own words. The research report should contain examples from the interviews that support the analysis. This is one component of what has been called the audit trail, which allows another researcher to confirm the findings through review of the record of the analytical steps taken by the research team. (Ryan, Coughlan, and Cronin, 2007).
- New problems will arise when discursive models are applied to real-world situations. Use of discourses in certain situations may cause contradictions that participants need to

address. Evidence of the existence of these problems, and the corresponding solutions will further strengthen the discursive model.

- Fruitfulness is the ability of an analysis to generate new approaches and explanations for research questions. This has also been described as transferability, the usefulness of the analysis in other contexts. Transferable results provide meaning to others not involved in the study and to the reader (Ryan, Coughlan, and Cronin, 2007).

Limitations. The limitations of discourse analysis have been attributed to its epistemological and ontological positions (Willig, 2001). The first criticism concerns the relationship between discourse and the subject. Discourse analysis emphasizes the role of social contexts, institutions, and cultural ideals in the formation of the subject. Discourse analysis gives less consideration for the internal emotional life of the subject. A second criticism concerns the existence of a material reality outside of discourse. There is disagreement on the relationship between the material reality and discourse and whether discourse is constrained by that reality (Willig, 2001). If one takes a strict constructionist position then there is no reality except what is defined and constructed by discourse. Yet this may be problematic as it can discount the reality as experienced by subjects. In the case of distress after preterm birth, the suffering of parents is not made less real because the understanding of distress is socially constructed.

Other limitations to this study come from pragmatic concerns. Every family has a unique, detailed story that is influenced by their social context and culture. This study will not examine the experiences of non-English speakers whose experiences and discourses of distress may be different from English speaking couples. Potential participants may have been reluctant to complete photo assignments, recruit their partners, or to return for a second interview.

CHAPTER FOUR

FINDINGS

The findings of this study identify how the participants constructed their distress that resulted from the premature birth. Because distress was left undefined, the participants found varied ways to describe the distress that they experienced. Conventional definitions of mental illness such as anxiety, depression, or post-traumatic stress disorder were largely absent from their accounts, even among the participants who had been diagnosed and treated for psychiatric illness subsequent to the preterm birth. The scope of the interviews included a broad timeframe from pregnancy, childbirth, hospitalization in the NICU, and the years of early childhood. The depth and breadth of their constructions of distress highlighted many important areas of difficulty that these parents faced through the unexpected and ever-changing journey of prematurity. The trauma was seen as ongoing, rather than a single event such as the early birth. They presented their distress as a natural and expected consequence of their traumatic experiences.

Participant Background Information

The participant sample consisted of eight participants in four couples who were interviewed from one to seven years after the preterm birth. The interviews were conducted in the participants' home, the researcher's home, or a coffee house. The interview length ranged from 8 minutes to 98 minutes, with most lasting approximately one hour. What follows is a short description of each couple, highlighting the context of the preterm birth. Pseudonyms chosen by the participants are used throughout.

Melissa and Jay, a heterosexual married couple, had twin boys who were born suddenly by cesarean at 24 weeks gestation after a probable placental abruption. One infant spent three

months in the hospital and his brother spent five months in the hospital. Melissa began medications for anxiety 7 months postpartum. The couple was interviewed in their home when the boys were 6 years old.

Brandy and Denny, a lesbian married couple, had a baby girl born vaginally at 25 weeks after less than a day of preterm labor. Their baby girl spent 89 days in the hospital and was discharged home on oxygen. Brandy, the biological mother, was treated for infertility and was on antidepressant medication before and after the birth. Denny self-treated for anxiety with St. John's Wort and acupuncture when their daughter was two to three years old. The couple was interviewed in the researcher's home when their daughter was 7 years old.

Brian and Karla, a married heterosexual couple, had twins born vaginally at 30 weeks after a pregnancy complicated by infertility, in vitro fertilization, vaginal bleeding, bedrest, hospitalization, cervical funneling, and preterm rupture of membranes. The infant boy and girl spent 51 days in the hospital and were challenged by feeding difficulties and reflux for the first year at home. Karla was treated for PTSD with counseling. The couple was interviewed in their home when the twins were 6 years old.

Mike and Velois, a married heterosexual couple, had a boy born at 29 weeks by cesarean due to intrauterine growth restriction and fetal distress. The infant spent six months in the hospital, had significant respiratory complications, and was discharged on ventilator support with a tracheostomy. Velois was treated for depression postpartum. The couple was interviewed at coffee houses when the child was approximately one year old.

Participant demographics are summarized in Table 1. These details help contextualize the analysis in the lives of the participants. Ages of parents and children were at the time of the interview.

Table 1. Participant Demographics

Alias	Age	Race	Education	Psychiatric Diagnosis	Gestation at Birth	Child's Age
Jay	34	White	High School	No	24	6 years
Melissa	35	White	College	Yes		(twin boys)
Denny	45	White	High School +	Yes	25	7½ years
Brandy	47	White	Graduate	Yes		(girl)
Brian	37	White	College	No	30	6½ years
Karla	36	Asian	College	Yes		(twin boy/girl)
Mike	34	White	Graduate	No	29	1 year
Velois	35	Black/White	Graduate	Yes		(boy)

In this chapter the findings are presented for each of the specific aims of the study. The first section of the chapter details the discourses of distress, and how they affected the participants. The first group of discourses included idealized identities such as the *perfect child*, the *good mother*, and the *good father*. The second group of discourses characterized relationships between parents and others, such as *social isolation* and *disciplinary power*. These discourses are summarized in Table 2. The second section of the chapter presents findings on the feasibility, benefits, and challenges of utilizing interview and photo-elicitation methods in a discourse analysis. Throughout, the findings are demonstrated with the words of the participants, and where appropriate, to their photographs. Although the participants did not assign captions to the photographs, for clarity I have chosen a short caption as well as an excerpt from the participant's narrative for each photograph.

Table 2. Discourses of Distress

Group 1: Idealized Identities	Group 2: Interactions
<i>Perfect child</i>	<i>Isolation</i>
Natural birth	Physical separation
Breastfeeding	“they just don’t understand”
Child’s body	
Milestones	<i>Medical knowledge and power</i>
	Parenting control
<i>Good mother</i>	Medicalized parenting
Guilt	Diagnostic power
Heroic feeding	Medical error
Placing family first	
<i>Good father</i>	
Return to work	
Finances	
Emotional strength	

Aim 1: Discourses of Distress

The traumatic nature of having a very early birth was an important context for distress of the participants. The Substance Abuse and Mental Health Services Administration (2012) has defined trauma:

Individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or threatening and that has lasting adverse effects on the individual's functioning and physical, social, emotional, or spiritual well-being.

An important example of the threatening nature of the preterm birth was the existential threat to the life of the baby: they feared that the baby would die during labor and birth. Even when the woman’s life was in danger, the focus was solely on the babies.

Brandy: *I was so scared. I was so scared before I pushed because I didn’t want to push because – I don’t know – lose her. And I wanted to give birth to my baby. My live baby.*

And I couldn't – I couldn't face the thought of her not being alive 'cause I'd worked so hard. You know, we wanted her so badly. We wanted her so badly. We worked so hard to have her.

Karla: *I remember when they were born – 'cause I had a vaginal delivery – and, um, my daughter came out, and I remember just looking at her and I thought there's something wrong with her. She just – her face was kind of like – kind of squashed looking and she didn't cry. And her – she ended up having a clubfoot, so her foot was turned around. And I was just like, "Well, that's the one that was dead." (Laughter.) And then they just took her away. I didn't even like see anything. They just took her away, so I just thought, well, she's dead.*

This fear did not resolve quickly for Melissa because her twins continued to be unstable in the NICU. She feared that they would die when she was outside the hospital:

Melissa: *Out of a seven-day week, I'd say probably five nights out of the week, we'd get a phone call saying you should come back in. So that was really tough, too. Like that balance and that terrifying like, oh, my God, I'm going to go home and they're going to die while I'm not here. And, you know, am I going to make it back in time?*

Melissa highlighted here another important characteristic of the trauma of prematurity: that it was ongoing, repetitive, and prolonged. The journey was unpredictable, and new challenges emerged to replace ones that had been resolved.

Melissa: *I think for me the distress mostly came from the length of time. Like we expected, you know, first just get through, you know, twenty-four hours, forty-eight hours, seventy-two hours. Then it's a week, and two weeks, and a month. And then it's just home from the NICU. And then it's just get off oxygen. And then it's just get through this next phase. And then it – you know? And it's like you just kinda keep setting these milestones, waiting for it to be over. And it's not over. So for me – and I think that's why I picked so many pictures is just to show that it's – it just keeps going.*

These interviews were emotional for the participants, despite the years that had passed since the birth. This was evident not only in their words, but also in their tears. Thus the trauma of prematurity was ever present in the background or foreground of these interviews and the discourses of distress that are described in the following sections. The first group of distress discourses relate to the identity of the key family members as a consequence of the preterm birth: the *perfect child*, the *good mother*, and the *good father*.

The perfect child

“*You want your baby to be perfect*” -Velois

Parents entered the childbirth experience with an expectation of normalcy. This included the expectations a healthy pregnancy that would continue to term, a vaginal birth, a postpartum recovery at home, the ability to successfully breastfeed, and a healthy baby. The idea that pregnancies, babies, and children should be normal was very powerful and the failure to achieve this ideal after a preterm birth caused these parents distress. There was a high expectation for a vaginal birth, which is seen as a successful rite of passage by many women (Crossley, 2007; Wolf, 2001). *A Baby Story*, a reality television series on the air since 1998, follows families through late pregnancy, labor, and birth. This show has contributed to the idealization of normal, term childbirth. A preterm birth comes as a surprise, with little knowledge of what to expect from such an experience. Hopes for a healthy child with normal physical and neurocognitive development are placed in serious jeopardy by the premature birth. Participants in this study were distressed from the failure to achieve this idealized birth.

Karla: *the loss of that dream, you never get over it – ever. And I – like I – that dream that I had of that birth experience, I’ll never – I know I’m never going to have it, and it’s a very hard thing to let that go and just, you know, be able to see how easy it is for everybody else to have that. So easy. It’s like – like breathing. Like, oh, my gosh. Like you just pop a baby – like this lady – lady can go in an airplane at thirty-nine weeks and have a baby on the plane. I mean, she’s – she even got that. So I – I’m okay, though, with not having that, but it’s still – that loss of that is still something that’s very hard. And I know other preemie moms, we feel that same way. Like there’s a lot of that, you know, it should all just be rainbows and like butterflies, and it’s like – (laughter) it was not.*

The birth of a new child is supposed to be a time for celebration. Parents are expected to be happy and to express that happiness in different ways. But preterm parents do not feel happy when they are scared.

Karla: *I remember them holding up my daughter, and I didn't feel like joy. I felt dread. I looked at her face and I thought it looked kind of squashed and it looked – it didn't look right to me. And she didn't cry when she was born. And I – I just remember feeling like this is not – you know, this is not really how it's supposed to be. And, um – and the same thing when my son was born, too. And I just feel like I lost – like I – I wanted that – the Baby Story experience, and I didn't get that. And it's really hard for me to know that I'll never have that.*

Even though Karla wanted to have another chance at a vaginal birth, Brian did not want to risk another preterm birth. As a couple they decided that both parents needed to agree to another pregnancy.

Baby diaries and journals are another way to celebrate the joy of birth by documenting the details and events from birth through infancy. This was problematic for Velois, who did not find the events of the birth worth celebrating.

Velois: *But we had a baby book that someone gave us. It's empty – the whole journal... They had a whole page like the night you were born. And I'm like I can't write about this. I mean, maybe I will, but it just – it seems like it's supposed to be happy memories and I'm like it was the worst day of my life.*

The gift of a baby book remained blank. The failed expectation of a happy birth day prevented Velois from journaling about the experience, which might have provided her some comfort or therapeutic outlet for her feelings about the birth. The cultural expectation that all births are positive experiences denies acknowledgement and comfort when the birth is traumatic.

Another strong ideal for normal childbirth is the expectation for mothers to continue to sustain their infants by direct breastfeeding, suckling the infant at the breast, providing complete nutrition. This is promoted by the professional organizations (Section on Breastfeeding, 2012) and seen as an idealized, instinctive infant care activity. The reality for prematurity is very different. Many early preterm infants lack the skills to breastfeed, yet the breast milk is life-sustaining. This leads many women to pump their breasts, which can be difficult and painful, and add to the distress. Similarly, Karla lamented how *A Baby Story* portrayed the automaticity

of breastfeeding: “You basically push the baby out and, oh, well, guess what? The baby’s already ready to breastfeed. And you can automatically put the baby to your breast and the baby’s actually latched. And like everybody’s like smiling and happy.”

After hospital discharge, feeding difficulties plagued Karla and Brian. Their twins developed severe gastro-esophageal reflux and resisted all liquid feedings: “this is supposed to be like a natural thing. Like kids are supposed to love to eat, and they are like clawing their eyes out ‘cause they don’t want to eat ‘cause it hurts so bad.” Karla needed to feed her twins at night when they slept in order to overcome this challenge and keep them from being re-hospitalized for weight loss. This success was bittersweet; the consequences of night feedings for dental health are shown in Image 1. Thus the circumstances failed to meet the *perfect child* discourse in two ways: the feedings were not natural, and the child was damaged as a consequence. The mismatch between what is supposed to be a natural activity and the reality for these participants made infant feeding a source of distress. Not surprisingly, the baby itself can manifest and represent the distress related to the perfect baby discourse. When parents looked at their infants, they could see signs of the prematurity and reminders of the perils that they faced. For Brian, the size of his twins was the focus of his distress:

Brian: *I just remember thinking like how can it be that they’re only three pounds each, or three pounds three ounces? When you always hear the weight of like your friends’ kids and stuff, that’s not something you ever hear.*



Image 1. "Rotten teeth"

Karla: *Here's going to be another thing that they're going to have to deal with as they're – because – you know, when they're older because of the fact that we had to feed them in their sleep. They're going to have all these cavities and rotten teeth. And I felt so guilty about that.*

Brian would take his wedding ring off and easily slide it up his infant's limbs; thereafter he would be reminded of their size at work when he played with his ring. He displayed this in

Image 2.



Image 2. "Ring"

Brian: *I would go off to work, you know, you'd be sitting in a meeting and you're sort of daydreaming. And that's where I would go all the time, just kind of spinning it around or taking it off and looking at it. And it was just a kind of constant reminder for me of how – how small these guys were.*

For Brandy the size of her daughter born at 25 weeks made her seem fragile:

Brandy: *She was just so small and so fragile. And – and I just remember having these really dark thoughts like I could just break her neck, you know, just so easily. And it was just – so all these really horrible thoughts that came into my mind. They were very distressing.*

Clothing was another reminder that a normal infancy had not been achieved. Newborn clothes could be too big or inappropriate for an infant still connected to monitors and oxygen. This was particularly problematic for Velois, whose baby came home on ventilator support. As shown in Image 3, there were piles of clothes that she could never use.



Velois: *And there were so many things that he never got to wear, um, because in the NICU, he had to be, um – he was so sick for so long, he was just naked with a diaper ‘cause they needed to be able to see his chest retractions. And that. Eventually, he was able to wear a shirt or something, but it needed to snap up because of all the tubing and the leads and the – glued to his chest. And he couldn’t have something that pulled over your head. And you can’t – you can’t take away his oxygen just to dress him in a cute outfit.*

Image 3. "Things he never got to wear"

She was left with piles of clothes that either could not be used or could not be shared with others because they had been irreversibly altered for a sick child.

Early during the NICU hospitalization, the visible reminders of prematurity were evident in what could be seen and what remained hidden by the life-support equipment. These images would be immortalized as the infant’s first pictures which heightened the distress of not achieving the idealized image of a newborn. This is evident in Image 4, where Melissa’s lone finger touches her baby’s cheek. Her baby’s face is nearly obscured by the respiratory

equipment, eye shield, and pacifier. The skin is thin, pink, and wrinkled. The adult finger and IV port demonstrate how narrow and small the child's fingers are. Melissa found this picture just wrong and distressing as a new baby photo.

For other parents, the NICU left visible reminders on the baby's body. Velois was reminded of the daily painful blood draws by the scars on her baby's foot:

Velois: *When he came home, he had just scar tissue all over the bottom of his foot. It was just hard little bumps from all the needles. And, I mean, that's distressing. Watching your child get hurt day in and day out wears on you. It really does.*



Melissa: *Everything about this is distressing. The whole situation. The fact that his eyes are still fused shut, and he's not breathing on his own, and he has IVs everywhere, and he weighs a pound. Um, yeah. I mean, none of it's right. And so to have that be your – the new baby photo is just – ugh.*

Image 4. "New baby photo"

Brandy found her daughter's image so reminiscent of the prematurity experience and an embodiment of her distress that she resisted participating in the photo assignment. At her second interview, she talked about her decision not to take any photographs:

Brandy: *Looking at my daughter reminds me of, um, everything. And so it's like most days when I look at her, um, it's – I'm reminded of what happened. From where she came, where she is now. And so there's worry and anxiety there, you know, that this is just so fragile. That even though she's almost eight, that anything could happen... So – so if I would've brought a picture, it would've – would've been of her. And I just felt very odd and just very superstitious about, ah, taking a picture of her in this regard.*

Parents continued to be concerned about the likelihood that their infant would achieve a normal life long after discharge from the NICU. These concerns included worries about physical growth and neurocognitive development. The focus on weight gain continued from the NICU, when the weight was checked every day. If growth did not progress after discharge as expected for a term newborn, then there was the risk of readmission to the hospital. Developmental milestone handouts, which were mailed by the Department of Health to parents of all children based on their birthdate, reminded preterm parents that their children’s development did not progress like term children. Developmental milestones needed to be corrected for the child’s gestational age – thus a six month old baby born three months early would be expected to be at the development of a three month old. This compelled parents to continuously recalculate and reconsider how old their baby was, as shown in Image 5.

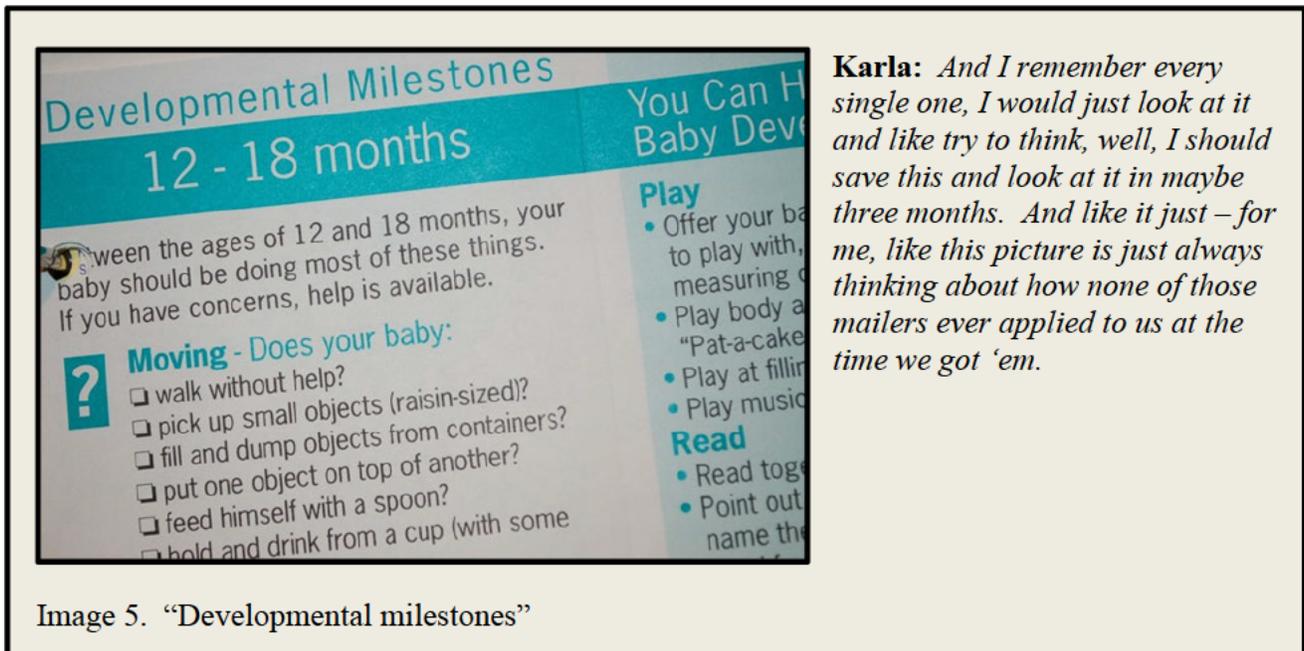


Image 5. “Developmental milestones”

Behind these self-evaluations – is my child reaching the developmental milestones? – was the ever present fear that new injuries of prematurity would be discovered. All those periods

of low oxygenation, infections, and setbacks would eventually take their toll on brain development. Cerebral palsy lurked in the background as the next bad news waiting to happen, the “next shoe about to drop.” This placed preterm parents in the position of having to do something to counteract this possibility. There was concern that one of Melissa’s and Mike’s twins was developing cerebral palsy, so he had many occupational therapy appointments. She framed this work as trying to achieve “normal” rather than as a more specific functional goal in Image 6. Velois and Mike continued to pay large amounts of money for donor breast milk when



Melissa: *just a long road of trying to be normal. And this is when, um, they were really concerned about cerebral palsy. So he was in OT for a long time. And just kinda that, you know, ongoing, trying to get them back to normal, healthy.*

Image 6. "Trying to be normal"



Image 7. "Loss of IQ points"

Velois: *It represents stress over my child's IQ. Because when you're born early, there's a certain, um, loss of IQ points that's been kind of statistically shown. When you're 2 pounds, you know, you're at risk for that. But if you're able to breastfeed for a year, there's also been shown that there's a bump in IQ. So we feel like we're obligated to do this to get him back closer to where he would have been if not for being born so early.*

Velois was no longer able to pump her breasts. The donor milk fees cost more than their housing expenses at the time. This desire to help their son make up his "loss of IQ points" was shown in Image 7. The donor milk was bought to help their infant son become the perfect child he was meant to be.

Preterm infants have many potential illnesses to overcome such as lung disease, retinopathy of prematurity, necrotizing enterocolitis (NEC), cerebral palsy. These participants faced distress when each of these potential complications was presented to them. For Karla, each success was considered a near-miss, and she worried that eventually there would be a health problem that was not averted or overcome:

Karla: I have to wait, and you get to follow a checklist and know that those things are going to happen whereas I don't even know if any of those things are going to happen. And I felt like I just was always playing this waiting game. Like there's always something I'm waiting for. The other shoe to drop. Like some other like red flag to show up.

This fear of not meeting developmental expectations persisted for years past preterm birth.

Similarly, Jay faced a potential crisis when his son was diagnosed with aortic root dilation:

Jay: *we thought we had kind of gone through everything. And we were like, okay, we made it through. I don't know how in the world we made it through. And my first thought was like, oh, crap. Okay. This is going to be – this is it. This is the big thing that we were – kept thinking was going to hit us. You know? And again, luckily we kinda skated by.*

This background fear, that there is a looming health crisis waiting to happen, was reinforced repeatedly by medical evaluations and follow up at high risk clinics. Doctors told Jay that his twins were “kind of miracles because they should be blind. They shouldn't be walking. You know [child] should have severe cerebral palsy.” Melissa felt anxious, almost to a panic, before every medical appointment, because of the uncertainty of what may be discovered.

After hospital discharge, parents worked hard toward a return to normalcy and wanted to see their children healthy, strong, and successful. Because of how health care is delivered – built in uncertainty, repeated screening – parents see ongoing tests of development, which reinforces the potential for failing to meet a guideline. Any reassurance felt tentative as there was the possibility of failing to meet another milestone in the future. The correction of gestational age reinforced the idea that these children were inherently “behind.” Parents compared their child's progress to the progress of other term and preterm children, even to the interviewer's child. At the end of her first interview, Velois reversed roles and interviewed the researcher on his experience of prematurity. This provided a comparison of the struggles met, but also some idea of what the future might hold as she looks ahead to her son's future progress.

Velois: *How old was, um – how far along was your preemie?*

Interviewer: *She was, um, twenty-eight weeks.*

Velois: *Okay. And how much did she weigh?*

Interviewer: *Two - twelve.*

Velois: *Well, do you have any long-term –*

- Interviewer:** *Ah, no. She's eight now – or turning eight in January. And, ah, you'd never know. Which is wonderful.*
- Velois:** *Were you able to like leave the hospital close to her due date?*
- Interviewer:** *Um, we left after six weeks. So – so pretty quick.*
- Velois:** *So she had a pretty good course then.*
- Interviewer:** *Yes. We were very fortunate.*
- Velois:** *Really? You didn't have to go home with like oxygen or supplies and stuff? Was she pretty much okay?*
- Interviewer:** *She was pretty much okay. There was a lot of struggling around breastfeeding.*
- Velois:** *Oh, I imagine. That's great.*
- Interviewer:** *Yeah. But she – she otherwise did really well. I mean, it was still an incredibly difficult experience.*
- Velois:** *Of course, Well, still – I mean, each week was so stressful for me. But imagine six weeks stretched into six-and-a-half months –*

The perfect child discourse positioned parents as having to *compare* their children to those born at term and having to *compensate* for their actual or potential deficits. Some parents eventually resisted this positioning that their child had to be compared to other children in order to be valued. Brandy sought reassurance multiple times that her daughter was developing normally from high risk pediatric follow up clinics until they told her to not come back. Before kindergarten her daughter was seen three times by a speech language therapist because she was not verbal, and was told not to come back because there was nothing wrong. Finally Brandy realized that the drive to compare her child to term children was not helpful:

Brandy: *she's not the kind of kid, you know, who's really incredibly verbose, and that's fine. That's just who she is. But she makes great art. So, um, that's how she speaks and – and just – and her imaginary play is just amazing. She makes friends. You know? When other kids were getting bullied, you know, she wasn't 'cause she's just like this cool, easygoing kid. You know? She has this great empathy. She has this wonderful, wonderful emotional intelligence...So there's all these – there's different kinds of intelligence.*

Thus Brandy resisted and eventually rejected the *perfect child* discourse. Similarly, Denny spontaneously shared Image 8 of her daughter hiking in the woods, looking strong, wearing her backpack.



Denny: *We went all the way down into this, you know, pleasant ravine and walked all the way back. And I wanted to take a picture of her there 'cause it's really beautiful woods. And, um, so when I took the picture, she wanted to, um, climb this tree. Um, and then she walked all the way back up the hill carrying her backpack and exploring. So it's great. She is indistinguishable from other children at this point,*

Image 8. "Walk in the woods"

The *perfect child* discourse influenced how parents thought about and acted for their preterm children. The *good mother* and *good father* discourses influenced how they considered themselves and made choices related their parent roles.

The Good Mother

The *good mother* discourse has a powerful influence on mothers' parenting behaviors. Although the majority of women in the U.S. return to work postpartum (Laughlin, 2011), the division of labor among parents has continued to place more responsibility for parenting on women (Knudson-Martin & Mahoney, 2009). Thus the good mother discourse promotes a myth of motherhood that a woman can do it all with minimal help (Choi, Henshaw, Baker, & Tree, 2005). No matter how families decide to balance work and family, good mothers place the needs of their family before their own needs (LaFrance & Stoppard, 2006). The pressure on women to be a good mother is given a sense of desperation by the precarious condition of the preterm child.

This led mothers in this study to feel guilty about the failure to carry the baby to term, to take extended leaves of absence from work, and to take heroic measures to provide breast milk.

Women felt guilty about failing to achieve a full-term pregnancy, even though they recognized that the early birth was not their fault. As the pregnant parent, these women inextricably tied themselves to the success of the pregnancy. In the past, the connection between preterm birth and illicit substance use such as cocaine was widely publicized in the media (Cleeton, 2003). Although this had receded from the media's focus, the association persists in government health education campaigns (Centers for Disease Control and Prevention, 2013). That they did nothing wrong did not alleviate the sense of guilt in these women.

Melissa: *I didn't do anything crazy when I was pregnant. I wasn't drinkin' and doin' drugs and bungee jumping. You know, like I was just being boring. And so I know I didn't do anything, but I wish I could have done something more, of course. Um, but I don't know what that would've been. But, yeah, I think there's always that feeling of guilt. Like this is my responsibility. I was the one carrying them.*

Clinical practices that have contributed to the idea that preterm labor can be stopped include administering medications to stop contractions and placing women at risk on bedrest (MacKinnon & McIntyre, 2006). These interventions, however, have not reduced the high rate of preterm birth in the U.S. (Maloni, 2011). Thus detecting that a woman is at higher risk for preterm birth does not provide an opportunity to prevent the early birth. Karla was in this position when her cervix was found to have funneling, a strong indicator of impending early birth.

Karla: *Then the day that they found that I had funneling, I just was like, "Oh, yeah, I know that's bad," but I felt like I didn't do enough to like impress on the doctors how bad I knew it was. And yet, I felt like, okay, you're the doctors and the experts. A perinatologist should know. If it was that bad, they should've known. Like if it's that bad, they should put me upside down on one of those tables and shoot me full of mag and, you know, all that kind of stuff. And they didn't do it and they let me still get out of bed. And I – my water – my – my amniotic sac – because I got up at two in the morning to go to the bathroom...And I remember thinking if I had only like told the doctor like – like*

insisted that they do something about the funneling, that maybe (crying) I could've stopped their premature birth...But I know like it – it was not like something I could've done. (Crying.) But I still feel guilty about that. I don't think even my husband knows that.

Both Melissa and Karla felt guilt even though their rational minds knew that they did nothing wrong. Karla chose to blame herself instead of her physician for ignoring the funneling of her cervix. The shame from this confession is so strong that she had not shared this feeling with her husband.

Breast feeding was another activity where the women felt a strong connection to the infant that influenced their feelings and behaviors. Breast milk is recommended by the American Academy of Pediatrics as the best choice for preterm infants because of its protective effect against severe infections such as sepsis and necrotizing enterocolitis (Section on Breastfeeding, 2012). Thus breastfeeding is not just an idealized image of normal postpartum behavior, as part of the perfect child discourse, but it is also an imperative for mothers to protect the infant from infection. After an early preterm birth, this requires heroic efforts by the woman giving birth. When suckling the infant at the breast is not possible due to the infant's undeveloped reflexes, cognitive organization, and muscle strength, a good mother is one who pumps for her preterm baby since the baby is unable to suckle at the breast (Sweet, 2008).

Velois: *I was still just waking up and they stuck a breast pump on me to start pumping. And again, I wanted to breast feed, and here I'm trying to get my body to pump when I'm in pain. You know, I hadn't held the baby. I hadn't heard him cry. There was no signal for my body to start producing milk, and yet I'm told this is vitally important for his health. And like nothing was coming out. You know, the whole pumping experience was really sad. Each time I did it, I felt sad. And I did it for five months. It probably was one of the hardest things I've ever done. And I never got to breastfeed – it broke my heart. Finally, I just was – so many blisters and I just couldn't like literally my skin was falling apart and I couldn't do it.*

Pumping the breasts takes more effort, provides less physical connection to the infant, and can result in emotional and physical pain. Despite these difficulties, these mothers were



Melissa: *The stupid like hospital-grade pump. Ahh... Just that that was my life. I was tethered to that thing the whole time we were in the hospital. And it is painful and awful this piece of equipment. Like I think any mom that's been on one of these pumps is like, oh, God, don't show me that picture. Just – yeah, not – not a fun piece of equipment.*

Image 9. "Painful and awful"

compelled to endure the pump, shown in Image 9, because it was expected of them. When she was unable to continue pumping, Velois and Mike ordered at great financial expense donor breast milk to continue to provide the benefits of breast milk.

Karla showed her commitment to feeding her twins when they began to experience severe reflux three weeks after their discharge from the NICU. The only way they could tolerate painful feedings was when they were asleep at night. She did this in order to avoid re-hospitalization or surgical placement of a gastric tube. Providing enough milk in this manner took great patience, and repeating the Lord's Prayer, depicted in Image 10. This was a fitting metaphor, as the prayer pleaded God to "give us this day our daily bread," referring to the nutritional challenge, and the grave ordeal, "deliver us from evil."

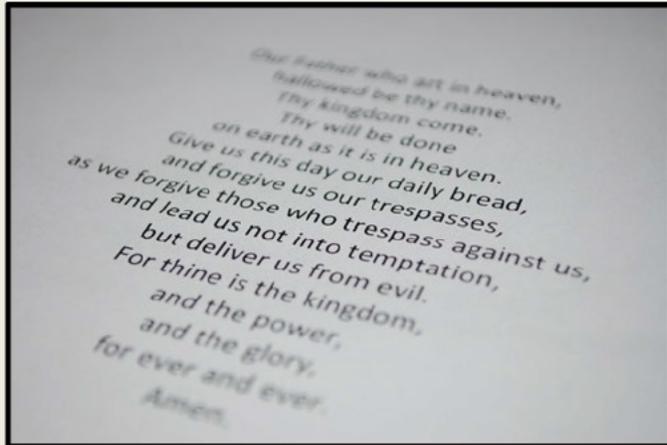


Image 10. "Our daily bread"

Karla: *we went through a period where they could only drink milk in their sleep. And, um, I thought many times during that time that I was going crazy. And I remember sitting, um, in my daughter's bedroom – she has a little couch in there. And you – you're just – I felt like all I would do is just wait. Wait, wait, wait for them to fall asleep. For her to fall asleep or for my son to fall asleep. But then – well, at – you know, once they're falling asleep, then you could try to feed them.*

But sometimes it would take like an hour or two. And like if you moved them, they

would wake up. So I was always in terror – like constantly afraid of them waking up because then maybe they would miss a feeding and they would be at like 12 ounces of milk for that day or whatever. So I would just sit like a statue with them in the room – like if I had one of 'em – and I would just wait. And I would say this prayer to myself over and over. And the thing is it is – for me, this prayer is not just a prayer, but it was kind of my way of keeping myself sane.

Another way that women conformed to the *good mother* discourse was by prioritizing time with the infant over career. For example, Melissa quit her job when her twins were born so that she could spend all day, every day with them:

Melissa: *We couldn't hold them, um, but you could put your hands into the incubator and just cradle their head – head and feet. And that touch – and the neonatologist said, you know, the more you can be here, the more you can cradle them, the more they can hear your voice, like that is the only soothing thing they're going to get out of their day because everything else is pokes and prods. And they're not meant to be out of the womb yet. So, um, we really took that to heart. Um, I was there every single day. I quit my job the day they were born basically... Um, but somebody had to work. So – and I knew it wasn't going to be me, so it had to be Jay. (Laughter.) Yeah. I mean – and it's just when – it wasn't something we had planned. I had never planned on quitting. It just – you just do what you gotta do.*

Melissa's career continued on hold after discharge from the NICU because the fear of infection kept them out of day care. Melissa stayed home with them for three years. Similarly, Brian and Mike returned to work, while Karla and Velois took time off from work. Velois also made the

choice to stay with her baby while her husband went back to work, even though this extra burden took a heavy toll on her mental well-being.

Velois: *I was there every day. I took an extra – I took six months off from work all together. To spend six months – it's like I was in battle. And that intensive care unit is so traumatic. And my husband did get to go to work and come back, and I think that gave him a little bit of a mental break. Which is not to say it was easy on him, but for me it was just like I definitely got depressed.*

Brandy and Denny, a lesbian couple, could not default to traditional gender roles because they were both women. While they visited the NICU every day, Brandy returned to work after two weeks so that her maternity leave would be saved for after NICU discharge. The decision about who would go back to work was based on who earned more income:

Brandy: *We'd been trying to make some decisions just about Denny's future. And Denny let me know, you know, what she wanted to do. And – and what she wanted to do was to, um, be able to stay home with (baby) and work two days a week. And we realized that with the salary that she was making, if she went back to work, she'd basically be working to pay for daycare. So what was the point? Um, so yeah. So it was only two days a week.*

Even though Brandy worked more than Denny, Brandy's priority was parenting:

Brandy: *I wanted to be home with her. It was okay going back to work. I mean, everybody was great. But, you know, I'm not one of these people who, you know, lives to work. I kind of work to live.*

Thus this couple negotiated the decision about working in a way that both mothers could be *good mothers*.

Mothers also prioritized the infant's needs over their own by remaining focused and emotionally strong, even when it was extremely difficult. Melissa did so by repressing her emotions, holding in her tears, and focused on the details of her twins' care:

Melissa: *And pretty much I just tried to keep the level head. Here's what I'm doing. Talk to the doctors. Talk to the nurses. Keep it all straight. And I always stayed pretty, um – pretty strong and pretty clearheaded while I was in the NICU. And I would just deal with my stress like when I left. You know? I wouldn't cry in the NICU. I would just ask questions. Take notes. Be the one okay, okay, okay. I'm dealing with it. And then*

when I left is when I would kinda like just lose it and break down. But I never – never thought to ask for like a psychologist or a therapist or anything.

Morse (2001) theorized that suffering after trauma is characterized by two types of reactions: *enduring* and *emotional suffering*. In enduring, family members focus on the present, the day to day tasks and suppress their emotions. Initially this is an effective coping strategy which helps the parent get through the struggles of the NICU. Melissa focused on the details, asked questions, and took notes. Only after leaving the hospital during the day could she her emotions and express the full extent of their suffering. For Karla this release did not happen until more than a year after the birth, when her twins graduated feeding therapy and were released from quarantine.

Not all the mothers embraced the role of the *good mother*. Denny, a self-described “non-biological lesbian mom,” characterized the time in the NICU as a better outcome than having her wife sick on bedrest for the remainder of the pregnancy: “It ended better for me to have a preterm baby.” She was initially resistant to her role as caregiver for her wife and daughter, and not ready to be responsible. Instead, she was happy to have the machines and nurses guide her into that role.

Denny: *for me personally that experience was – was really the best of the, um – of the possible options. Because Brandy...was having thyroid issues. And she was like way more lethargic than like the average pregnant woman. And she has like sleeping issues anyway. But the um like if she had been on bedrest, I – I don't think I would have been at the place in the relationship to like (pause) make it through. Like having this preterm baby and having all these machines (laughter) take care of the baby and all this technology take care of baby, um, (pause) made it easier for me personally. ... we slept in our own bed and, um, slept through the night, you know, the first three months while [baby] was in the hospital. And we had these like experts teaching us how to care for her and, you know, encouraging us and cheerleading us. And, um, that was a better transition for me.*

Denny's emotional attachment to the pregnancy was complicated by the decision that Brandy, the older of the two, would be the one to get pregnant. She had a role that complemented Brandy's role in how they reacted to the hospitalization and ensuing worries.

Denny: *I think a month after she was born, you know, I had that like dad freak-out. Like, oh, my God. You know, this baby. And like all these things could've happened. But I don't think – I don't think that it was my role to be like worrying in the moment. I think that Brandy kind of filled that role more. Like these are the things that could happen. I was more like the retroactive worrying.*

Despite these differences, Denny found other ways to conform to the *good mother* discourse such as prioritizing time with her infant over work. In summary, the *good mother* discourse caused distress for mothers through guilt, extreme challenges in feeding their mothers, and repressing their own needs. Fathers in this study showed very different reactions to the preterm birth, and different ways of expressing their distress.

The Good Father

The good father discourse is an ideal that prescribes the father's role in the family and involvement with parenting (Henwood & Procter, 2003). This may be constructed as a combination of traditional masculine attributes such as physical strength, stoicism, and supporting the family through employment with increased involvement in the home life and children. It has been argued that this discourse allows men to feel like they have increased involvement without sacrificing their power in the family or their careers (Knudson-Martin & Mahoney, 2009). Despite the increase in fathers' involvement, it is less common for men to take time off from their careers to be stay-at-home fathers, and men who do so face societal tension from violating the gendered expectations around parenting (Petroski & Edley, 2006). The fathers in this study found their involved fatherhood challenged by the circumstances of premature birth and hospitalization and they reacted to this by moving toward more traditional

masculine parenting roles. This reaction included returning early to work, focusing on financial concerns, and remaining emotionally strong.

The men in this study returned to work quickly after the preterm birth. While there was a need for one parent to stay with the ill infant in the hospital or at home after discharge, these families assumed that this would be the mother. Even if the woman had been employed, the man's career took precedence.

Mike: *I wanted to maintain my – my job, too, understanding that it would be – you know, it wasn't something that was going to get better, you know, in a few weeks, but that it was going to be a long-term process and that I couldn't let it completely wreck my career. So, you know, I took a few weeks off at different time periods during, you know, um, certain events that occurred. But for the most part, you know, I continued to work and would just go to the hospital right after work. And then we'd go home and then repeat that each day.*

Nevertheless, the dominance of work, along with the already limited contact in the NICU, made it more difficult for fathers to connect to their fragile infants.

Mike: *I didn't really know him that well. You know? He was so new and, you know, most of his life was in the hospital. So it's not like I knew his personality and was, you know, super attached.*

This disconnect between Mike and his son was noted by Velois and gave her sadness because she wanted him to be an involved father; but necessity gave her priority in spending time holding their baby in the NICU in order to stimulate milk supply.

Velois: *It was sad for me to watch my husband because he would come after work and all he could do was change his diaper. He couldn't hold him yet 'cause we – they were like – well, we decided it's better to get my milk started if I held the baby since we only had such a short period of time. And the first few weeks were supposed to be important for milk production. So he didn't hold the baby for like the first three-and-a-half weeks. It was sad for me to just see him touching his toe, and that's all he could hold. You know? You know, to drive after work and all he could do was wait until nine o'clock and change his diaper. And that really broke my heart 'cause he was trying so hard to be a dad. What could he do? He had like a few minutes a day to touch his son.*

The privileging of mothers' contact with the infant also placed a burden on these mothers that was recognized by the father. For example, Jay felt guilty about leaving his wife at the hospital in the sleep room while he went home to rest:

Jay: *but I remember, um, going back to – back to my house and trying to go to work. And, you know, she would stay at the hospital. And I just felt guilty about leaving my wife in this closet basically to sleep. And – and she stayed there for at least a month or two. So it was quite a bit.*

Fathers also found creative ways to balance their work and desire to be with their preterm infants, whether by adjusting work schedules or bringing work home or to the hospital to be their infant.

Brian: *We could bring our own stuff in there. It had Wi-Fi. So I could – I left work early every day and just worked in the afternoons from the hospital.*

Mike: *we've had nursing support, um, you know, 'cause he cannot be left alone because he doesn't have a secure airway. So – so I work, you know, hours that are really long, but then I have a couple of days off. And that's how we kind of divide it between my wife and I. And she took some time off from work. And, you know, that's how we've balanced our careers while taking care of him.*

The prominence of work in one's fathering role can be problematic when financial challenges result from the preterm birth. Jay felt significant distress from the devastating medical bills that left his family in bankruptcy and resulted in foreclosure of his home. Because he assumed work and financial security as his primary parenting role, while Melissa stayed home with the twins, he felt responsible for their financial failure.

Balance Forward	.00
Other Payments/Adjustments	.00
Pharmacy	33,647.80
Supplies	3,046.50
Radiology	2,087.30
Lab Services	16,468.80
Cardiology	6,192.00
Respiratory Therapy	26,069.70
Room/Bed Charges	116,280.00

of billing your insurance company. If you have new information or questions regarding
call your business office representative at 206-917-5723

CURRENT ACCOUNT BALANCE **\$203,794.10**

Image 11. "Everything got yanked from me"

Jay: *to this day, I still don't like going to the mailbox. I mean, it's just – 'cause you just – It's just always bills. You know? And it's just like we've – we've done well coming back and we – so we – we live in a nice house. Like I love it, but it's like, you know, just the stress of being like, okay, well, is this one going to get yanked from me, too? You know? 'Cause like we bought a new house before, and it was like – I guess it's how I feel. You get in here and it's like, man, is something going to happen and this is going to get yanked from me again?*

You know? You just kind of feel like things just get taken from you. You work

really hard to get 'em and you deserve 'em and then they get yanked from you. You know? And it's like I didn't do anything wrong. I had kids and everything got yanked from me.

The financial devastation of declaring bankruptcy and losing his home in foreclosure was a shameful experience for Jay. This violated his expectation for achieving the American Dream – one works hard, gets married, buys a house, and has children. This success was shattered by the premature birth, and he continued years later to feel insecure financially.

Another way that these fathers modeled the good father discourse was by presenting themselves as having mild emotional reactions whereas their partners were more emotionally reactive to the premature birth. They highlighted their different reactions as a gendered difference.

Mike: *And it's – it's been hard for me to understand kind of the loss I spoke of 'cause I – you know, maybe me individually or maybe it's a gender thing – I didn't have some of the same feelings that she had in terms of the birth process. To me, it was like a day, and then you're on to the next thing.*

Brian: *I don't go too crazy on my emotions up or down. Like if we get in an argument, like ten minutes later I'm okay. She needs like a day (laughter) to – to kind of get over it.*

Jay: *She's just very high-strung. She's not a high-strung person, but she gets very high-strung and very kind of testy on those days. And I'm like, "What – oh, that's right. We've got a doctor's appointment today." 'Cause I think it's just like we've gotten bad news so many times that it's like I think she just freaks out on those days and she's just like really high-strung on those days until it's over. And I keep telling her, I'm like, "Don't freak out until there's something to freak out about. That's what you do to yourself. You get yourself all worked up." And then you come home – and I'm like, "I'll give you a call after." And I'm like, "How'd it go?" "Oh, it looks great." And I'm like, "See? You know, just calm down." But I know she has a hard time with that. And I don't blame her, but I – maybe I just look at things differently.*

Yet we do have evidence that they experienced significant emotional reactions, both from their own accounts and from their partners' accounts. Thus they minimized their emotionality in their accounts in order to maintain their image of masculine strength. For example, Karla reported Brian's strong reaction to the imminent birth of their twins:

Karla: *I remember my husband just bawling and crying when he came into the room. And I remember telling him, "This is the happiest day of your life. Our twins are going to be born today. You're going to meet them today, and why are you crying? Why are you hysterical?"*

This emotionality is sharply contrasted later by how Karla describes Brian's lack of emotions at home. His emotional strength allows her to be a "giant mess" when she needs to. She therefore supports his construction as emotionally strong.

Karla: *Like he knew what we were going through more than anyone else, yet he had like the – he didn't have the emotional connection somehow. Like I was just – it's like almost like if you split up the pie, I had like ninety-nine percent of the emotional feeling about it, and he had one percent. And I felt like the one percent he had, it was only when it came to the extremely traumatic times that I saw him be moved by it... because he was just this stoic rubber wall that like nothing touched, that was good for me 'cause it felt like I could always depend on him. And I knew he would be there for whatever I needed, and I could be that giant mess (laughter), fall apart, and I could still have – he would still be there for all of us.*

Another consequence of prioritizing the return to work is that the fathers then deferred to their partners in matters concerning the care of the infants. This included communication with

physicians, coming to outpatient appointments, and closer contact with the infants. Thus this behavior supported the construction of mothers as experts in the infants' health needs.

Jay: *She's just better at doing the doctor's visits and stuff. Mainly, just to make sure that they ask all the questions that I will probably forget if I take them.*

Brian: *We took – for that, we also had to take them to a bunch of specialists, and nobody helped us or figured out what was going on. And actually, that stuff – my wife will have a much better recollection of that (laughter).*

Thus the good father discourse served as a mixed blessing for this small set of fathers. While the drive to work provided them a respite from handling the stress of prematurity in the hospital or in the home, it also kept them from getting as close to their infants as they wanted.

The perfect child, good mother, and good father discourses all related to the parents' idealized images for themselves and their roles in parenting. The next two discourses, *social isolation* and *disciplinary knowledge*, were more externally focused and related to how the parents interacted with their social networks and health professionals.

Isolation

Parents commonly expressed how the experience of prematurity was one of social isolation, both during and after the hospitalization. This included two aspects – a physical sense of isolation or separation and a chasm of understanding between premature families and family and friends who existed in a different world of understanding. This isolation was to some extent imposed from the outside (by medical professionals and the circumstances of the birth), but families became complicit in this separation at times.

The physical separation began immediately with the birth. As soon as the premature baby was born, the baby was rapidly removed from the mother in order to provide intensive care in the NICU.

Brandy: *they took her across the room and started working on her immediately. So (name reference) took a picture of her being carried across the room. But – and then, you know, the baby was gone upstairs. And I was so scared.*

It is common practice to exclude partners from the operating room during emergency cesarean surgery when general anesthesia is used. This separation means the partner cannot witness the birth or know firsthand the status of mother and infants.

Jay: *And they said, “Okay, great. See you later. And we’re going to kick you out ‘cause it’s not something that you need to be in here for – for the emergency C-section.” So I was kind of shuffled out into the hallway. And I don’t think it was, you know, anything mean or anything. I just – it was – you know? And I remember it being a really busy, normal hospital. And I went out there and it was like a ghost town. I mean, there was nobody out there ‘cause they were all, you know, in my wife’s room. (Laughter.) ...So I remember just – it was me in the hallway, you know, in the middle of a like kind of the little nurse section basically. And it was like nobody. It was weird. And that was stressful ‘cause I had no idea what was going on. And I knew my wife was in trouble. The kids were in trouble.*

After the immediate crisis of birth has resolved, isolation continued with physical barriers between parents and the infant. As shown as Image 12, incubators presented a tangible barrier to parent-infant contact. Direct physical contact was also limited by the presence of equipment such as monitors, tubing, and eye masks. The baby’s condition delayed holding the infant in skin-to-skin care until days or weeks after birth and was limited to a few minutes at a time (Image 13).



Image 12. "Talk to a little hole"

Melissa: *This is us just talkin' to the boys. So that's one of them in there. I don't know who that is... And that's what we would do is just sit and talk to a little hole.*



Image 13. "I get to hold him for ten minutes"

Melissa: *That was the first time that I got to hold [name reference]. And he was three weeks old. And kangaroo care. So it was the first time he was strong enough to actually do kangaroo care. So he had a CPAP on. He had wires and tubes everywhere. And it was kind of a mixed emotion here because it was great that I got to hold him, and that was an amazing thing. But it still was, you know, just distressing. And you look back and it's like, well, wait a second. He's three weeks old. I'm holding him for the first time and he's attached to wires. And I get to hold him for ten minutes and then he has to go back in the incubator.*

But there was also separation between parents as a division of labor was enacted. One parent would often stay at the hospital, while the second parent tried to maintain the family life outside the hospital. For example, Jay managed his own business during the day and slept at home while Melissa spent her days and sometimes nights at the hospital. Parents of twins faced

the separation of their twins when one infant was discharged home before the other or when one infant was transferred to another facility. This forced parents to make painful decisions on how to prioritize their presence with their infants.

Karla: *I remember thinking like I don't know what you're talking about. Like I don't understand. What do you mean? Like aren't you a Level 3 NICU? What do you mean we're going someplace else? And we have twins. You're going to split us up?*

Jay: *It was – it was – it was tough, too. I mean, um, at first, [name reference], the oldest by a – I think a minute, he came home – I think he came home – I want to say a month, but I think that's wrong. He came home first. So that was – it was a little bit logistically difficult because we had him. Um, we kinda had to have special circumstances to bring him back to the NICU. Because we were like, "Well, what do we do with him during the day?"*

Parents faced literal 'isolation' when infants became ill with contagious infections such as sepsis or NEC. Parents complied with contact precautions by wearing gowns, gloves, and masks in order to prevent the spread of infection, as shown in Image 14. This precluded skin-to-skin contact and made the time in the infant's hospital room physically uncomfortable. Concerns about infection continued after hospital discharge. Because these infants were fragile and had respiratory disease, an infection that would be inconvenient in a term infant could result in hospital readmission and returning to oxygen therapy. Hospital discharge was seen as a bridge to a more normal life, but the concerns about infection led to a different type of isolation in the home.



Image 14. "Full gown and garb"

Melissa: *That's one of our times in isolation. So that's me and my mom. And just the boys, any time they had any sort of – well, they both had sepsis and DIC and several like infections while they were in the NICU. So then everybody would have to go into full gown and garb. And it was awful. Those things are so hot and so uncomfortable.*

Melissa: *if we can just go home, everything will be fine and normal. And then you go home and you're like, oh-oh, it's not fine and normal. Now, it's the same thing in our house without all the people that I felt awkward being around before. But now there's nobody. You know? So it was – it was strange. 'Cause then we were home for three years. They were in the isolation basically in our house. So they weren't allowed in, you know, play groups or preschool or anything like that 'cause their immune systems were so weak. So we had the oxygen tanks and we had our delivery guy bring us oxygen every week. And that was pretty much it.*

Mike: *it's just like as days and days go by, it's like when will this end? You know, just like this – this never-ending nightmare of isolation and worries.*

Preterm parents reported a deep disconnect from family and friends who had healthy term infants. Participants shared many stories about term parents' misunderstandings of the preterm experience and uncertainty on how to interact with preterm families. This began with acknowledging a preterm birth. Does one offer congratulations or condolences?



Image 15. "All of these flowers"

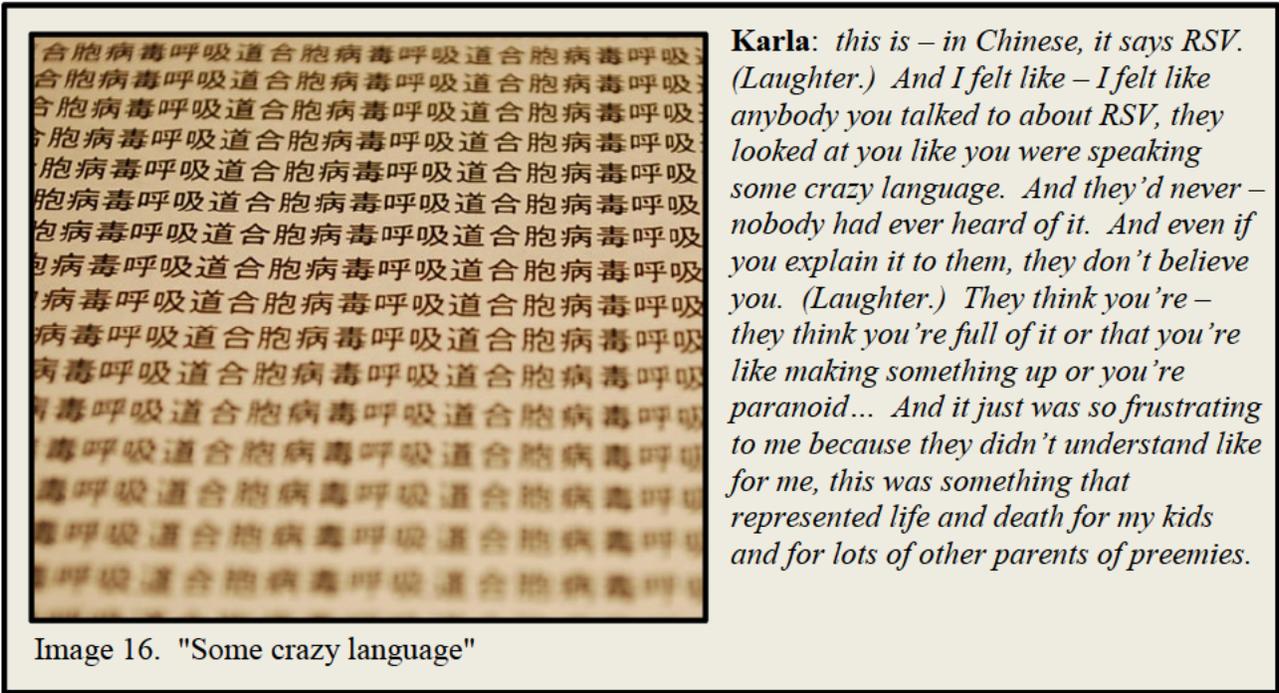
Melissa: *I just had all of these flowers. And, um, I just remember being like, "Get them out of my room." 'Cause it's – you know, when you have a baby, you might get some flowers. And it's like, oh, celebration. But everything was – so everything with these flowers was more like sympathy flowers versus celebratory flowers, at least in my mind... And all the cards were really awkwardly written. Like what do you write? You know? So it was just – it was a weird thing.*

Not knowing what to say made interactions between preterm and term parents awkward and uncomfortable. Some close friendships were dissolved by this tension.

Karla: *I didn't get emotional support from very many sources because it was – it's very hard to talk about having a preemie. I feel like people think it's – I don't know. It's like people don't want to talk about it. Like I remember when we had our babies, we felt like nobody wanted to say congratulations 'cause they were too afraid – like do they say congratulations? Or do they say I'm sorry that they came early or – and I just felt like – we hadn't even had our shower yet, so we had our shower after the babies were born. They were in the hospital and we had – it was like so awkward and weird. I mean, I don't think they knew what to do – what to say. And they wanted to be like joyous, but it was very much tempered by, oh, my gosh, your babies are on like life support basically. And, you know, it's like, "Here's a bathtub."*

Velois: *But it's lonely, and we've lost some friends through the experience. You know, there's one woman I'd been friends with, and I said, "Where have you been? Why didn't you come visit us in the hospital? Why didn't you call and let me vent or do something? You know, bring us a meal?" You know, some people just disappear.*

The failure to understand continued after discharge from the hospital. Friends and acquaintances did not understand the infectious risks preterm infants faced from respiratory syncytial virus (RSV). Karla photographed repeating Chinese characters as a metaphor for how she felt she spoke a foreign language trying to explain RSV to people.



Preterm parents had difficulty relating to the complaints of term parents. Their issues seemed trivial or petty in comparison to their concerns about development, life threatening complications, or challenges at daily functioning.

Velois: *And it’s a – like a couple of my friends had babies at the same time. Especially one, it’s so hard to see their kids. They’re like, “Oh, my baby can’t graze off of my plate anymore. I need to buy their own child’s meal.” And I’m like, “Oh, really? That’s great.” You’re lucky. You know? Or like, “Gee, so-and-so makes such a mess I have to clean the floor each time they feed themselves.” And I’m like, “Your child can eat. This is a good thing. I will clean the floor.” You know? Like they don’t know how they lucky they are. They really don’t know. I mean, I would love to have all the mommy problems like that. Mine are like, you know, is he breathing? You know. I’ve had nurses fall asleep. You know what I mean? Like – and it could cause brain damage if he’s – like a totally different set of worries. I’m getting up at night. Like is the nurse awake? Like is his trach still in? You know? A totally different set of worries.*

Parents found some gifts they received entirely inappropriate for their circumstances, which then increased their distress and their feeling of isolation. Velois’s mother-in-law sent a “My First Christmas” bib set, which was not useful for an infant on life support who was unable to eat. She also found that first Christmas not worth celebrating as a milestone (Image 17).



Image 17. "First Christmas"

Velois: *My mother-in-law got us a Baby's First Christmas bib last year for Christmas, which really, um, rubbed me the wrong way because at the time he was intubated by mouth with his mouth taped shut. And the poor little kid looked miserable. And I know she had seen lots of photos of him. And he couldn't eat and he couldn't even drool, so what are you going to do with a bib? ...It just – and I don't want to remember the first Christmas when it was miserable. We were separated.*

Connecting with preterm families also presented problems for these parents. For example, Brandy found that another preterm family could not provide support to Denny and her because it brought back their trauma:

Brandy: *There was, um – there was a couple who we were, um, in contact with through the hospital – another lesbian couple – who spoke with us a couple of times about (name reference). You know, just kind of sharing their experience. And then we actually met – we went out for breakfast one time – one of them was out of town – and we were going to get together with them and, um – but they called us – no, they sent an email and said they just couldn't do it. That like having the contact with us just brought back all of the – the trauma. And we understood.*

Similarly, Brandy found it difficult to provide support later to another parent who had a preterm infant because it was too painful to talk about, even many years later:

Brandy: *We attempted to, um, be in contact with a woman – she was a single mom. And, um, we contacted her, but when it came time to be – actually physically be there for her, we just couldn't. Just, um, that was too hard. I wish that we had, though. I hope that she had a support group. I hope that she had a support group. 'Cause we weren't able to come through. Just – it was too painful. It's still too painful.*

Another barrier to connection and support between preterm parents was the comparison of their infants' growth and medical conditions. If another child was faring better this could lead to jealous feelings, whereas a child doing worse evoked fear. The intensity of feelings and concerns about one's own child left parent's little emotional energy to consider the condition of another family's child. Parents found themselves comparing their child's outcome and status with others.

Denny: *But the family that reached out to us who had had a preemie, um, didn't want to continue the relationship because it was clear that our recovery was going in a different direction than their recovery had gone. And it was still stimulating for them to talk about that time. And so they dropped us because it was too hard to hear about our good fortune.*

Brian: *But for sure if you were comparing and your kids were always behind, you'd probably feel bad about it.*

In summary, parents described prematurity as an experience that began with separation from the infant, but continued as isolation from family and friends long after discharge from the NICU.

Medical knowledge and power

After preterm birth, parenting is constructed and practiced in the NICU under the guidance and control of NICU nurses and physicians (Lupton & Fenwick, 2001). This power dynamic is supported by the authority of the hospital and the expertise of the professional staff. Initially the parents are completely dependent upon the expertise of the medical professionals in the complex care of their fragile infants. This expertise has proven itself through the advances in neonatology which have extended the viability of early preterm infants to increasingly early gestational ages. From a Foucauldian perspective, disciplinary power can be productive and repressive (Foucault, 1977), contributing to the distress that these parents experience. In this study, distress resulted from loss of parenting control and medicalization of parenting,

dominance of technology in the conduct of care and diagnosis, and medical errors. Evidence for each of these effects follows as demonstrated in the transcripts and photographs.

In women with identified risk during pregnancy, the control of parenting behavior began with the woman's restricted activity through bedrest or hospitalization on the antepartum ward. At the birth, the parents had little control over what happened because the providers expedited the removal of the infant for care in the NICU. The woman giving birth had no opportunity to see or touch her infant in the birth room.

Brandy: *I didn't really get to see her. You know? I mean, they took her across the room and started working on her immediately. So [name reference] took a picture of her being carried across the room. But – and then, you know, the baby was gone upstairs.*

Velois: *So, um, the birth, you know, we did the IVs and taking in all the stuff. They gave me a spinal epidural. And then, you know, I didn't – I didn't get to see the baby. They said, "It's a boy," and I was just – you know, I didn't really react. And I didn't get to see him, um, which, was, um, hard. Um, I couldn't see what was going on and um couldn't see anything. So I really feel like I missed his birth. They whisked him away.*

From the moment the infant was 'whisked away' the providers and nurses in the NICU established control over parents' access to the infant. Ostensibly based on the infant's condition, the parents continued to have limitations placed on their contact with the newborn:

Karla: *And some days, they would say, you know, "Well, they had too many A, B, C events today, so maybe we need to give 'em a break and we don't want to have anybody hold 'em at all today."*

Velois: *I guess what was distressing is I didn't get to hold him for the first five days. Um, and then when I got to hold him after that, it was half an hour each day. It was very limited.*

In the context of twins, rules about visitation and co-bedding controlled how parents interacted with the infants. This could make it difficult to parents to divide their attention, particularly when each infant was in a separate incubator or room. Co-bedding of twins was not allowed, yet Melissa noticed that the more fragile twin fared better with close contact. The restriction of

human contact thus was not just between parent and infant, but from infant to infant. The special bond between twins was also disturbed by the routines and practices of the NICU.



Melissa: *So they weren't allowed to co-bed very often, but it was very funny because when they did, their sats would always increase. (Name reference)'s would increase 'cause he was so rocky as a baby, um, as far as his oxygen level and all that. But when he was having a really bad day, if you put (name reference) in there with him, he would even out. It was so funny. I mean, it's – the co-bedding made such a big difference. And they weren't allowed to do it very often. Um, (hospital reference) doesn't do co-bedding at all, and they broke the rules a couple times just because it was the only way to bring (name reference)'s oxygen level up. But it worked. It was amazing...*

Interviewer: *And what – what about this picture, um, represents distress for you?*

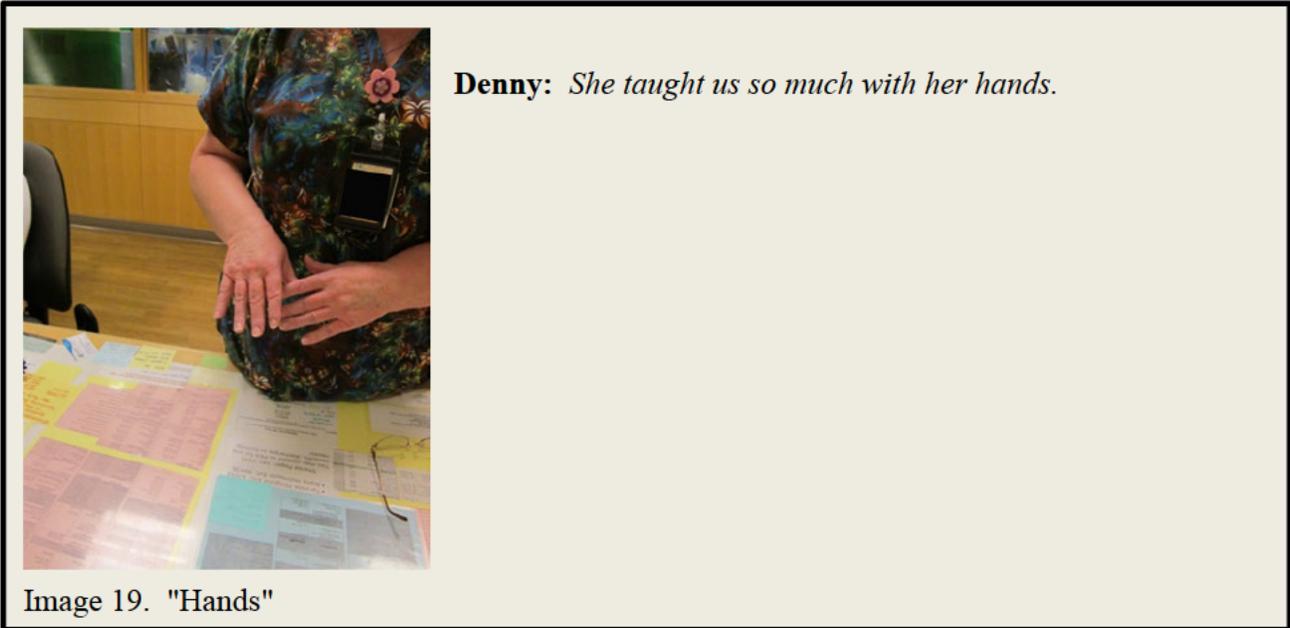
Interviewee: *I guess it's the fact that this is – should have been the norm for them, having each other and being together. And it wasn't. And they were kept apart for so much of their infancy. And they were so much better when they were together.*

Image 18. "Co-bedding"

As parenting behaviors such as holding and touching were restricted by the NICU staff, these behaviors were replaced with medical activities. Parents' involvement was reduced to physical care, such as diaper changes, weight checks, and feeding. Parents felt learning these instrumental activities in the NICU prepared them for home care and were grateful for the instruction.

Denny: I mean, obviously, they were great technically with the babies, but they were so gentle with us... And, um, just really great about teaching us how to, um, learn how to care for [baby's name] when she was so fragile. And I feel like that model has continued for me through her whole life.

Brian: And it was kind of a blessing in disguise just having someone taking care – teaching the ropes and taking care of the kids. By the time they got home, it was no problem for us to, you know, every other – do every other feed, getting them up every couple hours for that stuff. We were kind of used to all that by being around them for so long in the – in the NICU.



Nurses were similarly elevated to a heroic status, for performing activities that saved the baby before or after the birth. This facilitated their achieving credibility and to become seen as an expert by parents.

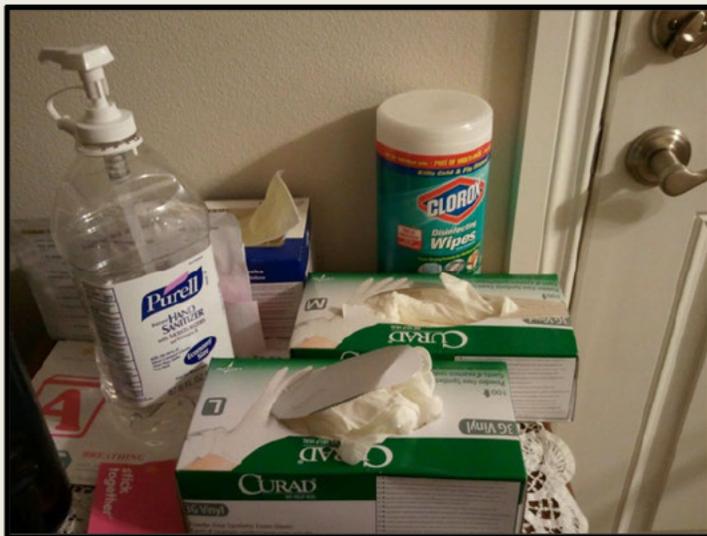
Brandy: the next thing I know, there was a nurse there. And I already had my IV. And, um, I think she had blonde hair and I think she was really pretty, but to me she looked beautiful because she was giving me something that was going to save my baby – that’s going to make me not push. And just like before she like pushed the plunger home, I said, “I love you.” And she said, “I love you, too.” (Laughter.)

Similarly the care of infants has been overrun by equipment such as monitors, incubators, and pumps, with less attention given to human touch. Thus, as demonstrated earlier, nurses would restrict human touch such as skin-to-skin care from concern that it would be stressful for the infant, even though research and the parents’ own experience demonstrated otherwise.

Denny: *Like having this preterm baby and having all these machines (laughter) take care of the baby and all this technology take care of baby, um, (pause) made it easier for me personally.*

Nurses had skills to teach parents such as holding, diapering, and bathing, but this reduced parenting to a set of tasks. Parenting is a socially constructed activity that is culturally determined and learned from family and friends, and is practiced and developed in the home. By learning parenting in the NICU, these parents were at risk of medicalization of their role.

The replacement of parenting with medical tasks was particularly evident in the families that had ongoing issues after NICU discharge. The needs to maintain home oxygenation, feeding tubes, or tracheostomy care put demands on parents to become quasi-nurses. This also turned the home into a medical environment. Many of Velois's photographed showed the medical invasion of her home, beginning with hand sanitizer, gloves, and masks at the front door:



Velois: *It's just sort of interesting clutter around the front door. I think the hand sanitizer will be there for some time. Um, it's kind of – you know, we're in the habit now, so I don't – I don't mind, but it's still kind of like you're coming into a medicalized place a little bit.*

Image 20. "A medicalized place"

The medicalization of the nursery was also evident by emergency airway management and CPR instructions, cabinets full of medical supplies, and oxygen tanks in the closet. Parents were given extra training by nurses in order to assure safety in the home before discharge:

Karla: *I felt like one thing the NICU gave me was I became – I was like a trained baby nurse. So I knew exactly how to take care of them. My son came home. Um, he still would have issues with, um, bradycardia when he was feeding. So he would stop breathing. And they came home when they were thirty-six weeks gestation. And so he would stop breathing, um, a couple times during – in the NICU, um, and it scared the NICU staff enough that they wanted me to have CPR training. So I took the baby CPR training, and I was the only one that could feed him ‘cause I could recognize when he would basically stop breathing.*

Thus Karla incorporated the nurse role into her home parenting. Illness care activities were time-consuming and left little time for Velois to nurture and interact with her infant:

Velois: *Sometimes I feel like I spend all my time nursing him and I don’t get a chance to like read him books and be his Mommy and just cuddle because I’m like filling a feeding bag, mixing this and checking that. You know, fixing his cuff, and you know, there’s just so much nursing work to do because the nurses aren’t there all the time... But we’re nurses, though. And my calling isn’t to be a nurse. It’s to be a mommy.*

Parents also found themselves engaged in activities that were painful or distressing to their children.

Melissa: *Oh, it’s awful. It’s so sad. And they’re looking at you like, you know, you’re supposed to be protecting me. And, yeah, we had – there were several instances, you know, in addition to this where you had to be the restraining – you know, doing awful things to your children, which is terrible.*

Velois: *But shoving a tube down your child’s nose without anesthesia when he’s just like gagging and you’re crying -- like why are you doing this to me? And you’re holding him down. God, it’s so brutal. You know then you’re taping his face. That’s hard. And, you know, the more we do it, the more it causes an oral aversion because he has these negative experiences in his face.*

Another way that medical professionals exerted disciplinary power on preterm parents was through diagnosis. The power to diagnosis is a gateway to decision making, treatment choices, and long-term consequences. Karla’s and Brian’s twins experienced significant gastric reflux, feeding difficulties, and poor weight gain. The struggle to feed the twins culminated in an emotionally devastating diagnosis, as described in Image 21.

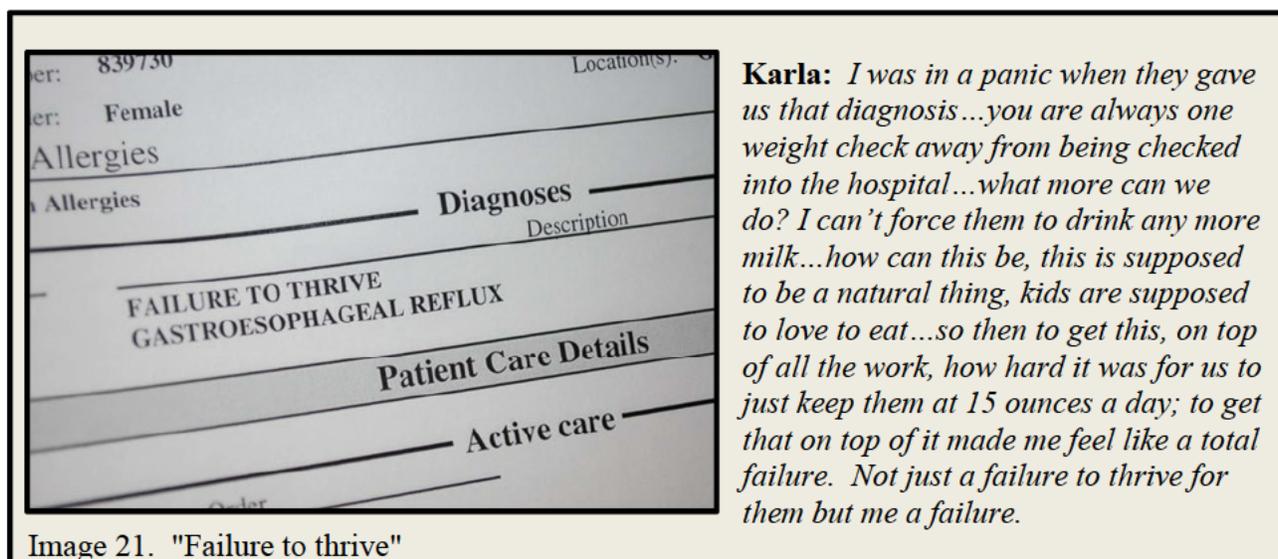


Image 21. "Failure to thrive"

A diagnostic imaging evaluation in order to determine the cause of the reflux exposed another problematic confrontation around diagnosis. Evaluations in the office captured a short moment in time, for which children and problems did not behave as they did in the home environment. A mother's experience and knowledge of the day to day problems was discounted by the technology and expertise of the physician:

Karla: *You know, like all the tests and everything, they're – they're great, but they can only test for the exact moment when something happens. And it was so frustrating to me like during the study that my kids were suffering from really severe reflux. And they didn't really reflux at the moment that the tests were going (laughter), um, and so it was really hard to be able to – you know, you wait so long to get an appointment, and then you wait so long to get the results. And then like the – you know, the maybe fifteen minutes that you have in that appointment room, it just – like you just never – you don't get what you're trying – what you're hoping for. And then you tend to get dismissed. And it's like I almost felt like the doctors would just – they just wouldn't believe – they wouldn't believe what we were talking to them about. And I felt very – very dismissed a lot. So this is just like looking through some of their patient records and just looking at some of what they wrote. I mean, they did see things, but not what I saw at home.*

Along with the power to diagnose came the power to do procedures. The decision-making that came with procedures was a contested space between parents and medical professionals. This included who will do the procedure, when it will happen, and whether parents even need to grant permission. Soon after the birth of his twins, Jay had consent forms thrust at him to grant

permission for blood transfusions. He was in no frame of mind or having the knowledge to consent to such procedures:

Jay: *And, you know, three or four hours later, we had twin boys, and they were in the incubators. And it was – it was hard. I mean, we didn't really, um – I mean, we were making decisions. Ah, they had so many blood transfusions that I was signing paperwork left and right. And it was just kind of – you know, like literally, I went to work that day and had no intention of having kids that day. And then, you know, you're – you're signin' papers goin', "I have no idea what's going on."*

On the other hand, Velois felt the desire to be involved in all decisions as a fully informed member of the medical team. She felt her position had legitimacy from her advanced education and her husband's medical knowledge:

Velois: *I got in a big fight with the head of the NICU 'cause I'm like, "I want a real – I want a real attending to do this. I don't want a resident practicing on my baby." And he's like, "Well, the next generation needs to learn." Blah, blah, blah. We really went toe to toe on that because, um, a couple of times, he just said, "Look, you're not part of the medical team." And I'm like, "Like hell I am. I am part of the medical team. That's my child." You know? "My husband's a [occupational reference]. Like I'm an Ivy League graduate. Like, you know, I'm not going to just sit back and let you decide everything." And he said, "Well, you signed the consent to have him treated here, and so therefore you signed away your rights." So he kind of said it's like the Jehovah's Witness law, you can't withhold blood. You know? Like I'd come in in the morning and they would have done some procedure without my consent. Like they made his feeding tube from an NG – a nasogastric – to a nasoduodenal – ND.*

Velois was able to exert more power in medical decision making once her infant son was discharged home. This included progressively weaning him off oxygen and the ventilation, and changing feeding from continuous to bolus feeds. Her success at managing these transitions vindicated her parental knowledge. This also demonstrated that medical power was place dependent; that the medical professional's "ownership" of the infant occurred in an institution and not in the home environment.

Velois: *We also had to take care of things in our own hands. The doctors had him on a continuous drip until August. So almost the whole first year of his life he was eating continuously. And I just said, "You know what? Mommy's instinct. We're switching to bolus feeds. He needs time to empty out. His stomach needs a break." And that really*

helped. We didn't even have an order for it. We just kind of went rogue and we're like, "We're doing this. I don't care."

It was easier to challenge the physician's expertise in the home because constant surveillance was not possible as it was in the hospital. Nevertheless the power of the medical practitioner reached into the home and it took an act of resistance to make the change in the feeding schedule. This level of assertiveness may not be available to others families with less education than Mike and Velois.

During the preschool years, Karla worried that her twins would have developmental delays. She remained vigilant for signs of problems. At one pediatric visit she commented how her son did not alternate his feet when going up and down stairs. When the physician saw this as a red-flag for a neurological problem, Karla was distressed by her own failure to anticipate and detect this problem. She saw her role as a parent to include this level of expertise. Thus medical care invaded her parenting role in both the expectation of this type of knowledge, and the hyper-vigilance required to detect any problems as they presented. The pediatrician's diagnosis highlighted Karla's failure to detect and diagnose. Ironically the concern was unnecessary because he later developed the ability to alternate his feet on the stairs.

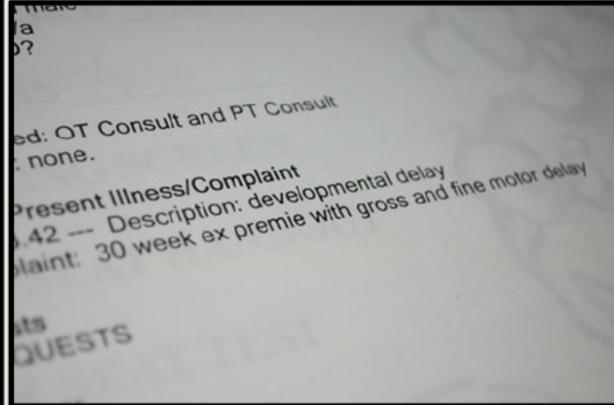


Image 22. "Red flag"

Karla: *when we got this little note, I remember feeling, um, I can't believe I missed – that I missed that. Like I've been watching them like a hawk, looking – like every single thing that they've – you know, the checklist and everything, like I've – like I would just like study them and like be very aware. Always in tune with like are there things that they're not doing right or that they should be doing better? ...like that doctor appointment where she said like that was a huge red flag, that was a total shock to me. And I remember coming home and I was so mad at myself because I felt like I had missed – like there was another thing I missed.*

It was not surprising that participants identified medical errors as part of their distress after premature birth. Given the prevalence of medical errors (Institute of Medicine, 1999), a prolonged hospitalization in the NICU would make an error inevitable. Three of the four couples reported medical errors as part of their distress. These included opiate overdose; life-threatening arrhythmia from improper PICC line placement; failure to use analgesia for PICC line insertion; and setting ventilator to adult settings after a safety check. Situations such as these challenged the disciplinary authority of clinicians and by extension the institutions involved. The parents, already under significant distress from preterm birth, were left with increased distrust of medical professionals, sadness about the child's unnecessary pain, and the trauma of near-death experiences.

The literature on medical error has identified the importance to patients and families of proper disclosure in restoring the trust between patients and families and the health care team (Iedema et al., 2011). The distress parents felt after medical errors was compounded by a delayed and appropriate disclosure of the error by those involved.

Velois: *Oh, here's something that, just talk about distress. A new nurse tried to do a PICC line, forgot to give him anesthesia first. Forgot to give him numb it up. Fumbled around and screwed it up. The next day, he was just crying, crying, crying. What's wrong with him? And finally, two days later, another nurse told us what had happened overnight. And no one – they'd forgotten to tell us. Oh, my God.*

Thus Velois experienced three-fold distress: her infant son experiencing additional pain, uncertainty about why he experienced pain, and the subsequent loss of trust. The possibility of future errors places an additional burden upon parents to be vigilant, despite the lack of necessary knowledge to do so.

Melissa: *while we were there, he, um, was overdosed. So then he got really sick and almost died... So the two hospitals use different pain medications. One uses Fentanyl and one uses morphine. And so when we went to the other hospital, they switched him from Fentanyl to morphine. And I don't know why because that's just what they use. But they don't have the right dosages for one-pound babies. Like it's just not figured out. And they ended up giving him too much, and he crashed. ...It's so frustrating. And it's hard because when you don't understand the medicine and what the mistake is and how it happened and who's fault it is, you know, it's hard to know where you can be an advocate and how to be an advocate when you just don't – you know, you don't have that background.*

Early during the hospitalization of Brian and Karla's twins, the neonatology team attempted to insert PICC lines into both of them. After waiting a longer than normal amount of time, they heard that the team had difficulties placing PICC lines in both infants:

Karla: *And then an hour-and-a-half later, the neonatologist comes in and said, "Well, ah, we tried putting a PICC line in your son and it wouldn't take for whatever reason. Like we just – every time we would try it, it wouldn't work. So we just gave up on him, and then we decided to put one in your daughter. So we put the PICC line through and we gave her the x-ray, and everything seemed fine except that her heart rate went from 120 beats per minutes to 250 beats per minute and she went into atrial flutter, ...And their transport team is like on their way and you're going to (hospital reference)." So I was like – I remember thinking like I don't know what you're talking about. Like I don't understand. What do you mean? Like aren't you a Level 3 NICU? What do you mean we're going someplace else? And we have twins. You're going to split us up? ...But, um – and it turned out that the PICC line was too close and it did cause her to go into atrial flutter, but once they pulled it out it was fine. And so thankfully, she didn't have to – there was this medication they were going to give her that could've killed her.*

Karla's distress included a long wait before notification that both procedures had failed; emergency transport of one twin to a referral hospital resulting in further separation of the family; a near-fatal cardiac event caused by improper placement of the PICC line; and the realization that the highest level of NICU care was not enough. Brian's version of this incident had the additional detail that a student nurse was involved in the incident. While the nature of the student's involvement in the error was unclear, it indicated their sensitivity and ambivalence about the involvement of trainees in the care of their infants.



Velois: *Okay, this next one's the actual ventilator. Um, we've got two of these in our house. This is using up our corner – decorating our living room. He's no longer on it. We keep it just in case. Um – um, it's interesting. I want to tell you an interesting story about the ventilator.*

Image 23. "An interesting story about the ventilator"

Medical errors were not confined to the hospital. Velois and Mike's son was discharged home on ventilator support, and a near-miss happened when the Respiratory Therapist did a home visit for an equipment safety-check on the ventilator shown in Image 23.

Velois: *One day, the RT tech showed up with no appointment. My husband and I were both out of the house. This woman didn't know what she was doing. Supposedly doing a vent safety check and almost killed him. She accidentally reverted back to factory settings and left it on adult settings. And luckily he was on a vent break 'cause we were working on weaning. And our best nurse was on duty. Right before she hooked it back up, she glanced over at the screen*

and realized the settings had changed. She didn't hook it up. He would have a bilateral – ah, what's it called? A pneumo –

Interviewer: *Pneumothorax?*

Velois: *He would have blown up – both lungs. He might not have survived the ride to the hospital 'cause he didn't have any reserves. If they'd blown up both of his lungs, he would've been right back in the ICU for months. That would've been horrible. We'd made so much progress. I was livid. And this was a supposed safety check, and like what did they do? They came and screwed up the machine, almost killed my child.*

As a consequence of this incident, Mike and Velois became even more vigilant in the home, more restrictive on visitors, and more worried about intrusions and dangers. This further reinforced Velois's need to function as a health care provider for her son, rather than as a parent.

Velois: *Suddenly, I'm like a nurse and RT, not by choice. It's interesting. And obviously though, if someone comes out to the house and you know more than them, that's – that's problematic. (Laughter)*

As a result of this incident, Velois and Mike barred the home medical agency from returning to the home for safety checks. This demonstrated how medical errors can deteriorate cooperation between families and health care providers and the importance of restoring trust after error.

Distress as pathology

Some of the participants had been diagnosed with a psychiatric condition, yet psychiatric illness took a minor role in their explanations of distress. Further, none of the photographs selected to represent distress referred directly or indirectly to mental illness or symptoms. Their entire focus was on their children and they had no capacity to consider their own emotional needs. They explained any psychiatric diagnoses as natural consequences of their traumatic experiences or as preexisting conditions not relevant to the prematurity experience.

Both Karla and Melissa described the importance of remaining in control and vigilant while their infants faced ongoing significant medical issues. They did not allow themselves to feel or express their emotions because the circumstances required them to focus on the infant.

Melissa: It just didn't really occur to me. I just – I don't know. I didn't – I don't know why. I think I just really wasn't like psychoanalyzing myself or anything. I just was kind of in la-la land when it came to myself. I was just really focused on everything else.

Karla: So, um, 'cause all the time I'd been nice and numb. And like just like nothing bothers me. Like this is just like I was like Ms. Stoic like everything like just, you know – like the best way I can explain it is like you're in a tunnel and you are like desperate to get on the end, and you just focus every piece of your body and your soul to get to the end. And you just focus on that.

Only when they were able to focus on themselves did they accept help for themselves through medications or counseling.

For other parents, psychiatric diagnosis was dismissed as a preexisting condition or a character trait that existed in the background. For them it was not a significant aspect of their distress after preterm birth. For example, Denny described herself as anxious and self-medicated with St. John's Wort. When she found a professional to talk to it was for help in handling a stressful situation and not because she had a pathological condition.

Denny: But so far I don't have a diagnosis.

Interviewer: And do you feel like you need one, or do you feel like you're okay with not having a diagnosis?

Denny: (Laughter.) I'm fine with not having a diagnosis...I'm not really a person that handles a lot of stress well. Like I'm a very like anxious, nervous kind of person. So –

Interviewer: So it's just a way that you are and not necessarily that you're – that you have a problem or you're sick.

Denny: (Laughter.) Yeah. I guess. Yeah. I've always had a really good startle reflex.

Brandy had depression before the birth and it remained in the background throughout the experience and did not enter into her account of distress after premature birth. Continuing on her antidepressant medication was important to maintain equilibrium and get through the normal postpartum fluctuations.

Interviewer: Do you – um, did the birth or the time in the NICU impact your depression? Or –

Brandy: No, not really. Ah, I think that continuing on the medications, um, was wise. I realized that that was not the time to come off. So, um, no. Ah, you know, I – I knew that all the feelings that I was having were to be expected and that there was going to be some – some postpartum stuff going on. I mean, I was like in a maelstrom of hormones. And, you know – and there wasn't any – um, so no. It didn't really. I just knew that it was just my body doing its thing and just releasing – um, basically just getting back to center. So –

Interviewer: So what you were going through was normal?

Brandy: Yeah. What I was going through was normal. Yeah

Psychiatric diagnoses had positive and negative consequences for parents. Karla was comforted by PTSD because it provided an external cause for her emotional reactions. PTSD as a consequence of her traumatic experiences with preterm birth was justifiable and did not reflect negatively on her as a person or define her as 'crazy'.

Interviewer: *So when she diagnosed you with PTSD, did, um – did it feel good to have a diagnosis?*

Karla: *Ah, yes, actually it did. Because I remember talking to her and saying, "All I want is people to understand what I'm going through. And I just want somebody to know. I want – I want somebody to understand the terror and the horror of everything, and not think I'm crazy." ... I just remember when she gave me that diagnosis, I felt like I could put a name to it, or I could just – it was better than saying I'm just crazy and just calling it like crazy. ... And I felt like I wasn't crazy. I just was suffering from anxiety from this PTSD. So it felt good to actually be able to say like, okay, that's, you know – it's a result. Like it's a label as a result of the traumatic experience versus it's just a personality like a crazy, you know, personality like character thing.*

Nevertheless, the diagnosis had consequences for her friendships. The diagnosis of PTSD was the "last straw for them on the camel's back" and resulted in losing some friends who were scared. Because the diagnosis "defined my crazy", her emotional reactions became too real for some friends. Similarly, Velois found it hard for others to understand what she was going through:

Velois: *And I'm still traumatized. I have trouble sleeping at night because of the PTSD, and I still dream about those things that I saw. And that's hard for anyone else to understand.*

Thus the PTSD was another piece of the distress that was hard for others to understand.

Aim 2: Incorporation of photo-elicitation into discourse analysis

This study provided ample opportunity to evaluate the feasibility, benefits, and challenges to the incorporation of photo-elicitation methods into discourse analysis. Most of the participants found the photo-elicitation assignment and interview acceptable, with two exceptions. Reasons for non-participation included a lack of time and discomfort with the implications of photographing distress. Nevertheless, there was an eagerness to participate by most of the participants, a drive to share their story through photographs. The use of photo-elicitation enabled participants to engage in their accounts in new ways, including locating their distress in space and time, use of visual metaphors, and reappraisal of past images.

The intent of the photo assignment had been for participants to consider their distress after preterm birth and use those reflections to generate new photographs representative of that distress. Instead many participants reviewed existing photographs from the life of the child as a memory aid and selected those that represented their distress.

Jay: *I was just kinda goin' back in and – and looking at, um, just all the old pictures. ... So it's kinda more like, "Oh, yeah. I forgot about that." ...It was just one of those memory lane type of deals.*

Brian: *The main things were looking back at an old photo album and seeing the weight thing, and then just kinda the – more of the pictures of my hands around the kids 'cause that put it back in perspective of how – how small they were.*

Denny returned to the NICU to take new photographs that helped her remember her family's time there. Even though her photographs were new, Denny used them as a stimulus for review

and recollection in the same way that Jay and Brian used old photographs. Jay also took some new photographs, but they represented an idea he already mentioned at his first interview – the financial distress from receiving large medical bills in the mail, as shown in Image 11. Thus participants found two ways to engage in the assignment to represent distress in images – by using feelings of distress to suggest photographs, or the opposite, using the photographs to suggest the feelings of distress. Either way, the photo-elicitation interviews further illuminated the discourses of distress for these parents.

The reflection necessary to complete the photo assignment was not without challenges. Denny acknowledged that the process was difficult.

Interviewer: *And how does it feel now to look back at a picture like this?*

Denny: *Well, I have to say the, um – the experience of, um, reviewing past trauma is actually an unpleasant one.*

Brandy's discomfort with the assignment went so far that she did not participate. She did not want to document how her distress was embodied in her daughter.

Brandy: *So – so if I would've brought a picture, it would've – would've been of her. And I just felt very odd and just very superstitious about, ah, taking a picture of her in this regard.*

By selecting photographs which represented distress, participants contemplated the connection between images, words, and meaning. For Karla, this was a struggle because she did not want the meaning to be lost if the words somehow were separated from the images.

Karla: *it's hard to put emotions into let alone just words, like typing it out. But it's hard even to explain it verbally to somebody. Like just explain, you know, how you're feeling. But it's so hard to just, um, take a photo and then hope that that photo – because you – with a photo, what's hard is you don't know – like there's an explanation that could become detached from that photo. And sometimes a photo is meaningless without that explanation. And so it was really hard to try to think of a way to take a photo so that the meaning would somehow become – would be intact.*

This demonstrated the importance of photo-elicitation in generating meaning. The photographs did not stand alone as data and required the connection in the second interview to participants' accounts.

One way that the photographs illuminated the discourses of distress was by placing the distress in specific locations such as the hospital or home. For example, Jay and Melissa identified the large giraffes in the lobby of the tertiary care center as distressing, because the twins transferred there for surgery. Although the giraffes, shown in Image 24, were intended as a playful focus to distract distressed children, they had the opposite effect on Jay and Melissa.



Jay: *And I just remember seeing those all the time and walking by 'em goin' (laughter), "I hate those stupid giraffes." Every time I walked by 'em, I'm like, "I hate those things." 'Cause we were there so often, it's just nothing – no real good memories came from seeing those. 'Cause you'd walk by 'em every time you went there."*

Image 24. "Those stupid giraffes"

Velois used photographs to locate her distress in the home, focusing on how her home was overtaken by medical supplies, oxygen tanks, and ventilators (Images 20 and 23). Even though the instructions for the photo assignment asked participants to avoid photographs with identifying features, many photographs included the child (Images 1, 4, 6, 8, 12, 13, 18, 26, and 27). Placing the photographic representation of distress in the child showed how personal the

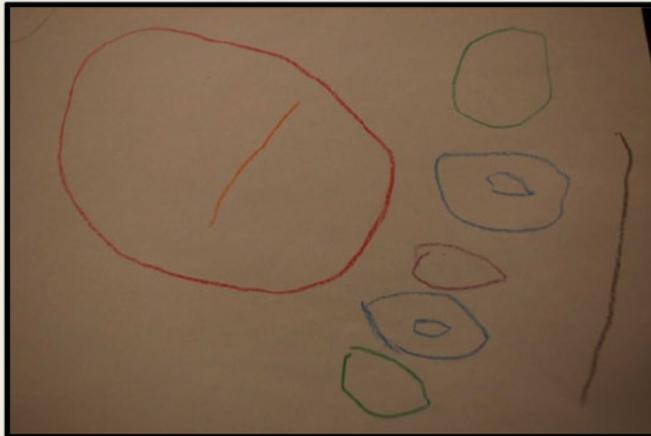
distress had become. For Brandy, the connection between the child's image and her distress upset her enough to prevent her participation in the assignment:

Brandy: *oddly enough, looking at my daughter reminds me of, um, everything. And so it's like most days when I look at her, um, it's – I'm reminded of what happened. From where she came, where she is now. And so there's worry and anxiety there, you know, that this is just so fragile. That even though she's almost eight, that anything could happen. And I know nothing's going to happen, but – you know, intellectually, but – so I – I still have so much worry about her... So – so if I would've brought a picture, it would've – would've been of her. And I just felt very odd and just very superstitious about, ah, taking a picture of her in this regard.*

Distress became tangible in these images and a conduit for explaining and demonstrating the distress that these parents felt.

Parents used visual metaphors as a strategy for making their distress understandable to others. For example, Karla chose a picture of an educational assessment, in which her child was given verbal instructions to draw circles and lines in order to build a face. While he was able to draw the individual elements, he was unable to meet the objective of building the parts into a meaningful whole (Image 25). While at one level this image represented the school challenges for this child, it became a metaphor for Karla's emotions. This demonstrated a strong connection between what her child experienced and produced and her feelings of distress as a parent. For Denny, walking in the woods was a vivid metaphor for a child strong, confident, and unencumbered by her preterm birth at 25 weeks gestation (Image 8). For Brian, the distress of prematurity was represented by his wedding ring, larger in diameter than his twins' limbs (Image 2). Size represented health, and he demonstrated their recovery through photographs showing how the ring had diminished as his children grew. The wedding ring reminded him of his preterm infants in the hospital while he was at work, which reflected the importance of his role in the family as husband, father, and provider.

Karla used other metaphors that she did not photograph. These included waiting for the next shoe to drop; the journey through a long tunnel; feeling like an emotionless robot; and separation at birth like cutting the strings of a strand of balloons. Denny also mentioned a



Karla: *when I saw his picture, it just made me feel like – it just was a very big – it was a very visual representation of how I felt (laughter) actually. Like all the parts are there, but they're just not – it's wrong. It doesn't matter. You can have all the parts there, but it's still wrong. (Laughter.) Like it was so frustrating to me to see him – like to see that he had been trying so hard, too, and that that was his very best and yet it's still wrong... like that picture actually really like depicted how I felt.*

Image 25. "It's still wrong"

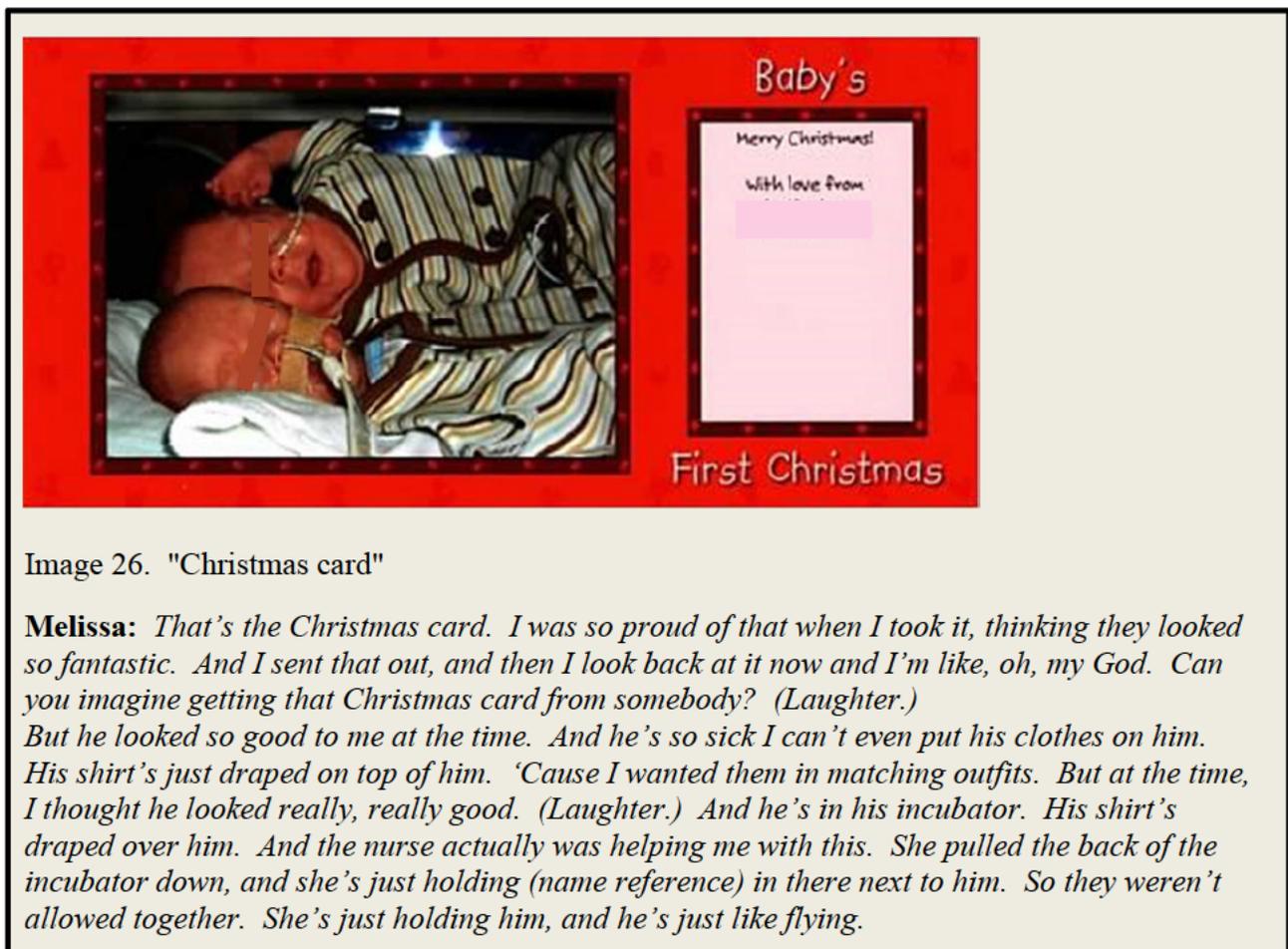
metaphor she did not photograph, the children's story *Flat Stanley* (Brown & Ungerer, 1964) which told the story of a flattened child who was restored with a bicycle pump. This became a metaphor for surfactant inflating her daughter's lungs:

Denny: *[Name reference] was reading Flat Stanley in the car on the way over here. And she could just – she's reading it for her – her reading level at school. And she was just at the end of the book where, um, his brother Arthur pumps him up with a bicycle pump, and his right foot stays flat and, um, he has to get pumped up. And like [name reference] and I talk about, you know, like the miracle that there was surfactant, you know, synthetically produced when she was born so that, you know, her lungs could be inflated and she could breathe. And – and I think she did have assistance to breathe, um, early on. And, um – and she was reading aloud to me, and I had this urge to like, you know, jump in and talk about the surfactant again.*

Because these parents were interviewed long after discharge from the NICU, they had the opportunity to look back across time at the birth, hospitalization, and early childhood. Photo elicitation facilitated this process because it involved three steps: reviewing or taking photographs; selecting which photographs to include; and telling the story of each photograph at

the interview. Parents' inclusion of old photographs provided an opportunity to reappraise photographs with a new perspective. Melissa found that with time, what had been a cute photograph of her twins' first Christmas (Image 26), was now representative of illness and distress in a staged photo.

Melissa exposed the artifice of the photograph in showing a staged togetherness of the twins. The meaning that she attached to the photographs changed over time from celebration to horror at their condition. Thus in her narrative of the prematurity experience, Melissa not only accounts events along a time continuum, but a changing perspective. This changing reality was elicited by her review of the photographs. The photographs did not tell a story by themselves – Melissa interpreted them and used words to convey the meaning.

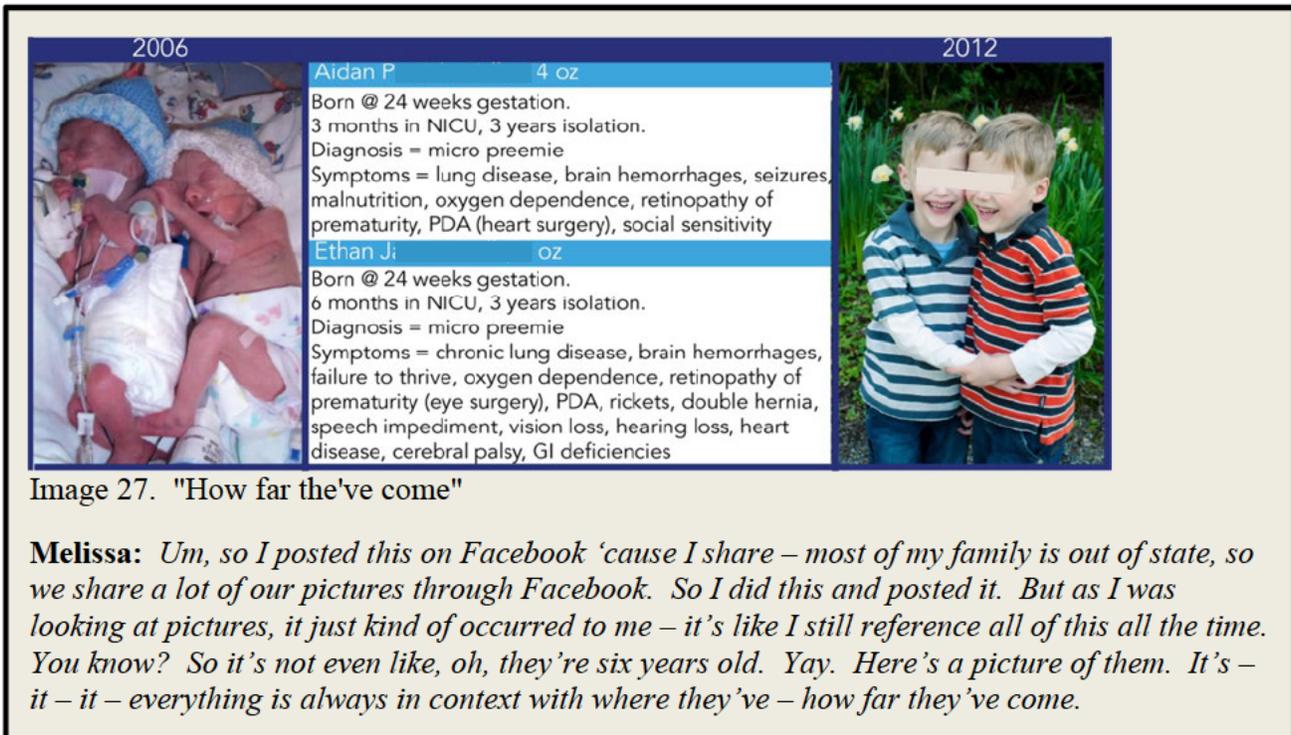


Looking back over old photographs also allowed Melissa to consider her twins' development as a long journey with ongoing challenges. The photographs as a complete set represented a timeline of struggle and new challenges:

Melissa: *I think for me the distress mostly came from the length of time. Like we expected, you know, first just get through, you know, twenty-four hours, forty-eight hours, seventy-two hours. Then it's a week, and two weeks, and a month. And then it's just home from the NICU. And then it's just get off oxygen. And then it's just get through this next phase. And then it – you know? And it's like you just kinda keep setting these milestones, waiting for it to be over. And it's not over. So for me – and I think that's why I picked so many pictures is just to show that it's – it just keeps going. And when you think you're over it, you just don't know what that next step is. You know? Um, so I think if I could show anything, it would be a real timeline of, you know, actually lining 'em up and just showing at every age there's always something. And it just keeps going.*

Photographs also provided Melissa the opportunity to show how far her twins had come in the six years since their birth. She posted a birthday announcement on Facebook showing the twins then and now, with a list of all the health challenges they had overcome (Image 27). Melissa reflected on how their adversity at birth had become part of their identity as children. While this birthday announcement was triumphant, there were shadows of sadness, in that Melissa has not let go of the trauma, even after six years. Their successful development is implied in the photograph, while the past troubles dominate.

The record of a baby's first year is commonly recorded in albums or diaries. This chronicle of milestones is part of the family and child's history, and becomes a reference for the child when he or she grows up and can look back on a part of life that he or she cannot remember. This practiced form of storytelling may be problematic for preterm parents, due to



the traumatic nature of the early beginning. One of the photographs Velois wanted to take, but didn't, was an empty baby book.

Velois: *But we had a baby book that someone gave us. It's empty – the whole journal. Because it starts with like week one and month one and month two. And like when is that really? You know? Like when he's three months old, but he's really a newborn. And, you know, they're talking about milestones, and it's just too depressing. They had a whole page like the night you were born. And I'm like I can't write about this. I mean, maybe I will, but it just – it seems like it's supposed to be happy memories and I'm like it was the worst day of my life. You know? (Laughter.) You know? He's going to read this some day and cry, so we haven't even filled it out, any of it. Um, I mean, he's been well photographed, so he'll still have those memories.*

The baby book remained empty because it failed to acknowledge the ambiguity of the preterm infant's age; milestones not achieved at the expected age; the trauma of special moments like birth; and concern that the memory book may upset the reader. This was a problem that went beyond the literal problem of the baby book, which served as a metaphor for the acceptance of

the prematurity. There was the need to acknowledge and celebrate, but how could this be done when the circumstances were so painful?

There was a difference in how participants approached their narratives between the first and second interviews. In introducing the first interview with a question, “tell me about the birth of your child...” the interviewer introduces the time element as an organizing structure for the interview. Thus participants began with a timeline, although the structure moved toward a structure focused on distress. For some, further details were elicited by other questions in the interview guide (Appendix E). For others, the interview moved forward with little need for the interviewer to use the guide or ask questions. In the second interview, however, the narrative was driven by the photographs and how the participant organized them.

Summary

The eight parents interviewed in this study presented a range of experiences of preterm parenting. For all of them, this was their first experience as parents, and the premature birth was unexpected. A common experience was the fear of death – will my baby survive? For some this fear was revisited with “call backs” at night due to worsening condition, or transport to a hospital with a higher level of care. The existential crisis for these parents served as the context for their distress and set the seriousness of the ongoing crisis for them as parents. As they grappled with their lives in the NICU and at home, parents utilized five discourses to talk about their distress: five discourses: the *perfect child*, the *good mother*, the *good father*, *isolation*, and *medical knowledge and power*. The construction of their distress was complex, often utilizing multiple discourses.

The discourses were found to work together in generating distress for these parents. For example, breastfeeding became a source of distress based on the *perfect child*, the *good mother*,

and *medical knowledge and power*. Breastfeeding was part of the idealized postpartum experience, was what good mothers did for their infants, and was supported by healthcare providers. Another example was actual or feared diagnosis of developmental delay was distressing because of *medical knowledge and power* and the *perfect child*. Healthcare providers or educators, in their capacity to diagnose difference generated distress in parents who feared that this would make their child imperfect. If this had been approached in a way that highlighted the continuum of normal child development perhaps the parents' distress would have been reduced.

These discourses placed parents in difficult and unexpected positions. The sense of loss from not achieving a normal, term birth drove some parents to desire to try again for a term pregnancy. Partners did not necessarily agree that the goal of a normal birth justified the risk of another preterm birth and all of its consequences. Mothers exerted heroic efforts to become perfect mothers, including pumping their nipples raw, living at the NICU, and challenging medical authority in order to protect their infants. Fathers suppressed their emotional reactions to the prematurity in order to remain strong for the family, and threw themselves back into their careers in order to provide. The failure of outsiders to understand the prematurity experience positioned parents as ambassadors, teachers, and advocates for their children. Notably Karla and Melissa continued to advocate by returning to the NICU to volunteer with other families going through similar experiences.

The medical power exerted by providers and nurses was a major source of distress for these parents. Conflicts over medical decisions, controlling behavior in the NICU, feeling dismissed in the doctor's office, and the dominance of technology in caregiving all contributed to their distress. Diagnoses, or the possibility of one, could be devastating in their impact.

Milestones defined a range of normality which did not necessarily apply to the preterm child.

This discourse positioned parents to advocate for their infants within the health system, to assert their position as parents, and to be hyper-vigilant for the child's health and development.

Under all these circumstances, it was a natural, normal reaction that these parents would experience distress. When this distress contributed to the development of psychiatric illnesses such as anxiety, depression, or post-traumatic stress disorder parents constructed them as natural consequences of their extreme experiences and less important than the causes of the distress.

Photo-elicitation provided an added dimension to the findings of this study and was acceptable to most parents. The conversations about the photographs helped the parents convey the depth and complexity of their distress. The method provided a tangible means for parents to look back over the prematurity experience, and to place their distress in physical space, locations, and in persons. Selection, appraisal, and telling were important steps in the generation of meaning from the photographs.

This study has implications for education, practice, policy and research, which are discussed in the next chapter.

CHAPTER FIVE

DISCUSSION AND CLINICAL IMPLICATIONS

The purpose of this study was to understand how parents talk about their distress after preterm birth. These constructions of distress showed how difficult the experience was, and how it affected their identities as parents, concepts of the normal child, and interactions with the medical system and personnel. These parents faced significant challenges to their transition to parenthood and parenting during early childhood after preterm birth. Participants identified the need for greater social support, as this was challenging because their childbirth and early parenting experiences were so different from the typical parent after term birth. The implications of the study findings are discussed below with a focus on education, practice, policy, and research.

Education

This study highlights the need to educate the public on the unique experiences of preterm parents and how to best support them. Participants in this study identified ways that friends and families can better support them through the difficulties of prematurity. Although it can be uncomfortable to face the uncertainty of preterm birth, it is important for friends and family to not withdraw their support. From the outset, they can express congratulations and concern about the welfare of the infant. While it may be tempting to offer reassurances such as “don’t worry, he will be fine” this may discount the parents’ well-founded feelings of worry and fear about the infant. Instead, family and friends should acknowledge the parents’ worries without trying to fix these normal and justified expressions. Instead, family and friends may offer support by volunteering to do chores or prepare meals in non-returnable containers. Gift certificates are the best form of gift because routine gifts of clothing or nursery equipment may be unusable,

inappropriate, or remind the parents of what has been lost. A close friend may serve as a conduit of information to the broader social network and organizer of the support offered, so that the parents need not explain repeatedly the status of the infant. Internet social networks such as Facebook may assist with these tasks. When the family is active in a church, religious, or other social organization, enlisting their support throughout hospitalization may be helpful.

Despite the high rates of prematurity and infant mortality in the United States prematurity is poorly understood by the general public. Much work needs to be done to heighten awareness of this problem and to provide information about the short-term and long-term impact on families. Otherwise, the expectation for normal, term birth will continue to prevent adequate support at the individual and policy level for this most significant problem.

As part of their education, nursing students and APRN students should have didactic and clinical experiences in caring for families facing preterm birth. This education should include grief and loss, communication skills, and facilitation of family presence at resuscitation (Kantrowitz-Gordon et al., 2012). Simulation can be a helpful adjunct to clinical experiences as a way to build confidence and to assure exposure of students to clinical situations that are less common. Involvement of students and trainees in preterm infants care in the NICU should be done with caution, as it was perceived negatively when there were adverse events in this study. Training needs should be carefully balanced with sensitivity to the vulnerability of these families. If students/trainees are involved, there should be continuity so that there is a demonstrable benefit to the families. Close supervision and asking permission from parents can increase acceptability to families and increase their sense of autonomy, in a context where they feel out of control.

Parents are in need of information on the typical emotional reactions after they experience preterm birth and NICU hospitalization. This may include guidance on normal feelings, warning signs for stronger reactions that may benefit from psychological counseling or support, and how to handle the reactions of others. Because families may feel overwhelmed by the preterm birth and hospitalization, information should be provided in a structured manner when parents are ready to hear and understand.

Practice

Effective nursing care for families after preterm birth should focus on being present for parents who are experiencing traumatic events. An awareness of the depth of these experiences can be demonstrated by acknowledging the difficulty and inquiring about their emotional reaction. It is important to listen, acknowledge, and accept the parents' distress without trying to cure them of their feelings. The need to tell was evident for many of the participants of this study and suggests that parents have the need to share their experiences (Vandermause & Wood, 2009). Participants felt the need to tell their story to someone who would listen without needing explanations or to try to judge or fix. They simply needed to be heard.

Brandy: And I just remember one day just feeling really tired. And I just said, "It's so hard." And one of my colleagues said, "I know." And that just was good. Because, you know, she didn't try to say anything more. She said, "I know." I knew that had their support.

Karla: The – the best part about the counseling... was that I got to tell my story uninterrupted. Because it's very hard when you sit down and tell your story to somebody, you say, you know, "My daughter had this PICC line put in." And then they say, "Wait. What's a PICC line?" And they're just being curious and kind and they want to know more, but every time you stop – you have to stop and define something for somebody – then I have to stop getting my story out. And I just wanted somebody that could listen to my whole story – the whole thing – and know what I was feeling.

Participating in these interviews provided an additional opportunity to tell their story.

Morse (2001) described the difference between *enduring* and *suffering*, and nurses can adjust their responses to parents based on which type of response they are in. Parents who are *enduring* are focused on getting through the day, specific tasks, and may be resistant to focusing on feelings. Nevertheless, quiet acknowledgement and supportive presence may be helpful. Nurses can ask, “how can I help you be a parent in the NICU?” and acknowledge that a preterm birth can be celebratory and distressing simultaneously. Parents who are in *suffering* are actively expressing their emotional distress, and will benefit from emotional support and presence. Family presence at resuscitation is a common occurrence in the birth room and the NICU. While this practice is endorsed by many professional organizations (Henderson & Knapp, 2006), the best way to support parents during these tragic events are not known. Nevertheless, designating a specific staff member to attend to the family is one practice that can support parents during a resuscitation event. Debriefing with the parents afterwards about the events, answering their questions, and supporting their experience of the events may be helpful in attending to their psychological needs.

Caring for parents after preterm birth may begin on the antepartum unit for those women identified at highest risk. A visit from the neonatology staff may provide information needs about what to expect on the NICU environment and care practices. On the antepartum unit, the parents may have fears and feelings that need to be acknowledged. These may include fear that the baby will die; these feelings can be acknowledged rather than discounted. As Karla said, “*I wanted somebody to talk to me about it, and nobody would let me talk to them. They all would say I just need to like not let my mind go there.*” It is difficult to talk about these fears without offering reassurance, but these feelings are independent of the quantitative risks and facts that are shared with parents. During the early days postpartum, these emotional reactions will evolve as

parents face the reality of the preterm infant in the NICU. Mothers and partners need attentive nursing care during this vulnerable time, whether they are on the maternity unit, in the NICU, or on a high risk unit. Similarly, in the long-term follow-up of preterm infants, parents will have different types of fears that should be acknowledged. As seen in these families, they can include concerns about growth, neuro-cognitive development, and milestones.

Parents in this study reported practices that did not conform to the current evidence on effective care for preterm infants and their parents. For example, there is insufficient evidence to suggest that confining women to bed reduces the chances of preterm birth, yet the practice may be harmful to the physical health of the woman (Maloni, 2011). Further, such practices imply that the woman has some control over the occurrence of preterm birth and supports the myth that preterm labor may be stopped. This promotes guilt feelings and compounds the emotional turmoil these women may feel. Among women on the antepartum ward, this has been described as the *risk discourse* (MacKinnon & McIntyre, 2006) and nurses should be cautious about how routine practices may contribute to these feelings.

Other practices that may be seen as controlling the parent-infant interaction need to be critically examined. Early separation of the preterm infant after birth increases the distress of mothers (Bialoskurski, Cox, & Hayes, 1999) and needs to be addressed by facilitating, whenever possible, early contact between parents and infant. If the mother or newborn's condition prevents early contact, other forms of contact such as photography and video contact may be facilitated. The evidence suggests that skin-to-skin contact is beneficial to both mother and newborn and should be facilitated whenever possible (Nyqvist et al., 2010). When an infant has had a stressful day, such contact may be beneficial, rather than further stressing the infant. Thus denying contact between parent and infant under such circumstances, as was experienced by

Karla and Velois, while well-intentioned, was detrimental. Further, such restrictions send a subtle message that skin-to-skin contact is an additional stress on the infant, which has not been demonstrated in the literature. Efforts to involve parents in the daily routines of the NICU should be balanced by not turning the parents into semi-professionals who then feel responsible for care outcomes and hyper-vigilant.

Parents in this study received strong messages about the dangers of infection after preterm birth in these vulnerable infants. This led to significant social isolation in the home; yet the messaging around this restriction was inconsistent. Efforts to prevent nosocomial infection in the hospital, which would seem riskier than in the home, were inconsistent. Nurses were resistant to adding extra precautions at the request of Velois and the ‘parade’ of staff at the bedside in the teaching hospital also went against these efforts to prevent infection.

Policy

In order to better support effective and evidence-based nursing practice in the NICU, hospitals need to develop care guidelines, policies, and nurse-training that support parents. Explicit guidelines that encourage skin-to-skin care and increased contact between parents and preterm infants are needed. This will help balance the use of technology in the NICU with a more humanized caring context. Institutions need to balance the need to provide experiences for trainees with the desires of families. The general consent for care, which includes the participation of trainees, is insufficient to address the fears of many parents and is not truly an option for these parents, who did not “choose” to have a baby in the NICU. Policies that encourage involvement of parents in the decision to include trainees, as well as proper supervision of trainees will help increase acceptance of this practice by parents.

Although it is common practice for family, especially parents, to be present during resuscitation and other invasive procedures, and consensus recommendations were developed there is a lack of explicit endorsement of this practice by the American Congress of Obstetricians and Gynecologists, the American College of Nurse-Midwives, and the Association of Women's Health, Obstetric, and Neonatal Nurses. Publication of position statements would provide professional support for this practice, as well as guidance on how to best facilitate parents' presence and involvement in these highly significant events. Hospitals may develop their own policies to increase family support during emergencies.

After hospital discharge, follow-up routines may present problems to parents. Through its EHR incentive program, the Center for Medicare and Medicaid Services requires that providers provide patients summaries of office visits as one of its meaningful use core measures. Such a summary was problematic for Karla, who received a summary with the diagnosis "Failure to Thrive." Medical diagnoses can be insensitive by implying judgment or stigmatized conditions; it is necessary to develop mechanisms to make the after visit summary more sensitive to the feelings of patients and to humanize diagnoses. Similarly, developmental milestones mailed to parents based on birthdays may cause distress to parents of premature infants who need to correct gestational ages in order to use the forms, and may have additional distress about not meeting the milestones as expected. These messages need to be adapted to the special needs and concerns of preterm families.

Several participants found returning to the hospital after discharge distressing. The practice of annual NICU reunions may be problematic to these parents. Offering to return to the site of distress may not be helpful to some families recovering from the traumatic hospitalization. The assumption that parents are full of gratitude for the care they received and the heroic rescue

from the brink of viability may misunderstand the distress and long-term health issues that may remain as consequences of the premature birth.

At the level of societal discourse, there is much work to be done to increase the discussion about the limits of viability and attitudes about disability. In the United States there is little financial or social support for parenting when the child is term and healthy and no guaranteed paid parental leave, making parenting challenging even when the child is term and healthy. This is further complicated by the political debate about abortion, which is more challenging to parents facing an unexpected and potentially devastating prognosis for a severely affected infant with disability. Quality of life issues were prominent for Velois and Mike as they struggled with a severely ill infant in the NICU, which raised for them the possibility of pregnancy termination if they had known the extent of the difficulty that they would face.

Research

There is a great need for further research in the well-being of parents after preterm birth. This in-depth study of four couples (eight parents) provided rich qualitative data that could be further analyzed. In particular, a secondary analysis could explore the overlaps and contrasts of discourses within a couple in order to extend the analysis to dyad. Laughter was noted frequently in these interviews and may have been a marker for topics of particular distress or incongruity. A focused analysis of the context and effects of laughter in these interviews could provide insight into the analysis of laughter in clinical and research interviews. Recruitment for this study identified potential participants who had separated or divorced after the preterm birth. While this made them ineligible for this study, future studies may include these parents in order to better understand how the premature birth contributed to the demise of the couple's relationship. Given the higher rates of partnership dissolution, understanding this outcome is

important in order to understand how to better support couples in order to prevent this outcome. The impacts of preterm birth on child outcomes may be worsened by the additional social and economic consequences of parental separation.

The inclusion of one lesbian couple in this study suggested that their discourses of parenting after prematurity can be different from heterosexual couples. Further study with a larger sample of lesbian couples is needed to provide further insight into the unique needs and experiences of lesbian parents of preterm infants. With increasing legal and societal support for marriage equality, this is an important area to pursue.

This study highlighted the traumatic nature of the birth and NICU hospitalization for these families. While the reactions and support of parents after these events is important, the events themselves deserve further study. How can the trauma of these events be reduced? Can parents be better supported during emergency childbirth, resuscitation, and surgical procedures? How can the disruption to family life during a long hospitalization be reduced? The risk of infection for vulnerable preterm infants after discharge is important to understand, and to determine what practices reduce this risk. Current practices that isolate the family in the home, as practiced by many of these families, come at a great cost to the family's social support. Social support after preterm birth was problematic for many of these families, both from term and preterm families. New strategies need to be tested on how to provide this support, whether in-person, in groups, or on the Internet through social media. Some of the mothers found comfort and purpose by volunteering in the NICU and providing support to families experiencing what they had gone through years earlier. Providing social support during NICU hospitalization can be challenging because of the stress of hospitalization, having to balance time at the bedside with other work and family commitments, and other barriers to engagement. A better understanding

of how the family's coping changes over time may provide direction for supportive interventions. Efforts to reduce distress with modalities such as Mindfulness Based Stress Reduction (MBSR) may be helpful (Muzik, Hamilton, Lisa Rosenblum, Waxler, & Hadi, 2012), but face similar time constraints. It may be effective to target such intervention to women at high risk of preterm birth, who continue in outpatient or are on hospitalized in the antepartum unit. Another approach is to test interventions that facilitate nurses' engagement with parents on the NICU in order to maximize cooperation and support of parenting under distress. This may yield additional benefit to improve the job satisfaction and retention of these nurses and is worthy of study in conjunction with patient-centered outcomes.

Conclusion

Velois: But, you know, I'm still grieving. I'm still sad. And I'm still traumatized. I have trouble sleeping at night because of the PTSD, and I still dream about those things that I saw. And that's hard for anyone else to understand.

Karla: All I want is people to understand what I'm going through. And I just want somebody to know. I want – I want somebody to understand the terror and the horror of everything, and not think I'm crazy.

Having an early preterm birth is a traumatic event for parents. This study highlights that parents' distress is a complex phenomenon that involves the failure to achieve expectations for the pregnancy, child, and parenting roles while facing challenges interacting with the care providers and social support systems. Care for these families must go beyond the technical care of the newborn and include attending to the parents' distress. The first step in helping these parents is to listen to their distress and to understand. Nurses are well positioned to help these families if they take the time to listen without judgment and acknowledge the emotional pain. This is only the first step toward helping these parents through the trauma of prematurity. More research is

needed on identifying how to best care for these parents who endure and suffer after preterm birth.

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Research Study

*WSU Institutional Review Board has reviewed and approved
for human subjects participation*

Volunteers needed

Fathers and Mothers of premature infants

*Has premature birth caused you or
your spouse/partner distress? Has your
relationship changed?*

*Will you share your story through
interviews and digital photos?*



Confidential audio-recorded conversations with a nurse researcher. You will receive a gift card in appreciation for your time.

Please contact Ira Kantrowitz-Gordon at Washington State University College of Nursing to learn more or to schedule an interview. Confidential private telephone: [REDACTED]

preterm study

APPENDIX B: TELEPHONE SCREENING FORM

Explain nature of study

- Purpose to achieve better understanding of parents' distress after preterm birth
- Interviews and photo assignments of both parents
- Two meetings for interviews, lasting about one hours each
- Compensation \$20 gift cards per interview per person

Inclusion criteria

- Had a preterm baby <32 weeks or <1500 grams
- Baby is more than six months old
- Baby has been discharged from hospital
- Baby has no major birth defects
- Parents in committed relationship
- Speak English
- Both parents willing to participate

Who am I?

- Nurse-midwife
- Doctoral student at WSU
- Preterm parent

If interested,

First name _____

Name of spouse/partner _____

Contact number _____

Gift card type _____

Location for 1st interview _____

Date and time _____

APPENDIX C: CONSENT FORM

Research Study Consent Form

Study Title: Distress after Preterm Birth

Researchers:

Roxanne Vandermause, RN, PhD, principal investigator

Ira Kantrowitz-Gordon, CNM, MN, co-investigator

You are being asked to take part in a research study carried out by Roxanne Vandermause and Ira Kantrowitz-Gordon. This form explains the research study and your part in it if you decide to join the study. Please read the form carefully, taking as much time as you need. Ask the researcher to explain anything you don't understand. You can decide not to join the study. If you join the study, you can change your mind later or quit at any time. There will be no penalty or loss of services or benefits if you decide to not take part in the study or quit later. This study has been approved for human subject participation by the Washington State University Institutional Review Board.

What is this study about?

This research study is being done to understand the distress that parents experience after premature birth. You are being asked to take part because you have had a premature baby. Taking part in the study will take about 2 weeks. You cannot take part in this study if you are under 18, if your baby has not returned home from the hospital, or if your baby has significant birth defects or has died.

What will I be asked to do if I am in this study?

If you take part in the study, you will be asked to:

- Complete a one-page demographic questionnaire.
- Participate in an interview with a member of the research team where we talk about your experiences of prematurity, how this has caused you distress, and how this has affected your relationships. The interview will be audio recorded. The interview should take between one to two hours.
- You will be instructed in how to complete the photo assignment, in which you take digital photos that tell your story of distress after premature birth. The amount of time this takes will vary. You may use your own camera or borrow one from the researchers.
- You will be scheduled to return for a second interview in one to two weeks to review your photos. The second interview should take about one hour.

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Valid until: 1/5/2013

- You may refuse to answer any question or ask for the audio recorder to be turned off at any time.
- You will be encouraged to invite your partner or spouse to participate in the study.

Are there any benefits to me if I am in this study?

The potential benefits to you for taking part in this study are: thinking about your current and past experiences may provide comfort or new insight.

If you take part in this study, you may provide knowledge that could help other families who experience distress after premature birth in the future.

Are there any risks to me if I am in this study?

The potential risks from taking part in this study are....

- During the interviews you may be asked questions that cause you to be upset or distressed
- If necessary, you will be given resources for counseling or other services if you desire to use them, at your expense, in order to handle your distress

Will my information be kept private?

The data for this study will be kept confidential to the extent allowed by federal and state law. No published results will identify you, and your name will not be associated with the findings. Under certain circumstances, such as if you disclose reportable activity (harm intended to yourself or others) information that identifies you may be released for internal and external reviews of this project.

Privacy will be maintained by conducting the interviews in a private location that is mutually acceptable to you and the researcher.

Your name will not be attached to any of the data. Identifying information will be removed from interview transcripts.

The audio recordings and transcripts will be stored on a secure server or a locked cabinet at Washington State University. Only the researchers and research staff will have access to the data, which will be password protected.

Interview data will not be shared with other participants, including your partner or spouse if participating.

When completing the photo assignment you are asked to choose photos that do not identify people or private locations. Any inadvertent identifying data will be obscured from copies of the photographs retained as data. You may keep original digital copies of the photographs for your own use.

The results of this study may be published or presented at professional meetings, but the identities of all research participants will remain confidential.

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Audio-recordings will be destroyed when transcribed. De-identified transcripts and photo-elicitations will be kept indefinitely for education purposes.

Are there any costs or payments for being in this study?

There will be no costs to you for taking part in this study.

You will receive a \$40.00 value retail gift card for taking part in this study. If you decide to quit the study after the first interview you will receive a \$20.00 value retail gift card.

Who can I talk to if I have questions?

If you have questions about this study or the information in this form, please contact the researcher Ira Kantowitz-Gordon, Washington State University College of Nursing,

[REDACTED] If you have questions about your rights as a research participant, or would like to report a concern or complaint about this study, please contact the Washington State University Institutional Review Board at [REDACTED]

What are my rights as a research study volunteer?

Your participation in this research study is completely voluntary. You may choose not to be a part of this study. There will be no penalty to you if you choose not to take part. You may choose not to answer specific questions or to stop participating at any time.

What does my signature on this consent form mean?

Your signature on this form means that:

- You understand the information given to you in this form
- You have been able to ask the researcher questions and state any concerns
- The researcher has responded to your questions and concerns
- You believe you understand the research study and the potential benefits and risks that are involved.

Statement of Consent

I give my voluntary consent to take part in this study. I will be given a copy of this consent document for my records.

Signature of Participant

Date

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Printed Name of Participant

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect.

I certify that when this person signs this form, to the best of my knowledge, he or she understands the purpose, procedures, potential benefits, and potential risks of participation.

I also certify that he or she:

- Speaks the language used to explain this research
- Reads well enough to understand this form or, if not, this person is able to hear and understand when the form is read to him or her
- Does not have any problems that could make it hard to understand what it means to take part in this research.

Signature of Person Obtaining Consent

Date

Printed Name of Person Obtaining Consent

Role in the Research Study

WSU IRB #12308-001
Approved: 1/6/2012
Valid until: 1/5/2013

APPENDIX D: DEMOGRAPHIC QUESTIONNAIRE

Demographic questions.

1. How old are you? _____ years
2. What is your ethnicity or race? _____
3. What is your highest level of education? _____
4. What is your primary activity?
 - a. work
 - b. student
 - c. parenting
5. How long have you been in a relationship with your spouse or partner? _____ years
6. How many weeks gestation was your baby at birth? _____ weeks
7. How old is your baby now? _____ months
8. Have you ever been diagnosed or treated for anxiety, depression, or similar conditions? _____

APPENDIX E: INTERVIEW GUIDES

Initial interview

Tell me the story of your premature child's birth.

What was it like to become a parent in the NICU? What were the challenges?

What kind of social support was available in the NICU? Afterwards?

Trouble dealing with term births of friends/family?

Tell me about your distress (persistent difficult emotions, feelings, or worries about your child).

Have you felt isolated?

Did you feel guilty (to blame) for the preterm birth?

Tell me about your partner/wife/husband's distress then and now.

How did you think and react to his/her distress?

How has it been to be a partner/husband/wife under distress?

What is the meaning of this distress? Is it normal? Does it require medical attention? Why or why not?

How has it been to be a parent to a premature child? (After NICU)

Do you worry about your child?

Knowing that your child was born early, do you think about him or her differently?

Division of labor as parents?

Have you thought about future pregnancies or children?

Photo assignment questions

Tell me about this photo.

Why did you choose to take this photo? What does it mean?

Were there any pictures you wished you could have taken but circumstances prevented you?

APPENDIX F: PARTICIPANT COMMUNITY RESOURCES AND REFERRALS

Resources for Preterm Parents

www.PtsdAfterChildbirth.org

Postpartum Support International

www.postpartum.net

(800) 944-4PPD

Washington chapter

<http://www.ppm-support.com/index.html>

(888) 404 – 7763 (PPMD)

Providers

<http://www.ppm-support.com/referrals.html>

Crisis Clinic

www.CrisisClinic.org

24 hour crisis line: 866.4CRISIS (866.427.4747)

206.461.3222

Community Psychiatric Clinic

www.cpcwa.org

206-545-2354

Compass Health

www.compasshealth.org

Care Crisis Line at 1-800-584-3578

Appointments, 1-888-693-7200

March of Dimes

Local chapter www.modimes.org/Washington

Online community www.shareyourstory.org

(206) 624-1373