

ABSTRACT

Premature Birth and the Impact on Family Systems

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Premature birth is a phenomenon that is increasingly prevalent and affects not only the nuclear family, but also many others. The impact on those surrounding the nuclear family is not well addressed in the literature. This study uses a case study method to investigate a family's experience of having a child born prematurely and explores the impact of the premature birth in the ecological systems to which the family belongs. In-depth, personal, semi-structured interviews were conducted with parents, extended family members, a work colleague, and healthcare professionals about how the family and these groups were mutually influenced by the birth. A theoretical framework of Ecological Systems Theory was used to explore the complex interactions of different layers of the family system. The results indicate that the impact of premature birth is substantial, wide-spread, and possibly underestimated, particularly for extended family members and in the work environment of parents.

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PREMATURE BIRTH AND THE IMPACT ON FAMILY SYSTEMS

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CHAPTER ONE

Introduction

Introduction

This study explores the experience of a family that has given birth to a premature baby and also investigates the perspective of healthcare professionals, family members, and coworkers who interacted with the family during the time of the premature birth. The goal is to determine the impact of the birth on the various interacting and interrelated systems surrounding the nuclear family. Because premature birth is a phenomenon that is becoming increasingly prevalent, this research is important in helping to define the nature of the experience of the birth of a premature child and in determining ways to support families going through this experience.

Statement of the Problem

According to Centers for Disease Control and Prevention, one in every nine babies born in the United States is born prematurely (2013). This amounts to fifteen million babies born too early every year (WHO, 2012). Prematurity is the leading cause of death in neonates and the second leading cause of death in children under five years; over a million children die from prematurity-related complications each year (WHO, 2012). Premature birth is a phenomenon that has become increasingly prevalent in the last several decades across the world. In fact, the rates of preterm birth are increasing in nearly every country from which reliable data is reported (WHO, 2012). Alexander and Slay (2002) report that in the United States from 1980 to 2000, the rate of low birth

weight (<2500 grams) increased 12 percent, preterm birth increased 17 percent, and very low birth weight (<1500 grams) increased the most dramatically, by 24 percent. Beyond the immediate consequences of increased mortality for premature babies, the long-term consequences include life-long health complications, cognitive and behavioral deficits, and economical and educational consequences for society as a whole. Premature babies are susceptible to many medical conditions that have the potential to harm the brain, such as respiratory distress syndrome (RDS) and intraventricular hemorrhage. One study found that children who were born prematurely may have brain abnormalities such as thinning of the corpus callosum, hippocampus volume reduction, and prefrontal cortex lesions (Ford et al., 2011). These may in turn causes subtle issues such as behavior problems and decreased intelligence quotient. Ford et al. (2011) found evidence that full-term children outperform prematurely born children in executive function tests, such as working memory. Petrou et al. (2001) reported strong evidence of more extensive healthcare utilization by prematurely born children than full-term children, including more likely rehospitalization; higher rates of school failures and learning problems when compared to full-term children; and higher use of social services such as child care, counseling, case management, and even institutionalization for physically and mentally disabled children.

A child born prematurely is at risk for many complications that can affect his or her quality of life, and can also affect those around him or her. For every one of the increasing number of premature babies born, a family is swept into a whirlwind of confusion and shock, forced to deal with many issues unique to having a premature child. Parents experience mixed feelings; they celebrate the birth of their child as a joyous

occasion, but anxiety, helplessness, and loss surround the birth as their baby is placed in the NICU and his or her health status is uncertain (Golish & Powell, 2003). Parents may have trouble relating to others, including extended family, who don't fully understand what they are going through, and they also can have difficulty communicating with one another (Frisman, Eriksson, Pernehed & Mörelius, 2012; Jackson, Ternestedt & Schollin, 2003). With more and more families experiencing this phenomenon of premature birth, it is vital to cultivate an understanding of what it means to have a premature child and the impact that it has on a family in order to develop practices to better serve these families and mediate the negative effects of premature birth. Further, the family is not impacted in isolation, but instead is a member of systems which are also affected by the event. The experience is defined not only by the nuclear family, but also by extended family (Blackburn & Lowen, 1986) and others who are touched by the birth. Premature birth is a complicated and multi-faceted issue that requires study from multiple perspectives in order to fully understand the phenomenon. A lack of understanding exists of the interactions between the nuclear family experiencing a premature birth and the various systems to which the family belongs.

Purpose of the Study

The existing research addresses many aspects of premature birth, including possible causes, the long-term effects for the child, the economic consequences, support for families, and more (Alexander & Slay, 2002; Ford et al., 2011; Hughes, McCollum, Sheftel, & Sanchez, 1994; Petrou, 2003; Petrou, Sach, & Davidson, 2000). The emphasis of the literature regarding impact of the birth on the family is on the nuclear family; many studies explore the impact of premature birth on the parents of the child (Balakrishnan et

al., 2010; Davis, Edwards, Mohay, & Wollin, 2003; Feeley, Waitzer, Sherrard, Boisvert, & Zelkowitz, 2012; Golish & Powell 2003; Jackson et al., 2003; O'Brien, Asay, & McCluskey-Fawcett, 1999). Fewer studies examine the impact on extended family, such as the grandmother of the child (Frisman, Eriksson, Pernehed, & Mörelius, 2012). However, the ecological impact on an entire family and its surrounding systems is not sufficiently addressed in the research literature. The goal of this study was to look beyond the nuclear family and explore the wide-spread effects of the premature birth of a baby using the theoretical framework of Ecological Systems Theory. Much may be gained by investigating the issues surrounding premature birth from the perspective of not only the parents but also the family, friends, employers, healthcare professionals, and other significant members involved in the functioning of the family system. The understanding gained from an in-depth investigation of the interrelationships within family systems may be used to help develop effective support for families undergoing the experience of premature birth, and may have implications for improved interactions between families with premature babies and the various systems to which these families belong, such as the healthcare system and the workplace system.

Research Questions

The guiding research questions for the study are: What is the impact of a premature birth on the family system? How does the impact spread to others surrounding the nuclear family? How do the family and system reciprocally affect each other?

Common Conditions

Premature babies (premies) face the possibility of having certain problems since they do not finish fully maturing in the womb before they are born. A booklet distributed by Abbott Laboratories, Inc. entitled "Your Late Preterm Infant: A Parent's Guide" (2011) discussed common conditions that they may face.

Breathing problems are frequently seen in premature babies because their lungs are not fully developed. One of the major causes of respiratory problems in premies is a lack of surfactant—a protein that reduces the surface tension of the fluid in the lungs so that the alveoli—tiny sacs where gas exchange occurs—will stay open (Abbott Laboratories, Inc., 2011). Without surfactant, the alveoli collapse in on themselves, and this reduces the amount of surface area for gas exchange. Surfactant begins to be produced in the developing fetus around 26 weeks of gestation (National Heart, Lung, and Blood Institute, 2012a). It requires time for the amount of surfactant necessary for functional respiration to build up in the infant's body. Almost all babies born before 28 weeks will lack necessary surfactant and will develop RDS (National Heart, Lung, and Blood Institute, 2012b). If a mother is known to be at risk for premature birth, corticosteroids can be given near the end of pregnancy to speed up the maturation of the baby's lungs and the production of surfactant, thereby decreasing the rigorousness of treatment needed when the baby is born (National Institutes of Health, 2014). When babies are born without enough surfactant, their condition is called respiratory distress syndrome (RDS) (March of Dimes, 2014a). A major breakthrough in therapy for premature babies was the development of surfactant treatment, introduced in 1990. Synthetic surfactant is created and then administered to babies who do not have enough

natural surfactant (National Institutes of Health, 2014). According to March of Dimes (2014a)—a major provider of the funds that were used in researching and developing surfactant replacement therapy—this treatment has reduced deaths from RDS by two thirds since its inception. Supplemental oxygen or mechanical breathing assistance such as a ventilator or CPAP machine may also be necessary for some premies. Ironically, these treatments used to help save a premie's life may cause damage to the lungs and the baby may develop a chronic lung condition called bronchopulmonary dysplasia (BPD) (March of Dimes, 2014a). Apnea is another respiratory problem that premies may have. The brain of a baby at 34 weeks' gestation is only 65% of the weight of a full term baby's brain, and still has much maturing left to do (Abbott Laboratories, Inc., 2011). The part of the brain that controls breathing is not fully developed, and a premature baby may "forget" to breathe sometimes. Caregivers can gently rub or tap a baby to help them begin breathing again.

Premature babies are more prone to develop infections due to their immature immune systems. One example is respiratory syncytial virus, which is a common illness for babies to catch (Abbott Laboratories, Inc., 2011). Healthy babies generally have no problem recovering from this cold-like sickness. However, for premature infants with underdeveloped immune systems, it can be much more serious and can lead to pneumonia or, in extreme cases, death. It is important to keep premies out of contact with people who might be sick and to practice good hand washing.

Jaundice is another common condition in premies. It results from a build-up of bilirubin due to immature liver function. High-powered lights are often used to help remove the bilirubin (Abbott Laboratories, Inc., 2011).

Premature infants also may have a difficult time regulating their body temperature. Much of a baby's insulating body fat is laid down in the last weeks of pregnancy, and premies often do not have the same amount of insulation that a full term baby would. Practicing kangaroo care, checking their temperature often, and being conscientious of their clothing and blankets are techniques to help premies keep a normal body temperature.

Premature babies may struggle with adequate blood sugar levels (Abbott Laboratories, Inc., 2011). Simply the work of staying alive is a lot for a premie's body to handle; it is difficult for them to breathe, regulate their temperature, and even eat. When they do eat, they generally eat less in one sitting than term babies do. They also sleep a great deal so that they can grow. These combined factors may mean that it is difficult for premies to get the nutrition they require, and they may need to be fed more often than a full-term baby.

Some premature babies may develop a gastrointestinal disorder called necrotizing enterocolitis (NEC) (March of Dimes, 2014c). This is inflammation and destruction of the lining of the bowels, perhaps due to weakening of the intestines from lack of blood flow or oxygen (Cleveland Clinic, 2014). A baby with NEC will require their nutrition through IV, because they must stop feeding. Antibiotics are given to treat the bacterial infection.

Premies can also have heart problems. In the womb, a fetus's heart operates via shunts that redirect blood around the lungs since the baby gets his oxygen from his mother and the blood does not need to be oxygenated by the lungs. One of these shunts is the ductus arteriosus, which connects two main blood vessels of the heart (March of

Dimes, 2014c). Sometimes the ductus arteriosus does not close after birth, and this condition is called a patent ductus arteriosus (PDA). When shunts do not close properly, the baby may not be able to pump enough blood and may not get the oxygen that he requires.

Another problem that premies face is bleeding in the brain, or intraventricular hemorrhage (IVH) (March of Dimes, 2014c). This can be very dangerous and can cause permanent brain damage.

Lastly, premies may have eye problems. Retinopathy of prematurity (ROP) results from abnormal blood vessel growth in the retina, the tissue at the back of the eye that receives light and compiles the information to send to the brain. In the most severe cases, the retina may completely detach. Children with this condition may lose their vision (March of Dimes, 2014a). The earlier the gestation of a baby when it is born, the more likely it is to have one or more of these health problems.

Definition of Terms

Family system - a social system; a boundary-maintained unit composed of interrelated and interdependent parts such that an alteration in one part affects all components of the system; a group of people who relate to each other in a way that creates a new entity larger than any of the individuals (Smith & Hamon, 2012). In the context of this study, the family system refers to not only the nuclear family, but also the members of systems surrounding the nuclear family who interact with the nuclear family.

Gestation - the amount of time a baby is in the womb from fertilization to birth (Abbott Laboratories, Inc., 2011)

Term birth - birth between 37 and 42 completed weeks of gestation (Abbott Laboratories, Inc., 2011)

Preterm or premature birth - indicates birth before 37 completed weeks of gestation (WHO, 2012)

Late preterm birth - birth after 34 weeks but before 37 weeks of completed gestation (WHO, 2012)

Moderate preterm birth - birth after 32 weeks but before 37 weeks of completed gestation (WHO, 2012)

Very preterm birth - birth after 28 weeks but before 32 weeks of completed gestation (WHO, 2012)

Extremely preterm birth - birth before 28 completed weeks of gestation (WHO, 2012)

Premie - nickname for baby born prematurely

Low birth weight (LBW) - weight less than 2500 grams, or 5.5 pounds (Gross, 2011)

Very low birth weight (VLBW) - weight less than 1500 grams, or 3.25 pounds (Gross, 2011)

Neonatologist - a pediatrician who specializes in treating and caring for premature and sick newborns (Abbott Laboratories, Inc., 2011)

Neonatal Intensive Care Unit (NICU) - area of a hospital with specialized equipment and staff that provides around-the-clock care to sick and premature babies (March of Dimes Foundation, 2009)

Infant mortality - a measure of frequency of death. Equals the number of deaths among children less than one year of age per one thousand live births (CDC, 2012b)

Morbidity - any departure, subjective or objective, from a state of physiological or psychological well-being. In practice, morbidity encompasses disease, injury, and disability (CDC, 2012a)

Adjusted age (or corrected age) - age based on a baby's gestation. Adjusted age is equal to a baby's actual age minus the number of weeks/months that he or she was premature. The adjusted age gives a better indication of where the baby should be developmentally than the actual age since he or she was not fully developed at birth (Abbott Laboratories, Inc., 2011)

Postpartum depression - a more severe, long-lasting form of depression than "baby blues" that can occur after having a baby (Mayo Clinic, 2012)

Central line - an intravenous line inserted into a vein, often in the arm, and threaded from there into a larger vein in the body close to the heart. Used to deliver medicines or nutritional solutions (March of Dimes Foundation, 2009)

PICC line - peripherally inserted central catheter line. A type of central line placed in one of the major blood vessels (March of Dimes Foundation, 2009)

CPAP - continuous positive airway pressure. Air is delivered to a baby's lungs through either small tubes in the baby's nose or through a tube in the windpipe. The tubes are attached to a mechanical ventilator to help the baby breathe, but it does not breathe for the baby. (March of Dimes Foundation, 2009)

Nasal cannula - small plastic tubes which fit into a baby's nostrils and deliver oxygen. Often used with CPAP (March of Dimes Foundation, 2009)

Mechanical ventilator - a breathing machine that delivers warmed and humidified air to a baby's lungs (March of Dimes Foundation, 2009)

Incubator - a clear plastic box that keeps babies warm and protects them from germs and noise (March of Dimes Foundation, 2009)

Bradycardia - slow heart rate (March of Dimes Foundation, 2009)

Kangaroo care - holding a baby with skin-to-skin contact (March of Dimes Foundation, 2009)

Surfactant - chemical substance that keeps small air sacs in the lungs from collapsing (March of Dimes Foundation, 2009)

Ultrasound - imaging technique that uses sound waves to make a picture of tissue (March of Dimes Foundation, 2009)

Summary

Premature birth is a growing phenomenon with serious implications for families and for society. Understanding the experience of premature birth and how far the impact of a premature birth spreads is vital in developing appropriate support for families encountering this event and encouraging appropriate interaction with those around them who also are affected by the birth.

CHAPTER TWO

Literature Review

Theoretical Framework

The impact of a premature birth can be viewed through the lens of Ecological Systems Theory. This theory suggests that the environment plays an integral and inseparable role in human development and processes, and humans are social beings who are interdependent on one another (Smith & Hamon, 2012). In order to understand individuals, it is vital to understand the systems to which they belong. Bronfenbrenner (1977) visualizes the ecological environment as multiple systems nested within each other. The components of these systems are interdependent and interactive. These systems include the microsystem, the mesosystem, the exosystem, and the macrosystem. His model emphasizes the importance of context in a person's development. He argues that human environments are so complex that research from an ecological perspective should take into account "as many theoretically relevant ecological contrasts as possible" (p. 518). Bronfenbrenner also emphasizes the importance of a concept called reciprocity. That is, one party does not exert an effect on another without the latter also exerting an effect back on the former. Further, he points out that many systems involve a number of interacting persons, and instead of limiting research to determining only the impact that two of them have on each other, analysis of large systems should include as many individuals and subsystems as possible. Bronfenbrenner's ecological systems model, with its integral concepts of context, interacting systems, reciprocity, and large, multi-

person systems, forms the basis of this study and informs the research questions investigated.

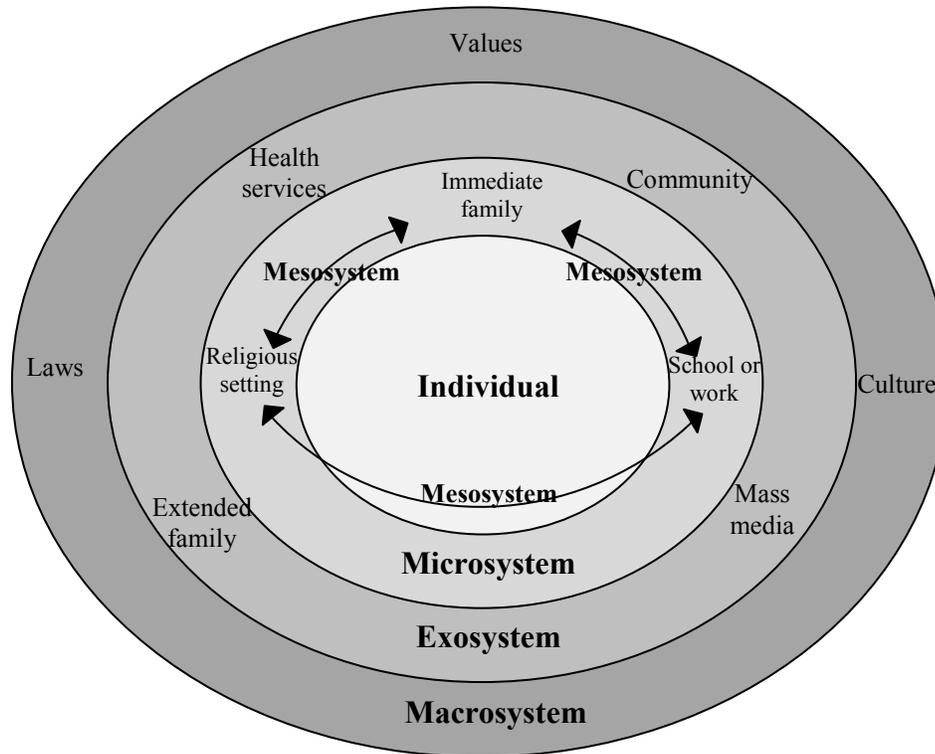


Figure 1: Bronfenbrenner's ecological systems theory (adapted from Berk & Roberts, 2009)

The literature regarding the impact of premature birth involves a great deal of interaction between the parents of a premature baby and their environment. The systems surrounding the family are affected by the premature birth, and the family is reciprocally affected by their surrounding systems. For example, the premature birth can cause strain in the parents' interpersonal relationships (Golish & Powell, 2003). However, their relationships conversely can be a source of support and can affect the outcome related to the premature birth (Affleck et al., 1991). The healthcare system is another example of

interaction between the family and the environment. The family will spend a great deal of time at the hospital, and the healthcare professionals involved in the care of the baby can have a tremendous effect in determining how the parents cope with the premature birth by offering support, encouraging parental participation in care of the child, and being friendly and welcoming (or by failing to do such things) (Chesney & Champion, 2008; Davis, Edwards, Mohay, & Wollin, 2003). The family, in turn, affects the working environment of those healthcare professionals. The impact of premature birth can spread to the parents' places of employment. Jackson et al. (2003) reported the importance of employers' attitudes about parental leave in determining how much parents (fathers in particular) were able to participate in the care of their baby. Employers can either be a source of support or a source of added stress. The birth of the baby also impacts the parents' place of employment, because the parent often takes extended leave, which affects the functioning of the workplace. The societal impact of a premature birth is also an example of the interconnectedness of humans; much of the cost of a premature child's treatment, along with the cost of later community support such as special education, is borne by society as a whole, not simply the family of the child (Petrou, 2003). The birth of a premature baby is not something that can be understood from the perspective of only one or two members of the system; it is an event that reciprocally affects a complex web of interconnected people and must be viewed as such in order for the effects to be fully understood.

Few studies have focused on premature birth from the perspective of ecological or systems theories, but several indicate the potential for these theories to inform the literature on premature birth. McManus and Poehlmann (2012) used ecological theory to

inform their study of neurological and cognitive function in preterm children as it relates to maternal depression and parent-child interaction because ecological theory "highlights the importance of different contextual effects on children's development" (p. 490). They accounted for the interactive effects of maternal depression, parent-child interaction, and social support on child cognitive function. The current study similarly sought to understand the impact of premature birth through several interacting sources, but on a broader scale. Rather than focusing on a specific deficit related to premature birth, this study sought to understand the experience of premature birth as a whole through the perspective of several groups of people involved directly or indirectly with the birth. Also, this study sought to explore the reciprocal nature of the interactions between involved parties. O'Brien et al. (1999) found a multifaceted and interactive effect of partner support, family functioning, perceived negative impact of the child, and maternal emotion and depression, leading them to suggest that a family systems approach may be appropriate in explaining the experience of premature birth. This lends credence to the pursuit of future studies of the experience of premature birth from a systems perspective. Davis et al. (2003) found that many mothers reported sources of stress from other areas and contexts of their lives outside of the NICU, "including bereavement, financial and work concerns" (p. 67). The researchers called for formal documentation and assessment of these external stressors in future research. This finding supports the use of the theoretical framework of ecological systems theory in understanding the complex interactions of various parts of parents' lives in forming the complete experience of premature birth. The current study addressed the need that has been described for additional research that relates these external factors to the experience of premature birth.

These previous studies informed the theoretical framework of the current study and suggested the potential value of this study as an addition to the literature on premature birth and how it is experienced.

Parents

Depression

The literature abounds in research regarding the impact of premature birth on the psychological health of parents, particularly on mothers. It is common for mothers in general to experience some postnatal negative emotions. However, there are added stressors on mothers of premature babies, including their infant's medical condition and hospitalization, that may put these mothers at higher risk of depressive symptoms.

Estimates vary from as low as 28% to as high as 70% regarding the prevalence of depression amongst mothers of premature infants. O'Brien, Asay, and McCluskey-Fawcett (1999) explored maternal depression after premature birth by following the mothers of 45 premature infants in a longitudinal study. Approximately half of the mothers in this study experienced symptoms of depression up to six weeks after bringing their baby home. Another study observed 40% of mothers of very premature infants experiencing depressive symptoms (Davis et al., 2003). Davis et al. (2003) reported that maternal stress was the variable most significantly correlated with maternal depression, of all variables tested. This supports the idea that increased amounts of stress related to the birth contributes to the increased risk of depression in mothers of premature infants. Depression can be an even more serious complication for mothers of premature infants compared to mothers in general because it is difficult for others to understand what these

mothers are going through. Outsiders may not recognize the severity of the situation or the loss that these mothers experience when their pregnancy goes awry, and this may lead mothers to feel even more withdrawn and depressed (Golish & Powell, 2003).

The factors that influence maternal depression are of vital interest in developing strategies to help mothers avoid depression or ameliorate its effects. Yet, the literature is somewhat mixed and inconclusive in this area. While one study reported that family demographics, including mother's level of education and work status, birth order of the child, and family income, were insignificant in predicting depression (O'Brien et al., 1999), another found a significant association between maternal education and depressive symptoms (Davis et al., 2003). Davis et al. (2003) unexpectedly found no statistically significant relationship between family social support and depressive symptoms. Yet, family dynamics were shown to be a significant determinant of mothers' emotional well-being and adjustment to their premature child in another study, where mothers who experience little depression and little discrepancy between their ideal and actual family functioning reported high satisfaction with the support they receive from their partner and felt that the birth of their child resulted in a relatively small change in their family functioning (O'Brien et al., 1999). Balakrishnan et al. (2011) reported a similar finding; maternal perceptions of lower social support were correlated with increased burden on the family. The null results obtained by Davis et al. (2003) may be due to the overwhelming number of women who reported having a supportive partner (97%). This high amount of partner support may act as a buffer against the stresses involved in being a parent of a premature infant. It is also possible that the small amount of variety in spousal support in the sample did not allow a correlation to be found, while a more

heterogeneous sample would allow greater detection of effects. The health status or morbidity of the infant, measured by variables such as birth weight and degree of prematurity, has shown no significant relationship to mothers' experience of depression in several studies (Davis et al., 2003; McManus & Poehlmann, 2011; McManus & Poehlmann, 2012; O'Brien et al., 1999). However, another study found infant morbidity to be significantly correlated to the perceived impact of the birth on the family, including financial burden, disruption of planning, family burden, and caretaker burden (Balakrishnan et al., 2011). This study used the same variables of birth weight and gestational age, yet they, along with many other measures of morbidity, showed a significant relationship to the impact felt by the family. This is an interesting result, and indicates that maternal depression must be related to factors other than perceived impact on the family. Studies have indicated that time is an important variable in how mothers perceive their experience. The infant's period of hospitalization seems to be the most stressful, with mothers reporting significantly more depression during that time than after their infants come home from the hospital. The depression levels for mothers is lowest right after their baby is released from the hospital, suggesting that this time may be a "honeymoon period" which "relieves the stress associated with travel to the hospital and coping with the unfamiliar and intimidating medical system" (O'Brien et al., 1999, p. 186).

Maternal depression can be a debilitating experience for mothers, but it can also have a negative impact on the child. A substantial body of literature has found adverse effects on premature children's development and function associated with maternal depression. The effects are more pronounced for premature infants than for full-term

children, perhaps related to the immaturity of their body systems and their lowered levels of responsiveness relative to term babies (Davis et al., 2003; McManus & Poehlmann, 2012). It has been reported that, either through either physiological pathways, social pathways, or a combination, maternal depression interferes with development of cognitive skills and language through early childhood as depressed mothers are not able to adequately respond to their baby and provide an enriching environment (Sohr-Preston & Scaramella, 2006). While a lack of independent effect of maternal depression on child cognitive function has been found in some studies, even so, lower cognitive function is associated with maternal depression for mothers with little perceived social support (McManus & Poehlmann, 2011). Increased social support seems to be most helpful in bolstering infant cognitive function for mothers who already show few depressive symptoms, while additional social support appears to be ineffective in increasing infant's cognitive function if the mother has elevated depressive symptoms (McManus & Poehlmann, 2012). Early social support also seems to have a greater mediating effect on children's neurodevelopment than later support (McManus & Poehlmann, 2011). The literature indicates that maternal depression can have a negative impact on development of a child, but the impact can be mediated by social support. This is an important impetus for further research that takes into consideration a multifactorial, ecological approach to the experience of premature birth.

Interestingly, however, some research has seen mixed results in the impact of maternal depression on the development of the child. Ruttenberg, Finello, and Cordeiro (1997) examined forty-six very low income Latina mothers of premature, very low birth weight infants, 57.8% of whom reported depressive symptoms at one month after

discharge of their infant from the hospital. The researchers found no significant difference in mother-infant interaction between the depressed mothers and the non-depressed mothers. This finding is contradictory to much of the previous research on this topic. The researchers hypothesized that cultural differences between Latina mothers and Anglo mothers, such as high family orientation and collectivist views in Latina families, may have contributed to the disparity in findings. This indicates the importance of culture and context in describing a complex phenomenon such as premature birth.

The Marital Relationship

The husband-wife relationship experiences stress during the birth of a premature child. For some couples, the crisis brings them closer together, while for others, their relationship is negatively affected. According to Golish and Powell (2003), if the couple believed that they had a strong and healthy relationship before the birth of their baby, the experience tended to bring them closer because they drew on each other for support. Affleck et al. (1991) found that most (70%) couples think that their relationship is strengthened by the experience. However, if there was conflict in the relationship before the birth of the baby, the crisis tended to exacerbate the issues.

Oftentimes, the two parents have different ways of coping with the stress of the situation. This can cause frustration, and it requires the couple to work hard to understand each other. Many mothers in Golish & Powell's (2003) study described their husbands as strong and supportive yet emotionally detached. They struggled with this, because while they did need their husbands' strength, the wives also wanted to see emotion and feel connected to their husbands. For some of the women, their husbands' lack of emotion made them feel that there was a lack of caring about the child, even

though they knew that was not the truth. The main way that the couples in this study dealt with this tension was to view the relationship as a team and stress the importance of open communication. Recognizing that their partners may react differently to the stress of the situation and respecting that fact helped the women manage their emotions and retain a close relationship with their husbands (Golish & Powell, 2003).

Attachment

Much research has been done in the area of attachment between premature babies and their parents. The results have been mixed. Some studies have found no significant difference in the proportions of secure and insecure attachment styles in mothers of premature babies when compared to mothers of term babies (Brisch et al., 2005; González-Serrano et al., 2012). The findings of Brisch et al. (2005) indicated that neurological impairment, but not prematurity in general, is a risk factor for insecure attachment. In other studies, however, premature infants and their parents have been found to be at an increased risk for attachment problems. For example, perinatal risk and the severity of problems in premature infants has been highly correlated with the risk of insecure attachment between mother and infant (Udry-Jørgensen et al., 2011). Hallin, Bengtsson, Frostell, and Stjernqvist (2012) even determined that there was a long-term negative effect of prematurity on attachment styles that persists into adolescence. Similarly, Borghini et al. (2006) found significantly fewer mothers of premature infants had a secure attachment when compared to a control group at both six months (20% versus 53%) and eighteen months (30% versus 57%) of corrected age. It is interesting to note an additional finding when premature infants were further separated into the categories of either low-risk or high-risk. This separation revealed a surprisingly high

rate of insecure attachment among low-risk infants. Since low-risk infants are born later with a higher birth weight, have fewer complications, and stay in the hospital a shorter amount of time, one would expect better outcomes in these families. However, this study indicated that parents of low-risk infants were affected just as much as parents of high-risk infants. Parents of low-risk infants, however, had a specific kind of insecure attachment. Parents of high-risk infants showed distorted attachment, which is characterized by some sort of emotional arousal such as distraction, confusion, or anxiety. Parents of low-risk infants, however, tended to display disengaged attachment representations, characterized by emotional distance and coldness. The researchers postulated that this difference was due to the nature of the hospital stay. Parents with low-risk infants tend to be less worried about their child, and this may interfere with bonding. Parents of high-risk infants, however, are often anxious about their child and feel the need to be near and involved. Strangely enough, these parents, although they experience more negative emotion, may be encouraged by that very emotion to be more involved with their child. This surprising finding revealed that although low-risk infants may have an easier period of hospitalization, families of these children still have their own unique problems, and there is a need for NICU staff to offer targeted support to these parents to encourage bonding with their children. While further research is needed to help dispel the inconclusiveness in the literature on attachment, the evidence of negative outcomes for premature babies and their parents is substantial enough to warrant the development of support for these families.

There has been a recent surge of interest in the research literature in a particularly successful way of fostering attachment with premature infants, kangaroo care. Kangaroo

care, which began in the 1970s in Colombia, involves skin-to-skin contact between the infant and a caregiver (Strand, Blomqvist, Gradin, & Nyqvist, 2013). In a study of fathers using kangaroo care by Blomqvist, Rubertsson, Kylberg, Jöreskog, and Nyqvist (2011), fathers did not express any worry about their infants. This is quite contrary to much of the literature; a consistent finding is that parents are concerned, worried, and stressed about their baby. Kangaroo care was a positive experience and made these fathers feel important and involved in the care of their infants. It even contributed to feeling like they actually became fathers; one indicated that he did not feel like a father until he was able to hold the baby. While many parents of premature infants describe loss of control as a particular challenge of premature birth, these fathers who participated in kangaroo care felt in control over their infant's care. These findings indicate that kangaroo care can have such a large effect as to *reverse* common negative experiences such as lack of control, separation, worry, not feeling like a real parent, and an overall negative experience. However, these fathers deemed the accommodations for staying at the NICU in order to participate in extended kangaroo care uncomfortable and inadequate, indicating that hospitals need to provide better accommodations to encourage this care method and the positive outcomes that result from it.

Common Emotions

Certain emotions have been described by many parents experiencing premature birth and contribute to our understanding of the phenomenon of parenting a premature child. Some of the most prominent emotions are worry, fear, anger and guilt.

Golish and Powell (2003) found that 92% of mothers in their study experienced anxiety about their child's health. Jackson et al. (2003) similarly found that both mothers

and fathers experience significant concern and worry for the baby, and Blackburn & Lowen (1986) reported that intense anxiety was felt by both mothers and fathers.

Many parents have expressed fear regarding whether the baby would survive or would have handicaps (von Gontard et al., 1999). Some mothers described a constant and frantic fear that their child could die at any moment (Affleck et al., 1991). Fear was reported in one study as the dominating emotion for parents (Blackburn & Lowen, 1985).

Anger is often associated with jealousy; mothers describe being angry with other mothers who have full-term babies because they did not get that experience (Golish & Powell, 2003). Parents also were angered by negative comments from other people about their baby (Golish & Powell, 2003).

Guilt was a significant feeling for many mothers, who place blame on themselves for somehow causing their baby's premature birth. More than one third of mothers in the study by von Gontard et al. (1999) felt responsible for the premature birth, and a similar proportion (40%) felt that they had caused the premature birth in the study by Golish and Powell (2003). This guilt contributed to more feelings of anxiety and fear for these mothers (von Gontard et al., 1999).

Golish and Powell (2003) included these emotions as part of the grieving process. They described an overarching pattern which they call the joy-grief contraction. Parents were excited about having a baby and wanted to celebrate the birth, yet they were upset about the loss of their ideal pregnancy and ideal child and needed to grieve that loss. Jackson et al. (2003) also found that parents felt happy about their baby yet grieved by the circumstances under which he or she was born. The mother of a premature baby generally is not able to completely bond with the unborn baby and get emotionally ready

for her pregnancy to end. When her baby is born prematurely, she may feel robbed of a normal pregnancy experience, and parents must then go through the process of letting go of their idealized pregnancy and birth. This can be complicated by parents' feelings that they should not allow themselves to grieve "because they were supposed to be experiencing the joy of their newborn baby" (Golish & Powell, 2003, p. 320). It may be difficult for parents to process their negative emotions if they feel guilty for having these emotions to begin with. Parents described wanting both congratulations as well as acknowledgement of the seriousness of the situation from those around them, further emphasizing the contradictory experience of both joy and grief.

Challenges and Stressors

Overall stress. It is vital to understand the sources of stress and the challenges that parents go through in order to develop appropriate practices to ease their stress. Parents' stress has been linked to stress in their infants, and therefore ameliorating parents' stress can lead to better outcomes for infants (Chesney & Champion, 2008). There are many unique aspects of premature birth parents report as stressful and challenging. However, interestingly, Dudek-Shriber (2004) reported that simply general stress appeared as the most prominent source of stress for parents. She concluded that stress felt by parents "may often be diffuse" (p. 517) and specific stressors must be uniquely determined for individual parents. Despite this finding, there are stressors shared by many parents that have stood out in the literature, and some of the most prominent of these will be discussed below.

Violation of expectations. It has been reported that a particular challenge of going through a premature birth is the violation of expectations about the experience. O'Brien et al. (1999) reported that the difference between expectations about family functioning and the reality of the experience is an important factor in the well-being of mothers of premature children. Affleck, Tennen, and Rowe (1991) described the frustration experienced by parents when their assumptions about the world, their pregnancy, and their baby are dashed. Many parents described doing all the right things to make sure the pregnancy progressed smoothly. For example, many mothers said that they made sure to eat well, exercise, not smoke, and reduce their stress levels. Fathers said that they tried to take on more household work and offer more emotional support for their wives. These parents expressed bewilderment that they still experienced a premature birth even after all of these efforts. Half the mothers in the study thought there was no chance of their baby needing NICU care while they were pregnant. This expectation was not only violated, but violated quickly and without warning when their pregnancy went awry. Affleck et al. compared the "sense of dashed expectations and shattered assumptions" (1991, p. 2) associated with premature birth to other experiences of victimization, such as losing a loved one or undergoing a natural disaster. In all of these events, a person is forced to reevaluate the basic assumption that there is order and benevolence in the world.

Lack of control. Many parents express a sense of helplessness and lack of control surrounding the birth of their child. Golish and Powell (2003) found that mothers in their study "desperately wanted to keep their baby from being born early, but were unable to control their circumstances" (p. 322). Affleck et al. (1991) found that parents in their

study felt that their personal control over the pregnancy was violated, even though they had done many things to make sure that the pregnancy was successful.

Status of infant. Although this category has been expressed differently by different researchers, there is an aspect of stress felt by parents related to the status of their infant. This includes the way the baby looks and behaves, the criticality of the baby's condition, and the uncertainty of the baby's prognosis (Affleck et al., 1991; Dudek-Shriber, 2004; Hughes, McCollum, Sheftel, & Sanchez, 1994). Many parents have depicted the shock they felt when they first saw their baby. Goldberg and DiVitto (1983) explained that while many parents have a mental picture of a "round-faced, rosy-cheeked" (p. 23) baby, premies' bodies are small and scrawny, with different proportions than full-term babies'. Sometimes it is not the baby's body that is disturbing so much as the many things poking into or coming out of it; "rubes and wires seem to emanate from every inch of skin" (Goldberg & DiVitto, 1983, p. 23). Vibrant imagery used by parents interviewed in Affleck et al.'s (1991) study depicted the red color of the baby, the tiny size and fragility, and the tubing and machinery attached to the baby's body. One mother recalled that her baby "didn't even look like a person. He was this tiny creature with tubes" (p. 4). Golish and Powell (2003) quoted another mother who said that all she could hear in the NICU was buzzers and beeps, and she felt like she was going to throw up whenever her baby's monitors would go off. The sight of the baby causes distress for many parents who are not prepared for it. In a study by Affleck et al. (1991), half the mothers participating said that the most difficult part of having a premature baby was not knowing whether their child would survive (Affleck et al., 1991). They described an almost frantic fear that at any moment, they might lose their child. Similarly, von

Gontard et al. (1999) found that approximately half of mothers interviewed feared the possible death of their child. Some parents also expressed a more general fear about their child's prognosis; they worried that the child would have disabilities or handicaps that would make it more difficult to care for the child and that would destroy the image they had created in their mind of a perfect child (Affleck et al., 1991). Similarly, Gontard et al. (1999) reported that 62% of mothers interviewed in their study feared the possibility of their child having handicaps.

Not feeling like a parent. It has been shown that a major challenge for parents of premature babies is that they do not feel like parents at all when their baby is hospitalized in the NICU. They are not able to assume the care-giving role that they expected and wanted. The inability to hold their baby after he or she is born and the long wait until they can take the baby home can cause parents to question their roles and feel that they cannot be real parents (Golish & Powell, 2003). One study found that a mere 38% of parents felt close to their child when he or she was born (von Gontard et al., 1999). Many parents have expressed feelings that the child they saw in the incubator could not possibly be theirs (Affleck et al., 1991). One-third of mothers in the study by Affleck et al. (1991) said that this inability to fully care for their child was the most disturbing part of the experience. Some parents have even said that they felt like they were giving up their child to the healthcare team and that their baby belonged more to the hospital than to themselves (Jackson et al., 2003).

Differences between mothers and fathers. The stressors discussed above have been described by both mothers and fathers. However, a factor that complicates the

understanding of the experience of being a parent of a premature infant is that differences exist between mothers and fathers regarding the extent to which they find certain aspects of the birth stressful. For example, mothers in one study had a higher overall stress score than fathers (Dudek-Shriber, 2004). In another study, mothers felt more need to participate in their baby's care and were stressed by their inability to be involved, while fathers were content to delegate their baby's care to the medical staff (Jackson et al., 2003). This is evidence that individualized assessment and support is needed for different parents.

Coping

Communication and social support. Several studies have identified that positive communication with others, and the social support that stems from that interaction, are common coping tools for both mothers and fathers (Affleck et al., 1991; Golish & Powell, 2003; Hughes et al., 1994). This communication and social support comes from several sources, including the medical staff, family members, and friends. Golish and Powell (2003) found that parents gathered as much information as possible from the medical staff in order to educate themselves and feel more confident about their child's care. Hughes et al. (1994) also determined that communication with the medical staff is important, but found that fathers were more likely to use this strategy. Mothers, on the other hand, were more likely to seek communication and support from their spouse. Golish and Powell (2003) similarly found that 40% of mothers sought to build and communicate a sense of teamwork with their husbands in order to navigate the experience of having a premature infant together. Family members were also an

important source of social support. Golish and Powell (2003) report that 60% of participants relied on supportive communication from their extended family. The ways that family members offered support included listening, reassuring, offering help, and being optimistic. Affleck et al. (1991) asked parents what kind of support had been helpful and what had not. In line with Golish and Powell's (2003) results, they found that expressing concern and caring, reassuring, and providing tangible aid were the most helpful ways that family and friends supported parents. However, it is important to note that parents within Affleck et al.'s (1991) study sometimes differed in what they found to be helpful. While for some parents optimism was appreciated, for other parents it was not. One mother described her frustration with her own mother: "My mother kept telling us not to worry, that everything would turn out all right. But she didn't have any idea what was going on. He was on his death bed. . . . I didn't want anyone telling me that he was going to be fine" (Affleck et al., 1991, p. 90). This indicates that support must be carefully tailored to each individual, and communication between parents and family members about what parents need and want is vital.

Meaning-making. A significant aspect of coping with premature birth is developing meaning for the experience. Parents find positive things that have come out of the experience to help them establish meaning. For example, some say that their relationships were strengthened, particularly the marital relationship; about 70% of mothers and fathers in Affleck et al.'s (1991) study thought that their marriage was stronger after the experience. Many parents also say that the experience made them a better person in some way; for example, they learned a lot, became stronger, or became more mature (Jackson et al., 2003). Affleck et al. (1991) similarly found that parents said

they experienced personal growth, becoming more patient, tolerant, empathetic, and courageous from the experience.

Downward comparison. Another method that parents have used to find comfort is downward comparison (Affleck et al., 1991). This involves comparing one's own situation to another person's situation that is worse. Mothers in Affleck et al.'s (1991) study compared their child's physical appearance and needs to other babies', selectively making comparisons based on the attribute of their own child that was the most positive. For example, mothers with very small babies said that there were other children who required more technological support, while mothers with sicker but larger babies compared their child to others based on size. Blomqvist et al. (2011) similarly reported that parents handled the unexpected situation of premature birth by comparing their situation with other parents', saying that it could have been worse.

Religious faith. Some parents of infants in the NICU report their religious faith as a mechanism of coping with the experience of having a premature baby. Hughes et al. (1994) interviewed 57 parents of preterm infants about their coping strategies during their experience in the NICU. About one third of both mothers and fathers reported relying on and their religious faith as a way of coping with the stressful experience. Similarly, Affleck et al. (1991) reported that one-quarter of mothers interviewed involved religion in their meaning-making process, saying that the experience was a test from God, was God's will, or was used to strengthen their faith (Affleck et al., 1991).

Healthcare Team

The NICU and a Brief History

Neonatology is a fairly new specialty. The first neonatal intensive care unit opened in Connecticut in 1965, and sub-board certification was created for neonatology in 1975 (Committee Report: American Pediatrics: Milestones at the Millenium, 2001). Since these beginnings, the number of premature births has grown as technology has advanced to be able to keep babies alive at earlier and earlier gestational ages. Healy and Fallon (2014) noted that in the 1960s, babies born before 28 weeks were not considered viable, while today babies can survive born as early as 22 weeks.

Artificial surfactant therapy was developed by the 1980s due to major research in the area of respiratory disease in premature babies. It revolutionized the field, allowing more babies to survive with fewer complications. Surfactant therapy as well as better monitoring technology has decreased the deleterious consequences of intensive respiratory treatment; for example, administering too much oxygen used to lead to widespread problems with retinopathy of prematurity (ROP), but now blood oxygen levels can be much more carefully observed and this problem can be avoided for the most part. Another major breakthrough in the respiratory care of premature infants was the development of corticosteroid treatment to jumpstart lung development in fetuses known to be at risk for premature birth; this treatment became mainstream in the 1990s (Healy & Fallon, 2014).

Nutrition for premature infants has also developed over time. In the first part of the 1900s, it was thought to be safest if premature babies were not fed until a few days after birth. In the 1960s, this idea was overthrown as a number of problems associated

with delayed feeding were recognized. Then, in the 1980s, as the body of research supporting the benefits of breastmilk grew, NICUs began to promote breastfeeding for premature babies (Healy & Fallon, 2014).

Also, the involvement of parents in the care of these babies has changed. Early on, NICUs did not allow families to participate in caring for their children (Healy & Fallon, 2014). However, evidence began to indicate that contact is important for both parents and babies, and now family-centered care is the norm in many NICUs. Family-centered care will be discussed in more detail below. Overall, the field of neonatology and the NICU have changed rapidly through the years. NICUs, informed by research, are continuing to implement better medical care and better processes for addressing the needs of premature infants and their families, including physical, psychological, and emotional needs.

Experience of Working in the NICU

Caring for a premature infant carries its own unique benefits and hardships. Healy and Fallon (2014) described the work environment of the NICU as physically and emotionally challenging yet also rewarding. This section will explore the literature that depicts what it is like to be a physician and a nurse in the NICU.

Neonatal nurses. Nurses in the NICU take care of fewer babies than physicians do (Affleck et al., 1991), and thus they are able to spend more time with and potentially develop closer bonds with infants and families. One nurse described becoming so attached to her primary infant that she cried when it was time for the baby to go home from the hospital (Goldberg & DiVitto, 1983). While doctors have reported being upset

when a patient does not respond well to care or dies (Clarke et al., 1984), doctors have not reported such emotional experiences as this one. Due to the nature of their work, nurses may experience more closeness and more emotion related to the babies under their care than physicians do. This postulation is supported by a quote from a nurse in Archibald's (2006) study: "I was so happy for that family; you would think it's my child" (p. 177-178).

Ethical concerns are not only left to physicians; they play a role in the neonatal nurse's job as well. Nurses in a study by Gallagher, Marlow, Edgley, and Porock (2011) believed that "advanced technology brought with it increased ethical dilemmas" (p. 1775). Nurses develop their own opinions and values around issues such as resuscitation, quality of life, and cost, which inform their patient care. Nurses, like doctors, have found navigating these issues difficult (Gallagher et al., 2011).

Archibald (2006) found that nurses' job satisfaction stemmed from compensation, team spirit, physician support, and advocacy. While nurses reported that they were happy with their salary, compensation was not merely monetary, but also came in the form of other benefits. Positive patient outcomes were a great reward for nurses. Small instances of others noticing and encouraging their performance meant a lot to them. Another benefit was the learning and knowledge that they gained working in the NICU (Archibald, 2006). The nurses appreciated the way that they and the rest of their nursing staff worked together so well as a team. They described an environment in which the nurses were always willing and prepared to help each other without question. Some also described feeling valued, appreciated, and empowered by the physicians they worked with, which contributed to their job satisfaction. Lastly, Archibald (2006) found that

offering support and training to new nurses was a satisfying part of their career. In contrast to the study of neonatologists' job satisfaction, in which almost 65% of physicians had at least minimally considered leaving neonatology and changing their specialty (Clarke et al., 1984), none of the nurses interviewed considered changing to a different specialty. One nurse expressed such content being in the NICU that she said, ". . . when I get old and rich, I will volunteer to be a "grandma" to hold and rock them" (Archibald, 2006, p. 178). While some of this difference between neonatologists and nurses may be related to the small sample size of nurses interviewed (8) or a significant separation of time between the two studies, the stark difference is still of interest and requires further exploration.

Neonatologists. Much of the literature about neonatologists has focused on their attitudes, beliefs, and practices regarding ethical topics such as treatment decision-making and end-of-life care (Feltman & Leuthner, 2012; Guinsberg et al., 2012; Ramsay & Santella, 2011). A significant aspect of practicing neonatology is wrestling with these ethical issues. Collins et al. (2009) found that the emergent theme in their study of beliefs of obstetricians and neonatologists as they relate to medical practice was the difficulty of making decisions about topics like abortion and resuscitation. This finding presents evidence that ethical issues regarding the beginning of life are not solely theoretical and are not simply matters of discussion, but affect physicians in practice. Physicians who treat premature babies must develop their own beliefs and act on those beliefs as a part of their daily work. Findings by Clarke et al. (1984) substantiated that ethical dilemmas are an important source of stress, although not as commonly cited as other stressors.

Clarke et al.'s (1984) study, although old, investigated the typical profile of a neonatologist and the job satisfaction and stress associated with the specialty. The findings indicated that, contrary to concern that neonatologists are dissatisfied with their work, most (75%) are satisfied with their career. However, almost all of those interviewed said there was stress involved in their job, and half of them ranked their stress as moderate or severe. Those who were more stressed were significantly more likely to find their job unsatisfying and to consider leaving the field of neonatology (Clarke et al., 1984). The neonatologists were asked what was satisfying about their jobs; the most common answer, by far, was patient care (62%), followed by teaching (24%), intellectual stimulation (22%), research (15%), offering clinical support to parents (13%), being a member of a multidisciplinary team (10%), and working in an acute care setting (9%). They were also asked what was dissatisfying; quantitative overload (including too many patients, too little personal free time, and a rigorous on-call schedule) was mentioned by almost half (48%), followed by stress of patient care (22%), inadequate financial remuneration (21%), administrative demands (16%), staff conflict (10%), research demands (7%), lack of status within pediatrics (7%), inadequate staff (6%), adverse effects on their family (5%), inadequate equipment (5%), and malpractice (2%). Many of these sources of dissatisfaction were also listed as sources of stress, including inadequate resources, research demands, administrative problems, and staff conflict. Other sources of stress were quantitative overload in the form of a demanding call schedule, nighttime calls, and time spent in the hospital; aspects of patient care such as death, lack of progress, and difficult decision-making; parental conflict; ethical dilemmas; feeling inadequately trained or knowledgeable; and conflicts with personal

commitments. These findings indicate that overall, neonatologists are satisfied with their job, but they experience a great deal of stress. More current research on this topic would be useful in determining if the day-to-day experience of being a neonatologist has changed over time as the field of neonatology has developed.

Relationship Between Parents and the NICU Staff

Having a child in the NICU is a frightening and stressful experience for parents. The NICU staff are the people with whom parents interact day in and day out, and therefore staff have an immense role in creating either a good or bad experience for parents. For example, Davis et al. (2003) found maternal perception of support from nursing staff to be significantly and negatively related to maternal depression. In their study, a decrease in nursing support by one percentage point increased the risk of depression by 6%. Chesney and Champion (2008) discussed the integral role that NICU staff can play in helping parents adjust to their abruptly new role as mother and father, particularly when parents are unable to physically interact with their baby. An important role of staff in this process is helping parents become comfortable with cribside interaction with their infant. While parents may not be able to touch their fragile infant, they can sit beside the incubator and talk to the baby to help form an attachment and to help begin the development of the infant's "social brain" (Chesney & Champion, 2008, p. 146). It is important "to provide a safe, authentic environment" (p. 147) and to relieve parents' stress by assuring them that their baby will be well-cared for. Relieving parents' stress early on can encourage better care giving and thereby reduce stress for infants as well. Early patterns of stress in infants may affect the programming of later stress responses, which in turn may affect behavior and cognition. Therefore, clinicians may

have the ability to affect future outcomes of infants simply by creating a safe, less stressful environment in the NICU.

Another important area where the NICU can offer support is in helping parents to care for not only the infant but any siblings as well. Balakrishnan et al. (2011) determined that the presence of other children in the home was one of the most significant predictors of impact of premature birth on the family. Impact was measured in this study as financial burden, disruption of planning, family burden, and caretaker burden. Having other children besides the hospitalized infant was related to higher total impact, caretaker burden, and disruption of planning. Therefore, quality childcare for siblings of premature infants could decrease the burden on parents. Building a strong relationship with families, encouraging them to ask questions, and including parents as much as possible in the care of their babies in the hospital can make the parents more confident in their abilities once their babies go home and hopefully decrease the stress experienced and the perceived impact of the child's medical conditions on the family. These various studies indicate that the healthcare staff, particularly nurses, have a great impact on how a premature birth is experienced by the parents and have an important role as a possible source of mediation of negative emotions if their job is done well.

During such a stressful time, communication is a key part of the relationship between the family and the NICU staff. In a NICU, primary nurses take on the majority of the care-taking of the infants and are responsible for usually only a few infants (Affleck et al., 1991). The attending physician, however, is responsible for all infants on the unit. This means that the nurses naturally have more time to devote to each baby and take on the majority of communication with parents. It is important to note that some

parents may be content with this arrangement, while some may not. Many parents have voiced the complaint that they do not get many opportunities to speak directly to the physician responsible for the care of their child (Affleck et al., 1991). Fathers interviewed in a study by Blomqvist et al. (2011) echoed this concern, saying that they "thought it took too long before they received the desired information, especially detailed medical information from a doctor" (p. 1993). In yet another study, a neonatologist admitted that the nurses are really the people that parents should go to if they need something because they are around the baby more and know the details of his or her care (Martinez, Fonseca, & Scochi, 2007). There may be several hierarchical layers between the bedside nurse and the attending physician, including pediatric residents, medical school graduates who are pursuing a specialty in pediatrics, and neonatology fellows, who have completed their pediatric residency and are training to specialize in caring for sick newborns. This further convolutes the chain of command and makes it less likely that parents interact significantly with the attending physician. The number of different members of the healthcare team can be overwhelming and confusing for parents. The concern that they do not receive enough communication from their babies' doctors has been an ongoing one for many years, and it does not seem that the problem has been ameliorated.

A gap seems to exist between the perceptions of parents and NICU staff in discharge planning. Cooper et al. (2007) reported that families did not feel prepared to take their infant home, and over one-third of participants did not believe that any discharge planning had occurred. This is sharply contrasted by the fact that nearly three-fourths of NICU staff believed that discharge planning began at admission in their NICU.

Jackson et al. (2003) reported a similar finding; mothers in their study did not feel ready to take their baby home and felt insecure about their ability to care for them. They believed that the decision to discharge was often made too quickly. This reveals an area of opportunity for providers to better communicate their intentions to parents and to make a concerted effort to make parents feel more comfortable in caring for their babies while still in the hospital.

Hospitals and NICU staff are constantly innovating to try to meet the needs of parents and families of hospitalized babies. They have implemented new models of care for premature infants over time in an attempt to meet the needs of families. One of these is family-centered care, which is becoming the standard in many hospitals. While the original model of caring for sick neonates discouraged interactions between parents and infants in order to keep infection risk down (Healy & Fallon, 2014), the model of family-centered care includes the understanding that the family is "the child's primary source of strength and support" (Cooper et al., 2007, p. S32) and strives to include, support, and empower the family. In the late 1970s, hospitals began to push parental visitation and involvement as research began to indicate that interaction between parents and infants led to better outcomes (Healy & Fallon, 2014). Now, many NICUs employ family-centered care. Cooper et al. evaluated the impact of the March of Dimes NICU Family Support program, an implementation of family-centered care, and found that this type of endeavor enhanced the quality of NICU care and created a more positive experience for parents, including feeling more informed, comfortable, and involved in their baby's care. The implementation of this kind of care is an important step in hospitals' attempt to meet families' needs during this stressful time. Another relatively new phenomenon being

implemented is single-patient rooms in the NICU. Pineda et al. (2012) explained that the single-patient room moves away from the traditional model of multi-bed open bays; it can decrease exposure to stressful stimuli and provide privacy for the family. Their findings indicated that the single-patient room was associated with significantly more visitation by parents. However, it was also associated with higher maternal stress. This could be related to the isolation that a private room entails (Pineda et al., 2012). More research is required to understand the impact of single-patient rooms in the NICU, but the prospect of this NICU design as a way to support infants and families is promising.

Conclusion

The literature indicates that NICU staff, particularly nurses, have a vital role in determining the environment of the NICU and the type of experience that parents have. Overall, there seems to be an upward trend in the quality of care that NICUs provide, and it seems that the field of neonatology as a whole is striving to take into consideration and act on potential areas for improvement in order to create better processes to help infants and their families. An area of particular concern, however, is the amount of communication that parents are receiving from their doctors. Parents as well as various members of the healthcare team have expressed that this is a problem for years, but the literature does not indicate that there have been any solutions implemented.

Extended Family

Experience of Being a Grandparent

Several studies have investigated the impact that a premature birth may have on grandparents going through this experience. The overarching theme that Frisman et al.

(2012) determined was that being a grandmother to a premature infant was a balancing act. They found that grandmothers experienced ambivalent feelings of happiness and joy mixed with seriousness and fear, as did parents in Golish and Powell's (2003) study. This theme of ambivalent, contradictory feelings is a well-documented phenomenon, with this result being reported in other studies as well (Hall, 2004a, 2004b). Several studies have indicated that grandparents' outlook and anticipated outcomes may adopt a pattern of remaining positive and hoping for the best, yet expecting the worst (Hall, 2004a, 2004b; Rempusheski, 1990). All of these results demonstrate grandparents finding a balance between two different sides of the experience.

Unlike most parents, who feel disturbed and shocked by the first sight of their premature baby (Affleck et al., 1991), grandparents have expressed awe and wonder at the NICU environment and at their grandchild. For example, half of the grandparents in Blackburn and Lowen's (1986) study complimented the NICU and the staff. Some grandfathers, instead of being frightened by the tiny size of the baby, were amazed that the NICU could keep such a small baby alive (Hall, 2004a). One grandmother described her granddaughter as "just perfect all over" (Hall, 2004b, p. 64). However, some grandparents have also described struggling with their identity as a grandparent; they do not feel like a real grandparent due to the circumstances of the baby's hospitalization (Hall, 2004a; Rempusheski, 1990). This is similar to the experience of parents at the beginning of the NICU hospitalization (Affleck et al., 1991; Golish & Powell, 2003), and both parents and grandparents feel more comfortable in their role when they are able to touch and hold the baby (Jackson et al., 2003; Rempusheski, 1990). Also, despite their positive impression of the NICU, grandmothers and grandfathers alike experience a great

deal of worry and concern for their grandchild and the parents (Hall, 2004a, 2004b). The worry is constant and does not dissipate when the baby is discharged from the hospital; rather, the specifics that grandparents worry about merely change. An important finding is that the concern that they experience is compounded because it is "a double concern" (Hall, 2004a, 2004b), meaning that grandmothers and grandfathers worry about both their own children and their grandchildren. Both grandmothers and grandfathers experience this "double concern," but with opposite priorities. Grandmothers have reported that their concern was first and foremost for the mothers' health, and their concern for the infant came after (Frisman et al., 2012). Grandfathers' first concern, however, was for their sick grandchild, and the well-being of the parents was secondary (Hall, 2004a).

Both grandmothers and grandfathers have indicated that they feel powerless and helpless because they cannot do anything to eliminate the suffering of their children and grandchildren (Hall, 2004a, 2004b). However, Frisman et al. (2012) interviewed a few grandmothers who had experienced a premature birth before; these grandmothers felt calmer when encountering the experience again. Both grandmothers (Hall, 2004b) and grandfathers valued and had a need for information and updates about the infant while he or she was in the hospital; they wanted to be "part of the inner circle" (Hall, 2004a, p. 18). Most grandparents have felt welcomed, respected, and acknowledged by the NICU nursing staff (Hall, 2004b), and even when they felt that their ability to visit their grandchild was restricted in some way, they seemed to be gracious and understanding about the restriction (Blackburn & Lowen, 1986).

Many grandmothers expressed a desire to be involved and supportive, but they were not sure how to do so and did not want to intrude, bother, or disturb (Frisman et al.,

2012; Hall, 2004b). Since the grandmothers did not want to burden the parents with their feelings, they often did not share their thoughts with them (Frisman et al., 2012). During interviews, Frisman et al. (2012) noted that some grandmothers became emotional while recalling the event, realizing that no one had asked them how the situation had made them feel before. Grandparents expressed having been so worried about their child and grandchild that they did not allow themselves to consider their own feelings or needs, but instead always put the parents and infant before themselves; they considered this their duty (Frisman et al., 2012; Hall, 2004b). This indicates that an opportunity for supporting families going through premature birth and creating better outcomes exists; giving the family tools to develop better reciprocal communication could reduce the strain experienced by both parents and family members.

Experience of Other Extended Family Members

Although an awareness that grandparents play a critical role in premature birth and their experiences are important to understand has been established, the impact on other extended family members has not been addressed. This reveals a gap in the literature. The impact of this event on family members, even those that are relatively removed from the birth, may be underestimated. This study begins to fill this need by investigating the experience of the aunt of a premature baby.

Relationship Between Parents and Extended Family Members

Communicating with extended family and friends can become a struggle for parents with a premature baby. Golish and Powell (2003) reported parents saying that no one could really understand what they were going through. One mother in the study was

disheartened that although her family was "supportive," they did not treat her like a "real new mom" (p. 320). She felt that the focus was not on the celebration of the birth, but on the baby's illness. Many mothers echoed this feeling of wanting to be treated just like any other new mom. However, they also wanted their families and friends to understand the gravity of the situation. The parents said that their families were not sure how to respond to the situation. Often, nonverbal communication took over when family and friends were unsure what to do or say. This was frustrating for parents because their loved ones expressed dismay and fear at the baby's condition, while the parents were proud of their child and wanted to share that feeling (Golish & Powell, 2003). The birth of a premature child is a difficult situation because many times, the individuals involved in the premature birth are experiencing this phenomenon for the first time. This means that they have no previous history that helps them know how to behave and how to communicate (Golish & Powell, 2003). This leaves parents, extended family, and friends alike unconfident and unsure about how to handle the situation, and this makes communication between parties difficult. Despite these challenges, extended family members play a critical role in providing social support to parents. Golish and Powell (2003) reported that the majority (60%) of participants in their study relied on supportive communication from their extended family. Ways that grandparents have said that they provided support for their children who were experiencing the hospitalization of a premature child include both emotional and practical aspects, such as being there for them in both body and spirit, listening, caring for other grandchildren, and taking care of the house (Hall, 2004b). Rempusheski (1990) also found that being there and offering their presence was deemed important. According to Frisman et al. (2012), grandmothers

thought that their supportive role was vital to the parents, who were in a crisis and needed their support. Grandfathers in another study said that they could tell that their support made a difference in the stress level of the parents (Hall, 2004a).

Work Environment

While the unidirectional impact of a mother's working conditions on the possibility of premature birth has been studied (Kabir et al., 2009; Meyer, Nichols, Warren, & Reisine, 2008; Rossin, 2010; Saurel-Cubizolles et al., 2004), the opposing scenario—the impact that a premature birth may have on parents' coworkers or at their place of employment in general—is not represented in the literature. However, it is possible, and perhaps likely, that the birth of a baby prematurely does impact the parents' place of employment. One example of why this might be true is that the parent often takes extended leave, which affects the functioning of the workplace. Research is needed in this area to better understand the reciprocal relationship between the parent of a premature infant and his or her place of employment.

Society

Ethics

Ethical issues surround the area of decision-making with regards to medical care for babies, particularly premature babies. An important ethical dilemma with which parents and healthcare professionals must wrestle is how aggressively to treat an extremely premature infant. There is significant ambiguity in definitions and cut-offs that healthcare professionals such as neonatologists and obstetricians use in practice. This is evinced by a finding by Ramsay and Santella (2010) that physicians who worked

in the same hospital defined live birth, fetal death, and the gestational age of viability differently. This incongruence needs to be remedied in order for statistics to be useful and for a standard of care to be implemented.

To complicate matters more, the age at which an infant can be viable has begun to overlap with the gestational age at which abortion is still legally permissible in many jurisdictions, leading to ethical questions and concerns regarding the beginning of life (Collyns, Gillett & Darlow, 2013). Many countries use 24 weeks as a cut-off for legal abortion, while medical intervention has allowed babies born at as early as 22 weeks gestation to survive. Only about 1% of babies born at 22 weeks survive to be released from the hospital, but babies born between 22 and 25 weeks of gestation have a much higher chance of survival—about 40%—and many of these babies fall under the maximum gestational age for abortion. The physicians interviewed in Collyns et al.'s (2013) study discussed the complex analysis of costs and benefits that must go into making a decision about abortion or preserving life and related the difficulty of making such decisions.

A factor that can impact the ethics of decision-making is religion. One's religion is a deeply personal experience and can have a great impact on how events in life are perceived and handled. A person's religion can lead to the adoption of certain values about the concept of life, which can steer the person toward particular decisions about the medical treatment of a premature baby. For example, Arad, Braunstein and Netzer (2008) hypothesized that in their study of very low birth weight, premature babies with intraventricular hemorrhage (IVH) born in two university hospitals in Jerusalem, Israel, a higher rate of survival would be seen for religious and ultra-orthodox Jewish families

than for secular Jewish families (p. 362). The researchers' explanation for the difference in survival rates is that a strong religious affiliation is an indicator of a higher value for the "sanctity of life" than for "quality of life." Indeed, using multivariate regression analysis, the researchers found that the odds of survival were greater for infants of religious and ultra-orthodox Jewish families than for infants of secular Jewish families when the groups are compared to a reference Arab group. The authors provided a rationalization based on the Jewish *Halakhic* tradition, which deems medical intervention that accelerates death to be unethical, regardless of the reasons or outcomes. Haward, John, Lorenz, and Fischhoff (2012) also explored this topic in their study of parental decision-making. The researchers administered surveys to 309 individuals, 38% of whom had an experience with a child with disability and 33% of whom had an experience with prematurity. The study sought to find if either the order in which care options were presented or the amount of detail with which they were presented affected the decision that the parents would make. The options were comfort care (CC) or intensive care (IC). The researchers found that neither order of presentation nor amount of detail were significant in the decision that parents made regarding their children's care. They concluded that individuals have pre-formed preferences about their children's medical care that are based on their beliefs and values. In fact, 29% of participants were classified as highly religious according to the Duke Religion Index Scale, and these participants were significantly less likely to choose CC and reported valuing the preservation of life over quality of life. Lam, Wong, Liu, Wong, Fok and Ng (2009) reported similar findings after interviewing mothers and fathers of both term and preterm infants. Parents with regular religious worship were significantly more likely to decide to

save the infant at all costs and were more tolerant of potential disabilities. Also, parents of premature infants as a whole were more likely to try to save the infant at all costs. The congruent findings by these studies indicate that religiosity can be an important factor in the decisions that parents make regarding their infants' healthcare. Further, these decisions may have ethical implications for healthcare professionals and for society.

Economic Considerations

Petrou (2003) reported that the relationship between the gestational age of an infant and cost is clearly inverse. Golish and Powell (2003) agreed, stating that the earlier a baby is born, the longer the hospital stay is likely to be, the greater the risk of long-term health problems is, and the higher the cost. Many families' bills can reach astronomical numbers quite quickly: a Seattle couple accumulated \$2.2 million in hospital bills during the first 18 months after their twins were born prematurely (Rochman, 2012). Insurance paid for much of the cost, but the couple was responsible for \$450,000, which is staggering debt for most young couples, and is a setback that they may not be able to overcome. The birth and hospital stay alone is expensive, and that does not include the travel, accommodation, and childcare expenses that the family may face (Petrou, 2003). Often, parents must take extended time off of work, which puts further financial stress on the family. On top of the immediate expenses of the birth, some children may require medical treatment after they have left the hospital, and even sometimes for the rest of their lives, due to health complications related to prematurity. Petrou (2003) reported findings of up to 24 times more healthcare costs used by premature children when compared to full-term children during the first year of life. Much of these costs may be covered by insurance and would not be felt by the family.

However, the money paid to hospitals by insurance companies is collected from other customers in the form of premiums, and therefore these insurance payments represent a cost to society. Children born prematurely may also use substantial amounts of non-healthcare resources. For example, low birth weight children are 50% more likely to be enrolled in special education, contributing to an estimated cost of over \$772 million per year in the United States (Petrou, 2003). Prematurity, then, involves high costs not only for the family of the child, but also for society as a whole, and these costs can be spread out over a child's entire lifetime.

It is important, considering the high costs to society of the treatment of these babies, to determine efficient allocation of resources. Cost-benefit studies have been undertaken to measure whether the benefits of the treatment of premature babies outweigh the costs and to determine the most efficient use of neonatal resources. Petrou (2003) reported that whether a treatment is cost effective depends on the treatment and the patients on whom the treatment is being used. Studies have been done attempting to make a conclusion about the overall lifetime costs and benefits of neonatal care, and these studies seem to find that treating babies born less than 1000 grams results in a loss, but treating babies bigger than this results in an economic gain. Petrou, however, found fault with this approach of making sweeping generalizations about lifelong costs versus benefits. These studies are based on limited information and several assumptions, and are therefore most likely biased. In more narrowly focused studies, however, economic evaluations have been done for specific treatments, such as administering surfactant in babies with respiratory distress syndrome. The use of surfactant seems to have a neutral or, in heavier birth weight babies, even beneficial effect on costs if used to treat RDS, but

costs outweigh benefits if surfactant is used as a preventative measure for babies who do not already have RDS. More studies are needed to determine the cost effectiveness of various treatment methods for premature babies in order to provide the best care to these babies and families in the most efficient way.

Current Study as a Response to the Limitations of Previous Research

Although much research has focused on the experience of parents who undergo the birth of a premature child, the experience of others surrounding the nuclear family is notably lacking. The body of literature that does address the family's surrounding systems is limited to the role of healthcare workers, such as physicians and nurses, and the role of grandparents. However, it is likely that the impact of premature birth spreads much more widely. The current study sought to determine the far-reaching effects of premature birth in a family using a case study method, which allowed in-depth exploration of the interrelationships between the family and its systems. Whereas the previous research has been limited to the healthcare team and grandparents, the current study investigated the experience of additional members of family systems, such as the aunt of the premature baby and a parent's coworker. The current study enhanced the existing literature by exploring the experience of premature birth for a wider breadth of individuals than previously has been studied.

CHAPTER THREE

Methods

Participants

A convenience sampling technique was used. A family, including a mother and father of one daughter born 12 weeks premature, was chosen based on the length of time elapsed since the birth of the child and willingness to participate. The daughter was born four years prior to the interview. The researcher required the family to have at least two years of elapsed time since the birth in order to avoid negative psychological effects from discussing the event. The remaining participants in the study were recruited using a snowball sampling technique, whereby the parents determined what individuals had a significant role in the birth of their child and helped put the researcher in contact with these individuals. Thus, the composition of the sample was dictated by the experience and relationships of the family being investigated. The total number of participants was seven. The participants included the mother, father, grandmother, and aunt of the child, as well as the mother's coworker and a nurse and physician from the hospital at which the child was born.

Instrument

A case study design was chosen in order to investigate one family's experience of the birth of a premature child in depth. Patton (1990) explains that the purpose of a case study "is to gather comprehensive, systematic, and in-depth information" (p. 384). This methodology was appropriate because addressing the research questions required

gathering a holistic, in-depth understanding of complex, interacting relationships. This study design was approved by Baylor University's Institutional Review Board. Personal, one-on-one, semi-structured interviews were conducted with each participant. The mother and father of the child were interviewed separately. The interviews included both broad, general questions about the experience as well as questions directed toward individuals with specific roles in the system. The questions aimed to address the impact of the birth on each member of the family system, challenges faced during the experience and ways that they were overcome, perceived support received or given, and interrelationships between individuals within the system. As this study uses a phenomenological approach in investigating the experience of the birth of a premature child, the research questions and the interview questions are broad in nature and scope. The objective of phenomenological research is to explore the nature of an experience. As Marshall and Rossman (2006) discuss, this process requires flexibility. The researcher began with purposeful research and interview questions but also remained open to exploration based on the responses of those interviewed. The participants were encouraged to tell their stories, and then the researcher followed the path of the participants' responses while still maintaining structure through the planned interview questions. The interview questions used are listed in Table 1, categorized by the role of the person interviewed.

Table 1: Interview Questions

Role	Questions
Parents	<ol style="list-style-type: none"> 1. Please share with me the story of the birth. 2. What were some milestones? Describe your emotions at those milestones. 3. When did you know that your baby would be born prematurely? How did you handle the information? 4. Describe the transition coming home from the NICU. 5. What was the financial impact? 6. What was the religious/existential impact? 7. Did the experience impact your perception of parenthood? How? 8. What was the impact on your relationships? 9. Was there an impact on previous or future children? 10. What has been the health and educational impact for your child? 11. What has been challenging? 12. What were your needs? 13. What support did you receive? What was the most helpful? 14. Were you involved in day-to-day care of your child while in the formal healthcare system?
Healthcare professionals	<ol style="list-style-type: none"> 1. Why did you choose to go into your field? 2. How does working with premature babies and their families impact you? 3. What are the benefits of your job? 4. What are the challenges of your job? 5. How do you deal with the challenges? 6. How do you include families in day-to-day care of the child?
Extended family members	<ol style="list-style-type: none"> 1. Please share with me the story of the birth. 2. What did you do when the baby was born? 3. How did you balance celebration of the birth with the seriousness of hospitalization? 4. How did the birth affect you? 5. What was challenging? How did you deal with it? 6. How did you offer support? 7. How did this experience affect your relationship with the child and her parents?
Work colleague	<ol style="list-style-type: none"> 1. Please share with me the story of the birth. 2. How did the birth affect you? 3. What support did you offer? 4. What challenges did this situation present and how did you deal with them? 5. How did the birth of the baby affect the employment of her parents?

Data Collection

Each participant signed an informed consent, which stated the purpose of the research and the how it would be conducted. The participants were informed that interviews would last approximately one hour, would be held at a time and place convenient for them, and would be digitally recorded. They were informed that participation was completely voluntary, that there could be both risks and benefits of participation, and that their personal information would be kept confidential. Participants received contact information for the researcher, faculty advisor, and chairman of Baylor's University Committee for Protection of Human Subjects in Research.

The interviews were recorded using a Sony ICD-UX71 IC Recorder. The interviews ranged in length from nine minutes to one and a half hour. Two of the seven interviews were conducted over the phone because the participants lived too far away for an in-person interview. The interviews were transcribed for analysis, using no personally identifying information. After transcription, the interviews were sent to the participants to review and verify their accuracy.

Data Analysis

The process of data analysis began with transcribing the interviews into text. The transcriptions were then read several times, first to get a general understanding of and familiarity with the interviews, then to glean details and patterns. The data were categorized into "experiences" and "relationships," in accordance with the research questions, which aimed to determine both the impact of the birth on the family and those who surround them as well as the reciprocal relationship between the family and the surrounding systems. The "experiences" category included the experience of being a

parent, experience of being a healthcare professional, experience of being an extended family member, and experience of being a work colleague. The "relationships" category included the relationship between parents and each of the systems they belong to, namely, the relationship between parents and healthcare professionals, the relationship between parents and extended family members, and the relationship between parents and a work colleague. These categories were informed by the theoretical framework of Ecological Systems Theory, which emphasizes the layers surrounding an individual and the interrelationships between these layers.

Protection of Human Samples

As the subject of premature birth is a sensitive one and the event of the birth may have been difficult or painful, participants may have experienced negative emotions from recalling the event and answering questions about it. However, the interviews also encouraged participants to relate positive parts of their experience, such as support they received, methods they used to cope with challenges, and the positive role that the experience had on their relationships. The participants were given a list of resources available for counseling and support if the interview process caused them any distress.

Loss of confidentiality is also a potential risk. Interpersonal relationships are vital to this study, and therefore names could not be completely omitted. However, pseudonyms were assigned to every participant to protect their identities. Data were kept in a secure location to which only the researcher and the faculty advisor had access. The data will be kept in a locked file for up to five years, then destroyed.

Verification

Creswell (1998) describes the many various viewpoints that exist concerning verification of data in qualitative research. While some qualitative researchers attempt to apply traditional quantitative approaches of assuring validity, including internal validity, external validity, reliability, and objectivity (LeCompte & Goetz, 1982), others believe that qualitative research is inherently different than quantitative and thus requires its own unique measures. Creswell suggests the use of the term *verification* rather than *validity* in order to establish qualitative research as a separate and legitimate area of inquiry.

Though there are various perspectives regarding this issue, overall, the methods that qualitative researchers have used to deal with the question of validity within qualitative research include adopting quantitative practices, coining new terms that better reflect the nature of qualitative research, reconceptualizing the idea of validity, or disregarding it as a distraction. For example, Lincoln and Guba (1985) exchanged the terms internal validity, external validity, reliability, and objectivity for credibility, transferability, dependability, and confirmability in order to better reflect the nature of qualitative research. Richardson (1994) reconceptualizes the idea of validity and visualizes it as a metaphoric crystal, which grows and changes, reflects externalities, refracts within itself, and provides not a single truth, but different perspectives when viewed from different angles.

Creswell (1998) suggests using at least two of eight verification procedures that he has compiled to ensure validity of any study. These eight procedures include (1) prolonged engagement and persistent observation in the field, (2) triangulation, or using multiple and different sources, methods, investigators, and theories, (3) peer review or

debriefing, (4) negative case analysis, in which the researcher revises hypotheses as the research process proceeds, (5) clarifying researcher bias, (6) member checks, (7) writing with rich, thick description to allow the reader to interpret information, and (8) employing an external auditor. Some of these techniques are more applicable to certain types of qualitative research than others. For this case study, the researcher used four of these eight suggested methods. The nature of the study lent itself to triangulation (2) because information was gathered from multiple sources about the same event—a premature birth. The researcher also used a peer review process (3) with the faculty advisor. Creswell (1998) describes this reviewer as "an individual who keeps the researcher honest; asks hard questions about methods, meanings, and interpretations; and provides the researcher with the opportunity for catharsis" (p. 202). The researcher also employed member checks (6), in which transcripts were sent back to participants "so that they can judge the accuracy and credibility of the account" (Creswell, 1998, p. 203). Rich and detailed description (7) was also used in writing the accounts of the participants. Creswell (1998) explains that this "enables readers . . . to determine whether the findings can be transferred" to other settings (p. 203).

CHAPTER FOUR

Results

The data analysis resulted in the separation of the findings into the categories of "experiences" and "relationships," in accordance with the research questions. These categories are addressed below for each of the subsystems explored, including the parents, the healthcare system, the extended family, the parents' work environment, and society as a whole. All names have been changed to protect the participants' confidentiality. The child who was born prematurely will be called "Ella," her mother, "Naomi," and her father, "Brent." The grandmother of the child (Naomi's mother) will be called "Lydia" and the aunt of the child (Naomi's younger sister), "Abby." The nurse will be called "Caroline" and the physician, "Dr. Williams." Naomi's co-worker will be called "Ryan."

Overview

Naomi and Brent's pregnancy with Ella was their first pregnancy. Both of them reported that the pregnancy was relatively uncomplicated, except that Naomi was sick with reflux that remained undiagnosed for the first four months. After she was put on medication for the reflux, Naomi said "everything was going pretty good" until the unexpected birth. Overall, although the pregnancy was "pretty normal," Naomi did not have an enjoyable experience being pregnant:

I had reflux really bad. I didn't get morning sickness very often, but um—no, I really didn't enjoy being pregnant. I was sick a lot. I couldn't really find food that tasted good—I mean, I did not care for being pregnant. I enjoyed like feeling her

move around, and I was excited about having a kid, you know, but I did not enjoy being pregnant.

Naomi had a family history of preeclampsia and described herself as "completely neurotic" about making sure that everything was going well with her pregnancy. She worked as a middle school and high school band director, and thus had access to the school nurse. She visited the school nurse weekly to check her weight and blood pressure. On December 16, during one of her routine visits, the nurse told Naomi that she had very high blood pressure, and suggested that she go to the hospital. Naomi was admitted and told that she would be in the hospital until the baby was born, but her obstetrician was not sure when that would be. The original estimate was around a month. However, Naomi's blood pressure could not be controlled, and this hospital did not have an appropriate NICU in case the baby had to be born. Naomi was transferred to a different hospital with a NICU that could accommodate her baby. After staying in the hospital overnight, the doctors told Naomi and Brent that they were booking a spot in the operating room for the following afternoon, December 18, to take the baby. However, that afternoon, December 17, there was a sudden opening, Naomi was rushed into the OR, and Ella was born at 3:30 PM. She was born at 26 weeks of gestation, was 14 inches long, and weighed 2 pounds, 1.2 ounces. Ella subsequently spent three months in the NICU before she was able to go home. At the time of the interviews, Ella was four years old and had thus far exhibited no developmental problems associated with her prematurity.

Parents

Marital Relationship

Naomi and Brent both described a positive impact of Ella's birth on their relationship. Naomi said that their marriage was strengthened, they learned more about each other, and she gained a new appreciation for the man she married:

It did not shake our relationship in any form or fashion. I—of course I think we came out stronger, because there was a lot of things that we had to deal with that a lot of people don't have to deal with. Um, we got to know each other a lot better. . . . [He was] just everything you could ever want in an ideal partner. . . . there's no way I could have made it through that without him. There's no way. Absolutely no way. So I would say overall, we're stronger. And we had a good relationship to begin with. But . . . it really, at least for my part, let me really see what kind of father that he was going to be and what kind of husband, what kind of man he was going to be for us in our life.

Brent also describes a "newfound respect" for his wife after going through this experience together:

I think it gave us each a new appreciation for each other. You know, I got a newfound respect for what Naomi could go through and what she could handle. I had never thought that she couldn't do anything like that, but you know, once you actually see it in the act . . . Because it is a crazy situation to have to handle, you know, having a three month premature, two pound baby that you have to go visit in the hospital every [day] for three months. It's not something you're ever really prepared for, so you're not sure how you're going to respond if it comes up, but yeah, so I found—I think personally I had much more newfound respect for her. Not that I didn't have any at the time, you know, but just this additional, of how she handled everything. She did spectacular. Which, having that just strengthened our relationship.

Naomi pointed out that she and Brent had a good relationship before the premature birth occurred. This strong foundation most likely helped Naomi and Brent navigate this experience together and ultimately come out of it with a stronger relationship.

Experience of Being a Parent

Attachment. When asked about how the hospital stay impacted their ability to bond with their child, both Naomi and Brent expressed concern that they were not able to bond as well as they would have liked initially. Naomi said: "It made me—it made me scared that I wasn't going to have that bond." Naomi's ability to connect with Ella the first time that she met her was particularly affected by Ella's appearance:

I don't know—it's weird, 'cause like when she was first born and we first saw her, it was—it didn't seem like she was a real kid. You know, 'cause she's all tangled up and wrapped up in all this stuff and I'm like, is that a real child?

Brent also said that the hospitalization made developing attachment more difficult, particularly due to the lack of physical touch:

Um, it was definitely hard. I mean, you didn't feel like you could bond as much because you couldn't really hold her. Even in the beginning when we had touch time, it was just that, touch; it was not holding, it was not feeding, not changing diapers. It was simply reaching in and putting your hand on her. That was—that was it.

However, neither Naomi nor Brent thought that the problem was long-lasting.

Both said that eventually they did develop a bond with her, it just happened more slowly or in a different way than they anticipated. Naomi explained:

I don't think that—I think it just delayed—maybe delayed it, or I didn't have that "here's my new—aw, I'm just in love with this child" right away, because I just—I mean obviously I love her and she's my child. I don't think it affected the bond. I think maybe it just delayed it, or made it occur in a different way than you would—because I mean especially as soon as she got home, we could just do whatever we wanted. It was much less clinical and much more like a family.

Brent said that even though the NICU environment made it difficult to feel bonded to Ella, he still felt a connection to her:

You know, so not being able to hold her or anything. So yeah, that affected it. But it was still the very strong sense of, you know—and for whatever reason that

sense is there, whether it's evolutionary, or whatever causes that sense—she's in a room of babies that all look like her, but I know that's my daughter. I feel a special bond with that one. I feel empathy for all these other babies—they're in this similar situation—but that one's mine. I feel the most empathy for that one. I feel the most connection. . . . It was there. I felt a very strong connection to her in that regard. Yeah, I mean, looking back, I wish I could have held her and everything from the beginning, and that was hard to deal with at the time, but . . . I still felt a very strong connection, just wasn't able to bond with her or express it in a way that I wanted to, at least at the beginning.

Naomi and Brent's testimonies indicate that the NICU environment made bonding to their child more difficult and forced the bonding to occur differently than they had expected or wanted. However, they both still developed a strong bond to their child and did not report feeling any long-lasting negative effect on their attachment with her.

Emotions. Naomi described being *angry* during the time of Ella's hospitalization:

"I remember several times being very angry that they were taking my blood pressure, which didn't help my blood pressure [laughing]. I was—you know, hormones—just a wreck." She also described a more general feeling of anger, not directed toward anyone or anything in particular:

I was very angry. I have a pretty bad temper anyway, so I was just very, like—it was like, I don't even give—I don't even give a shit. It's just—I felt like one of those older people who, they just don't care anymore. Things are coming out of my mouth. I was upset. A lot.

Naomi also experienced a sense of aloneness and *emptiness*. After growing another person inside of her and having a constant companion for months, she deeply felt Ella's absence after she was born. She sharply contrasted the experience of being in the hospital with that of coming home without their baby, and how that made her feel:

So we went home, which was really weird. It was kind of like all of that go-go-go-go-go-go, do this, do this, do this, do this, do this, and then you get home and it's like, nothing. It was really kind of weird, and it was really odd, because I just felt very by myself. Very alone. Which was—I mean, because she—I had

been growing a child for six months, and she had been there, and you know of course by that point you could feel her moving, and swimming around, and kicking—I mean it was—we were fully aware that there was another human being there, you know? It was not as abstract anymore, as it was when you first get pregnant. So I just felt very, just alone in my own body, which was very weird. . . . Because, like, I had this baby, but I didn't have a baby yet. Like she was still in the hospital.

Although not in precisely the same way, since he obviously did not feel the physical absence of another human being from his body, Brent also experienced some of this emptiness when they came home from the hospital without Ella:

Naomi came home and we were obviously happy that she got to come home, but again, it was mixed with the feeling of, you know, we didn't get to bring our child home. She's 70 miles away, and it's gonna take us an hour to get there. So it was a little empty feeling, you know.

Brent further indicated that this empty feeling seemed to be related to the expectations that they had of what the birth of a child should be like:

You prepare yourself for this, we're going to go to the hospital, and we're going to have a baby, and we're gonna bring it home, and we're gonna be parents, and we're gonna play house, and we're gonna change diapers and do all this parent crap, and then you come home and you don't have any of that. You just have the realization that you've gotta get back in the car and drive back down to the hospital to see your kid if you want to.

This emptiness was relatively short-lived, though, and was ameliorated when they were able to bring Ella home. "Like we could actually start having a family, is what it felt like," Naomi explained. The morale of the parents increased substantially when their daughter was finally home from the hospital and a sense of normalcy was restored.

Brent described feeling *resentful* at the loss of what should have been a joyful occasion. He reported this feeling with reservation, sighing as he began his statement and seemingly down-playing it by describing it as "slight:"

And then, you know, [sigh], for me, personally, a feeling of slight resentment, you know, because it is supposed to be a joyful time. This is supposed to be one of

those milestone joyful things that you—you know, you graduate from high school, you graduate from college you get married, you have a baby, you know, you have ten year anniversary, twenty year anniversary, thirty year anniversary, and then you die. There's only a handful of big milestones that you're supposed to feel like super joyful at, and this is one of those, and it really doesn't feel that good. And so, you know, there was, at least what I felt, some resentment, and of course a silly type of resentment, not aimed at anything in particular. I'm not sure I believe in any kind of, you know, force that controls anything, so I'm not really resentful at that, that I don't believe in, but still, it's there nonetheless. You can't control it, it's a response that happened. I feel resentful that I didn't get to have the joyful experience that most people get to have whenever they have a kid. So that was there, and is still there in some respect.

Brent seemed to think his own resentful feelings were illogical, saying that they were "silly" and were not aimed at anything or anyone. However, he validated them by saying that it is a response that one cannot control. It seemed as though he did not want to be resentful or to appear resentful, but he still admitted to his feelings. He did not know who or what to blame for the event, yet he still felt that it was unfair that his experience did not live up to his expectations and to the societal norm of a joyful birth. It is interesting to note that his feelings have not faded away, and that even four years removed from the event, he still resents his loss to an extent.

Worry was an emotion that both parents felt throughout the experience and even still at the time the interviews took place, four years after Ella's birth. Naomi said, "I was—you know, hormones—just a wreck. Not to mention just trying to recover from surgery, on top of worrying about Ella." She also described the NICU experience as "stressful and crazy and worrisome."

Both parents strongly experienced contradictory emotions of *joy and grief*, and seemed at a loss for how to handle these two conflicting feelings. Brent recalled feeling both joyful but also scared, and he related the constant interplay between the two: "And you know, so it was terrifying, but then mixed with the obvious joy of seeing your child

for the first time, but then kind of an immediate switch back to terrifying, because it's like, oh okay, she's tiny." Naomi recounted feeling that whether people were congratulatory or sympathetic, neither one was correct:

I just couldn't deal with it. I could not deal with it. I would go through these weird things, like, someone sent me flowers that said, "Get well soon," and I was like [scoff] "Get well soon? I had a baby!" And then somebody would send me something that said "Congratulations," I'd be like, "What?! Do they know my baby's in the hospital?"

These ambivalent feelings were echoed through much of the interviews and reflected that although the parents were excited and happy to have their baby, there were also many negative aspects to the birth that interfered with their ability to be joyful.

Stressors and Challenges. Naomi and Brent described several aspects of the birth and hospitalization that caused them stress. One theme that arose from Naomi and Brent's remarks was a sense of *unpreparedness*. The sudden, unexpected birth did not give them enough time to process what was going on. The stress of the rapid succession of events was compounded for Brent because he originally thought that Naomi's blood pressure problem would be an easy fix:

I started off on the 16th when she called me just thinking, okay, something's wrong, we'll have it checked out, not a big deal, to 24 hours, having our baby that was still supposed to be three months, nearly, away. So yeah, there wasn't a lot of time to really process.

Naomi spoke to how unexpected the premature birth was since she had had a fairly uneventful pregnancy:

Because until this point, you know other than this week, and me just not enjoying being pregnant, I had had a pretty normal pregnancy. Even at this point, I'm laying in bed and she is fine. She didn't have to be born because of a problem with her. So I mean, it's terrifying, you know?

Both used the word "unsettling" in their interviews to describe the time of the birth and talked about the rapid change of plans for the birth even within the hospital:

We thought we were, you know—Naomi was probably going to be kept in the hospital for about a month's time . . . And then we got to the next hospital and they said, well, no, it's probably going to be more like a week, and then the next day it was like okay, it's going to be tomorrow, and then it was like okay, it's going to be now. So um, yeah, it didn't leave a lot of time to process any of it.
(Brent)

Naomi also described the intense flurry of activity and how hard that was for her.

Although the procedure itself did not scare her, the frantic atmosphere did. She needed the process to be slowed down and explained to her, but instead she felt like she was "on the edge of her seat:"

So they like whisked me away to do the emergency C-section, which is terrifying in itself. Like I wanted to have a C-section anyway, a scheduled C-section, so I wasn't necessarily scared of the procedure, just like, I really needed—I'm totally neurotic—so really needed somebody to go step by step with me to work me through it, but I didn't—you know, I didn't get that. . . . Really like, hectic, frantic pace, which was really unsettling.

Naomi even mentioned the lack of preparation for the little things, such as taking photographs of the birth, which most parents would be sure to do under normal circumstances but Naomi and Brent did not have the time nor warning to be able to do: "We were so unprepared. Like we didn't even have a camera, anything." The feeling of being unprepared extended to taking Ella home from the hospital as well. Brent discussed his feelings of inadequacy about their ability to care for her due to the sudden shift from hospitalization to their baby being home:

So when you have a baby that's like, you know, tubes are running out and IVs and stuff, and it's like you can only touch them every three hours, and only for a little while, um, it kind of starts putting this sense of, oh, they're super fragile. And there's not a lot of transition from that to, take them home now!

The sense of being overwhelmed and unprepared for the birth of their child pervaded the entire experience and was an important defining aspect of the birth.

It was difficult for Naomi and Brent to take on their parenting role due to the circumstances of Ella's birth; they experienced the challenge of *not feeling like parents*. Brent retrospectively illustrated this feeling when he described how joyful and relieving it was to bring Ella home:

So yeah, just obviously overjoyed, not only at the fact that we get to bring her home, but the fact that, okay, we can establish, not a normal routine, because obviously it's going to be a baby at home. That wasn't our normal routine beforehand. But, you know, we're not gonna have to drive down here every day. We get to establish a new normal that doesn't involve going to the hospital. It's going to involve—we have our kiddo. We're actually going to be like parents now, instead of like, "Aww, your kid's—like, you're parents but your kid's not there, so you're not really like parents." Or at least that's the feeling you have, kind of.

Naomi expressed this sense of unreality as well; she said that when she saw Ella for the first time she "it didn't seem like she was a real kid." This sense of not being able to fully become a parent while their child was in the hospital seems to have a root in social perception, as he made the statement "you're parents but your kid's not there, so you're not really like parents" from a second person's perspective. The freedom that Naomi and Brent experienced when they were able to bring Ella home significantly aided them in overcoming this source of stress and finally feeling like real parents.

Both Naomi and Brent said that one of the most difficult parts of having a premature child was the *uncertainty* of how she was going to turn out and what complications she might have. Naomi emotionally recalled this sense of uncertainty even before Ella was born: "I remember asking if she was going to cry, and they said they didn't know [paused, teared up]." This moment was one of only two times in the entire

interview that Naomi began to cry, indicating just how traumatizing it was to face the prospect of having a baby yet not knowing what might be right or wrong with her. This struggle continued after Ella was born: "It was definitely over 24 hours before I got to see her. And to be honest, I was a little terrified to see her because I didn't know. I didn't know." Brent was particularly distressed by having to wait for years to determine if Ella would have developmental problems:

Part of the mental experience of this whole thing, though, is the not knowing. That's been one of the hardest things about the experience, you know, is starting from the night before, when the doctors came in and spent about an hour telling us all the things that are— at the time, to you, sound like "This is gonna happen to your child." . . . And the physical things, you know, you could rule out pretty quick. As soon as she was born, it's like, okay, she's got ten fingers, ten toes, she's got all arms, legs, all that stuff's there. . . . but it's all of the mental stuff that you can't—can't rule out until you get there. So there's the constant thing of, you know, not knowing.

Naomi and Brent both used the exact same phrase, "waiting for the other shoe to drop," to describe their agonizing uncertainty about their child's development. At the time of the interview, Ella had exhibited no signs of any problems. Yet her parents still could not quite rest assured that she would be completely normal:

To this point, she does very, very well with everything she's supposed to do 'til this point, but we don't know if she's going to be dyslexic once we get into reading and stuff like that, you know. So, I'll probably feel comfortable when she's about 30, you know. It's like okay, she didn't experience any of that. But yeah, there's always that expectation of kind of *waiting for the other shoe to drop*. Okay, here it is, this is finally—cause you know, it feels a little too lucky at this point for her to be, you know, normal, and having gone through all that. (Brent)

. . . we were both very like—and we still are this way to this day—like holding our breath 'til she does something. You know, holding our breath 'til she crawls. "Okay, she can crawl, she's semi-normal." "Okay, she can talk, she's—she's okay, she can talk." Um, we still get that way to this day, and she's going to be starting school in a couple years, and I think, "Okay, so everything else has been normal, so what learning disability is she gonna have?" You know, like, because from the very beginning, we were told she was going to have problems. So it's—we have a lot of that just *waiting for the other shoe to drop* mentality that we deal with. Or I

deal with. I think that Brent does to some extent. I know he did at first, but like I still deal with it to this day, like "Okay, what's going to be wrong with her?" 'Cause nothing yet. There's gotta be something. That's not normal. She's supposed to be—you know? (Naomi)

It is important to note that this severity of stress was experienced by parents who had a child with absolutely no negative outcomes from her prematurity as far as they could tell at the time of the interviews. This, then, can be seen as a baseline level of stress for a family *without* having to deal with ongoing medical or developmental complications, which would most likely contribute additional stress.

Another source of stress for Naomi and Brent was *lack of control*. An example that was discussed by both parents involved the implications of Ella's birth on their ability to have future children. Naomi was told by her doctors that it was inadvisable to have any more children. Before this, she and Brent had talked about more children, and they had both been content with only having one. Naomi, in fact, had not even been sure that she wanted a child to begin with. She explained:

I've never just grown up wanting—knowing that I wanted to have children. . . . But you know, I met my husband, and he's the one, and you know at some point in our relationship, I wanted to have a kid with him, you know? I wanted to have a family. . . . We hadn't thought much past the first one, and it was like, you know I had said, at some point I had said, no, I don't really want a second one.

Even at the time of the interview, she explicitly and emphatically stated that she never wanted to be pregnant again:

Um, even if I had had less problems with Ella, or you know she was born at 32 weeks for the same reason, or if I had had a normal pregnancy, I'm not sure that I would have done it again. Just—I did not enjoy being pregnant. Even the normal parts I did not—I did not enjoy. I have a wonderful, beautiful child to show for it, and I'm very thankful, and I would not trade her for anything on the planet, but I do not want to do that ever again.

Brent leaned toward the same side of the question that Naomi did. Although not quite as vehemently opposed to having another child, he still did not think it was necessary:

I'd kind of always been on the fence about having any more children. I wasn't opposed to the idea, but it wasn't something that I felt—you know, I wanted to have *a* kid, but you know, beyond having *a* kid into having *kids*, it wasn't anything that I felt needed to happen.

However, when the doctors told them that they would not be able to have any more children and they lost the ability to make that choice and to have control over how they created and built their family, they second-guessed their previous positions. Naomi explains:

But then I didn't have a choice, and it was kind of like, well, I don't really know how I felt about that and I was kind of upset about not being able to have a second one, even though I really didn't know if I wanted a second one. And even my sister was a little insensitive about it, like, "Well, you said you didn't want one anyway." And I'm like, "Yeah, but I don't get to make that choice anymore. Like, I can't change my mind in a year or two. I just—I don't have that choice."

Brent reacted similarly to the loss of control:

But then, once someone tells you you can't, there's the whole psychological—that being denied, it all the sudden makes you want to do something. And you know, now you feel like you're missing out on something that you may have not even wanted in the first place, but now you can't have it, you know? . . . Now that you know it's not a possibility, you kind of entertain that "what if" type scenario.

Naomi and Brent's reactions indicate that feeling in control and being able to make decisions for their family were important to them, and it was distressing when this ability was taken away from them.

Coping. Brent predominately used a mixture of two types of coping: *problem-solving* and *avoidance*. He seemed to react pragmatically to most of the events that he described. For example, when he thought that Naomi would be staying in the hospital for

several weeks after she was admitted for her high blood pressure, he seemed to be merely concerned with the practical aspects of where he would stay during that time:

Naomi was probably going to be kept in the hospital for about a month's time, but you know, we'd make it work. I'd probably stay in a hotel down there or something, since it's an hour away, but we would figure out a way to make it work.

He focused on "making it work" and "dealing with it," saying that there was no other option:

Whenever you think about it from the outside, it seems like oh god, I could never deal with anything like that, but then when you're tasked with doing it, it's kind of like, okay, well, this is the situation. We either deal with it or—well, you've got to deal with it, you really don't have a choice. So it was scary, but you know, just carried on as best we could and got through it. . . . it was settling into a new routine of waking up, going to work, we'd both get home about the same time, about 4 o'clock, get in the car, drive down to the hospital, and we'd usually stay there til about 10 or 11, drive home, and go back to sleep, and we did that for the next two months basically from that point. So again, it was one of those situations where it didn't leave you a lot of time to dwell upon it or sit there and antagonize over it. It was just like, okay, let's go see her. . . . It was just going about everything and making things work, and trying to get things done, you know, trying to lead a normal life as far as we had to go to work . . . but then still being able to make it down, and of course see our baby who was down in the hospital an hour away.

Brent mostly was preoccupied with the practical aspects of developing a routine, completing tasks, and doing what needed to be done. Although he was working hard to keep the family going and to keep up with real life, he tended to avoid the core issues. He simply did not think about the details of the birth, hospitalization, and its aftermath, and instead reported that there was not anything he could do to change the situation, so he responded with, "just kind of don't really think about it too much." In place of scrutinizing the intricacies and emotions of the experience, Brent focused on dealing with the immediate problems that it presented:

No amount of thinking, or pondering, or praying, or, you know, consulting, that would change those set of circumstances. So my personality type has been like okay, we'll just deal with it as it comes. Let's prepare ourselves, you know, deal with the problems at hand, and whatever comes up will come up and we'll deal with it then.

The interplay between these two methods helped Brent adjust to the new demands and stress placed on him by the premature birth.

Naomi indicated that *social support* was the most important way that she was able to cope. When she was asked what the most important and helpful source of support was, she replied that Brent was the primary source:

Just probably my husband. Probably my husband. He very much—whatever he was feeling, we didn't really discuss it until after the fact. He was very much whatever I needed, whatever Ella needed, took priority, and I think that was probably the best. I mean, I appreciated everything anyone did for us. I was wonderful to have, and the concern and supports and prayers and all that stuff. But I think it was probably just my husband. I mean, he was exactly what I needed. He knew when to leave me alone, he knew when to help me out.

She talked about how selfless he was, and she said that she could not have made it through the experience without him:

I mean, he is an incredibly wonderful, patient man. So I think that sometimes I probably got on his nerves, or sometimes he wanted to say to me, "Just suck it up," or "It can't be that bad," but he never—I mean he was very supportive. He never said any of those things to me, he did whatever I asked him to . . . and in the hospital he was—he was—I mean he was a rock. . . . there's no way I could have made it through that without him. There's no way. Absolutely no way.

Her mother was also a major source of support:

Yeah, my mom stayed for—I don't think she stayed—she stayed for about a month, which was a big help because she was there to—she went down to the hospital like when we were at work and spent time with Ella, which was nice to have someone in my family there when I couldn't be there. Um, she helped keep up with laundry, helped keep up with household stuff. Um, that was very nice.

Lastly, she described the staff at her workplace as being very concerned and supportive:

And just, you know, at—the staff at the middle school was very awesome. They were just always offering to do whatever they could do, very concerned, they always wanted to know—they wanted to do like a baby shower, they wanted to know—you know, just like, it was very, very nice. It's like having an extra family. I mean I have been here a long time, so it was like having an extra family and it was, it was very nice.

These three sources made up the core of Naomi's support system which allowed her to process and cope with the premature birth of her child.

Naomi also used *comparison* with other children and families as a way to make her feel more secure about her own premature birth experience. Despite the stressful situation that she was in, she realized that it could be worse, and this helped her cope:

We were very lucky she didn't have complications. I had a friend whose child was born—I mean, it was almost the same story as mine, just a few months earlier. I mean, like, literally we had the same problem, the babies were born around the same gestation, and he had all kinds of problems. Like, he had to be on a ventilator for months, he had to have heart surgery, like just—I mean it was just—he's okay, he's been fine now. He has a lot of lung-type problems because he had been on a ventilator so long. They had to go home on oxygen. So we were very, very, very, very, very, very, very lucky. We were very lucky.

Brent and Naomi also found meaning amidst a crisis, and this *meaning-making* helped them cope with the situation. When he described the positive impact that Ella's birth had on his and Naomi's marriage relationship, Brent found a good thing that came from an overall negative experience:

It's not anything you'd ever want to go through in order to strengthen your relationship, but you know, it's nice to be able to look back and see any kind of positive aspect to it instead of just dwelling on the negative aspect that it happened in the first place.

Naomi similarly found some positive aspect of the overall negative situation:

But it wasn't all bad. It was just something to get used to. And looking back, I can say that it was actually very interesting to watch her develop. Because most people don't get to see that. And being that everything turned out okay, I feel okay in saying that I found it kind of interesting.

Brent and Naomi both found a way to take away something positive from the situation, although overall it was stressful and taxing, and this helped them to partially justify the occurrence of the premature birth. This was a way for them to try to comprehend the event and find purpose in it.

Healthcare Team

Experience of Working in the NICU

Two of the many healthcare professionals that participate in the care of infants in the NICU where Ella was hospitalized were interviewed, including the nurse manager, Caroline, and the lead neonatologist and medical director, Dr. Williams. NICU staff work in a collaborative environment; Caroline listed other disciplines besides physicians and nurses that all come together to form the NICU team, including NICU pharmacists, nutritionists, dieticians, physical therapy (PT), occupational therapy (OT), social workers, case management, lactation consultants, and nurse practitioners.

The experiences that Caroline and Dr. Williams related were very different from each other. One indication of this difference can be seen simply in the length of the interviews; the effusive nurse manager spent approximately 50 minutes speaking with the researcher, while the physician spent only nine. This was despite the fact that the questions prepared for the healthcare professionals were the exact same. The physician's was the shortest of all seven interviews in this study.

Nurse. Caroline was very positive about her role and eager to discuss it. She had served as a night shift nurse, a bedside nurse, a charge nurse, a supervisor, and at the time

of the interview was the nurse manager. Caroline recalled deciding that she wanted to be a "baby nurse" at an early age and related her reason for her choice:

Well, I think most people, myself included, we just, we love babies . . . as long as I can remember, I've just always loved babies. My sister was born when I was eight, so the day before my eighth birthday, went to the hospital and I saw the nurses taking care of her, and I realized, oh I want to be a baby nurse.

She said that one of her favorite parts "that I really love about my job is . . . a thing called rounding," where she spends an hour per day going through the unit talking to families and asking them how they are doing. As nurse manager, she no longer gets to spend all of her time in the unit with families, which she said is a downside of moving up in administration, but she still is able to interact with families through rounding. She described the bonding that a neonatal nurse experiences with infants and their families: "You get so attached to the babies and the families, and when it's time to say goodbye, you want to be like, 'Oh, keep in touch, send me a card!'" She also indicated how vital it was for neonatal nurses to understand that caring for children means caring for parents as well:

When you're a neonatal nurse, you're not just taking care of the baby. You are taking care of the family; it's a package deal. . . . There's a lot of psychology involved with caring for these families. And the bedside nurses that get it, do really well. The bedside nurses who have not gotten it yet, they struggle. . . . when I was in nursing school, I didn't realize it was a package deal with the families. Once I became that neonatal nurse, I figure out real quick, I gotta learn how to coddle these families.

Yet as much as she emphasized the bond with families, she also explained that learning appropriate boundaries was an important part of her nursing career: "I had photo albums for probably the first couple years that I was a nurse, and then I kind of realized, I've got to scale this back." Although she described becoming very close to families, she said that as a nurse, maintaining professionalism is important:

You can't really be you, because sometimes they don't get you, so you have to almost play the part of the NICU nurse. These are the things you say, these are the things you do, and then over time, as the family—you get to know them—you can just kind of relax a little bit.

The main benefit of working as a NICU nurse for Caroline was how rewarding it is to see a baby that was so sick and be able "to turn them around and send them home, it's like, oh my gosh, you were so sick and now look at you." She explains:

It's a very rewarding job, because you get to take this family on a journey that they're never going to forget. They'll forget some of it, but this is going to be a journey—especially when they're tiny—and just knowing that you make a difference in that parent's life and the baby's life.

She also described some of the challenges that neonatal nurses face:

The challenge for the neonatal nurse is that it's a fast food society. We want it now. And also technology—there's huge, huge, advances in technology. Now just with what we do, like as far as the better ventilators, the better way of giving medical care, but also the technology behind it. So there's the electronic health record—back in the day, everything was on paper . . . So all of these scanning/safety/high-tech advances have increased the workload at the bedside. . . . I would say that is probably a disadvantage, a barrier, that nurses complain about, is that all this technology has kind of increased their workload.

Overall, Caroline exuded happiness and pride in her career, and the interaction with babies and families in the NICU seemed to be the driving impetus for going into and then remaining in the field of neonatal nursing.

Physician. The interview with Dr. Williams lasted nine minutes. The brevity of the interview may be indicative of the hurried nature of a neonatologist's work. He answered questions quickly, briefly, matter-of-factly, and without elaboration. This was quite contrary to the way that Caroline conversed, and seems to support her observation that neonatologists are very busy with many babies and do not have a lot of extra time. When Dr. Williams was asked why he chose to go into his field, he responded:

Well, because I knew I was not the office-type physician, so when I was in the hospital, I knew I wanted critical care. . . . I mean, my other choices were adult ICU or either hematology/oncology or, I guess, I guess, for my feeling, it's like dealing with patients that probably have a high chance of mortality, so a pretty risky business.

This response seems rather logical and self-centered. It is completely contrary to the highly emotional and others-oriented response that Caroline gave to the same question:

"As long as I can remember, I've just always loved babies." However, Dr. Williams then went on to say that "the NICU gave me relationship with the parents, intensive care, plus medical care that I need," indicating that having a relationship with the parents of the infants he treats is important to him. The benefit that he received from his job was "that we're saving lives, basically." He enjoyed being in high-stakes, life or death situations.

He described the NICU as "an up and down:"

It's very satisfying if your day goes well, and if the procedures go well and we're successful with the procedures and the babies are recovering and turning around for the better, then it's good. And there are some days that everything is the other way around. The procedures are not as successful, or we're not successful with the procedures, and babies are sick, and we're taking time to establish a baseline and make them well. So it's very emotional and physically hard by the end of the day.

His feelings about his job, then, seemed to be at least somewhat outcome-oriented.

Besides the general stress and difficulty of his line of work, he reported that a particular challenge of neonatology was that "still technology is not to the par . . . so the biggest challenge probably is frustration with the procedures that we do—that they're not—we're not able to—there's not a high percentage of things that we can do." Dr. Williams felt supported and taken care of by the policies of the hospital and the staff around him, however:

Well lucky enough we have pretty decent schedule restrictions, so time off working time. And help from my partners. We call each other during the day

time and say from "how are you doing?" to "do you need help?" to call restrictions, like you can't do more than four days in a row during the daytime or three days in a row on nighttime.

Dr. Williams expressed that although his job was stressful and he didn't always feel satisfied with the level of care that he was able to provide, he felt that he was able to deal with the challenges with help from his partners.

Relationship Between Parents and the NICU Staff

Naomi and Brent both demonstrated a high opinion for the NICU at the hospital where Ella was born. Naomi commented, "That is an excellent hospital and they have an excellent NICU." She described being very involved in Ella's care from the very beginning: "They really did do a good job of trying to get—have us involved as much as possible." Brent agreed that although there was not much they could do to be involved at the beginning of Ella's hospitalization, "they did a really good job, as time went on and she got bigger, incorporating us into, you know, taking a more active role in—in caring for her." This commitment to supporting and involving parents continued all the way until discharge; Naomi and Brent said that the hospital gave them the opportunity to stay at the hospital in a hotel-style room the night before they were supposed to take Ella home, so that they could be in a safe environment if they had any questions or problems during their first night alone with their baby. Brent evaluated the program as "kind of cool" and said "that was nice that they did that. It made us feel a little more secure than if we had just gone and picked her up and brought her home immediately." They also described a strong relationship with the nurses. Naomi commented:

They were very helpful. They were very accommodating. They were very patient . . . there was a couple of nurses that, um, I wouldn't say that we were buddy-buddy with, but we were always excited when we saw them, you know . . . It was a good relationship.

She even said that on Christmas Day, she and Brent brought the nursing staff cookies, which is indicative of a close and appreciative relationship. Brent was also very complimentary and even more effusive about the relationship they shared with the nurses:

The nurses were awesome, and we had a very, very good relationship with the nurses. . . . she had the same nurse, one of the same nurses forever . . . we had a very good relationship with the nurses because they were the ones in there doing everything.

Caroline spoke to the reciprocal nature of this relationship: "you know, you just bond with the parents." Caroline said that the inclusion of parents in the care of their child, which Brent and Naomi experienced, was a specific goal in their NICU:

You really want to incorporate them as much as possible as early as possible. . . . so they can change the diaper, take their temperature, and then reposition them, and then however they're being fed, whether it's a tube feed or whatever, getting them involved with that, so they really feel like they're a part of the team.

She pointed out, though, that this is a fairly new trend: "Really, I'd have to say in the last five years the NICUs have finally figured out, you know, we're so focused on—we need to take it up a step." She also admitted that they are still figuring out more about how to support families and working to improve their support:

We're all about family-centered care, family-centered care, but we're starting to realize the psychology of—especially now, with the technology of in vitro and all of that—starting to need more support. So we actually have an on-site social worker who is available to our families.

Caroline cites other examples of ways that the hospital offers support to families, including bringing in "volunteers who are former NICU parents who come into the unit and offer face-to-face support," offering bereavement rooms and a palliative care team,

distributing March of Dimes informational material to parents, having managers and leaders visit family members each day, implementing a "quiet time" in the NICU each day to allow families and staff to de-stress and "harmonize your inner well-being," and organizing a carnival-style "premie reunion," during which families are invited to come back and see the doctors and nurses and other families that were in the hospital when they were. "That's a very rewarding and therapeutic time for everybody," Caroline explained.

However, while Naomi and Brent report high satisfaction with the nursing care, an area that seems to be lacking is parents' communication with the doctors in charge of their babies' care. Brent quantified the minimal amount of contact they had with the neonatologists and contrasted it sharply to the high amount of contact and support they received from the nursing staff:

You know, the doctors that were in charge of our case, and who eventually delivered Ella and everything in the beginning, we saw them a lot in that first, you know, 12 hours of us being at the hospital . . . But after that, I think I saw her doctor—two more times after that? Not, I mean, not very much at all. So it was the nurses that we had a very good relationship, and they were the ones that were—were doing everything. I mean, they were the ones taking care of her, ordering all the tests, doing the tests that they were qualified to do, doing feedings, and they were the ones that encouraged us and instructed us on, okay, here's what you can do, okay, we're gonna do this now. They were the ones that when you came in, they would tell you how the day had went, you know, "Okay, well she had this episode early today," or you know, "We're down a little bit in weight," or whatever the circumstance may be. They were the ones that kind of informed you, and when you said okay, so she had three bradycardic episodes today. What was that again? Is that the one where—? You know, it's like, okay, and they would explain everything to you, and they were very kind, and made sure you understood everything and were comfortable, and were also encouraging whenever it came time to do things . . .

Naomi did not remember receiving any communication from Ella's doctors at all: "Even the doctors rotate kids, so it's—we really didn't see—like we saw a name on paper, but I

really, I never met—I don't think I ever met that person who was the doctor on the paper." Ella was in the hospital for about two and a half months, and Brent and Naomi visited her daily. Assuming they visited seven days a week for three months, they would have been at the NICU 70 times during Ella's hospital stay. Between Naomi's and Brent's recollections, Brent reported a higher amount of contact with doctors. Even using his more conservative estimation, the parents spoke to a doctor two of the approximately 70 times they visited, which equates to 2.9% of their visits.

Caroline, as an insider on the healthcare team, corroborated the lack of communication from physicians, stating:

The neos, they do update the families every day, but they're just not—I mean, think about it. A nurse can have up to four babies, but a physician can have up to 35. They have to oversee 35. So it's really—I would say that I probably see them getting closer to the parents who are here long-term. . . . But if it's a shorter time frame, mm mm, it's "Here's your update. Peace out." I think it's that way with everybody. . . . You'll get—you'll see a little bit sometimes from a physician if the baby has been here a while and they get sick and they might not make it. You'll see the physicians will try to comfort. But really, no, most of the support comes from the bedside nurse and other resources. But from the M.D. and N.P. side, not so much. And I think it's just the nature of their work. You're just so—you're responsible for so many babies that it's—my perception is that it's difficult to take that time to dive a little bit deeper.

She went so far as to say that the nurses often have to "clean up" after a doctor has talked to the family:

The physicians come in and they explain the medical diagnosis, what the plan of care is going to be, and then we have to come in behind and kind of either clean up because it wasn't presented with the warms and fuzzies, or they didn't understand a word the doctor just said, so you kind of have to break it down even further.

On the contrary, when Dr. Williams was asked how much time he is able to see and interact with families, he replied, "We spend a long time interacting with them. Probably per family, probably, at least probably 15-20 minutes per parent." He also reported that

interacting with parents was rewarding to him, saying that "the NICU gave me a relationship with the parents."

Extended Family

Experience of Being a Grandmother

Lydia's position is a unique one because not only did she have a granddaughter who was born prematurely, but also her own daughter, Abby, was born prematurely. Lydia, then, was able to compare these two experiences of being both a mother and a grandmother to a premature baby. Abby was born eight weeks early, at 32 weeks, by emergency C-section, due to preeclampsia and partial placenta previa. Abby developed necrotizing enterocolitis, a problem with the intestinal tissue, and was hospitalized in the NICU for six weeks. Lydia contrasted the NICU when Abby was born with the NICU when Ella was born:

When Abby was transferred to the NIC unit, it was a big room. It was a giant room, full of bright lights, and they were on these little warming tables, and hooked up to everything. But it was just this big room, and I mean, they were just bed to bed to bed, lined the walls, and some in the middle of the floor. It was loud, noisy, and it was bright. And you could see what was happening to all the babies all over the place, and it was very difficult. And then when Ella was born four years ago . . . it was so different. You go down into this nice, quiet, dark area and they have a little hub with all these little spokes going off of it, and every little baby was in their own little spoke. And blankets were covering the isolettes, and no bright lights. Everything was dim, everything was quiet. And she was in the isolette, she was nestled in this—it looked like a little nest, it looked like. And it was different. What they've learned and what they've done in that amount of time just blew me away. I was just stunned. And it was much more peaceful, much calmer. It was hugely different.

Abby's premature birth affected Lydia greatly for several years, and, she explained, still plagued her even when Ella was born:

Abby had issues and came early, and it was worse than being a first-time mother, because they send you home with all these things to look out for and think about. It's just hard, and it's just the strangest thing. It was—I didn't actually—I was always thankful and appreciative that Abby was there, but I couldn't enjoy her birthdays for about, 'til she was about three or four. It would just come flooding back. . . . And then when Naomi was—when she had to go through it and Ella was born, it often came back again.

Although Lydia had had a terrible time with Abby's prematurity, she felt at ease and confident with Ella. When relating her experience with Abby, she said, "Abby was born and we weren't sure if she was going to make it." Yet when relating her experience with Ella, Lydia pronounced, "I never doubted she wouldn't make it." She said, "It seemed easier with Ella. I don't know if it was because I was older, because I had been through it, or what. I don't know why. But it was easier for me." Lydia expressed having the utmost trust in the NICU staff caring for Ella: "I felt that she was in such good hands where she was." She described an adoration that she felt for Ella: "Ella—she was so much earlier, and she was so tiny, and she was so precious. . . . She was perfect, and she did beautifully. She is our miracle. She's—she's phenomenal." Lydia felt that after having had her own premature baby, she was prepared for what would lie ahead and could offer her assistance:

I felt like I knew what to expect and to hopefully be able to help my daughter and my son-in-law with what they were going to be dealing with. . . . I at least knew what I was going to be looking at the first time I saw her.

Even amidst these positive responses, the situation was still "difficult" for Lydia. She worried about both Naomi and Ella: "She was my firstborn, and it was my first grandchild, and um, you just want everything to be perfect, and it just wasn't." She worried about Ella's condition, although not for too long. Ella was taken off of her respirator after only six days, indicating that her health status was relatively stable: "my

concern and fear seemed to lift when Ella was about six days old, when the nurse told me what she told me—'Sometimes we just have to get out of their way, and just let them do their thing.'" Her fears resurfaced later, but were subsequently squelched: "I was a little concerned that first year with physical development sometimes. . . . But she developed just fine, and she crawled and she walked, and she did everything." Lydia was more concerned about Naomi: "It was just hard to see your—your child—you know, cause Naomi had problems with the blood pressure for gosh, several weeks after the birth, and that's your child, that's your baby."

Experience of Being an Aunt

Abby was in a unique position because she and Naomi were pregnant at the same time and even due within a month of each other. When she received the call that Naomi was going to the hospital, she was scared about what could be wrong:

I was in my third trimester, so that's very scary, just because whenever you are pregnant, you read everything about what goes on and what exactly happens certain time frames so I feel like, um, it was a little more terrifying because I knew all of those things.

Abby continued to recall an intense, panicked fear throughout the interview: "It [pause] was terrifying. I—I can't really explain it in any other way. . . . it was all very scary, it seemed more like an emergency medical situation instead of like bringing your baby into the world." She described her fear as constant and relentless:

It makes you terrified. It—your mind cannot help but go to, you know, what if she doesn't make it? That is a constant fear. . . . every day, you wonder if you're going to get like a call with really terrible news.

Another theme of the experience for Abby was a sense of shock: "We were all just kind of shocked, like, 'no.' You always think, okay, I know they said that, but

something will happen where she will not be born today. It doesn't even seem like a possibility. . . . It was just absolute shock." She found it difficult to comprehend and process what was going on, especially because it all happened very quickly.

Abby also remembered how sad the situation felt:

And then seeing her for the first time, you know we couldn't touch her or anything like that, but I had this moment that was just kind of really sad, where I was thinking, I am pregnant with a baby who is farther along on the inside by a month than this baby who is now out. This is my niece, this is—she's here. Like, it's too soon. . . . it just feels like it is not a birth. It makes you very sad.

In fact, Abby was emphatic that there was nothing happy at all about the situation:

You know to be honest, and maybe this is my fault, but there was absolutely nothing happy. There was nothing happy. No part of me could find any way to be happy, because you see this baby, and so you're excited, but you see a baby that is hooked up to machines and you can't touch, you can't hold, it's not like the same experience.

On top of her concern for Ella, Abby had to deal with her feelings about her own pregnancy. Ella's birth brought to the forefront of her attention the terrible things that can go wrong with a pregnancy, and this scared Abby for her own unborn child:

Like, um, it made me question the health of my own baby. Part of it, you know, if I'm being terribly honest about an awful situation, I was a little like, "I want *my* baby." You know? Like a little bit—that's pregnancy, but um, you just feel really—I don't know. It puts all these things in your head—because I was expecting—about health, the terrible things that can happen.

Lastly, Abby felt helpless and unable to do anything for her sister and brother-in-law:

The biggest challenge for me was knowing the best way to be a part of the situation. . . . You know, in situations where you feel so helpless, you just want the smallest thing to be able to do, and this situation doesn't really play out that way.

During this stressful, scary time, Abby said that she relied on her husband as "a major confidant with my experience in the whole thing." to help her deal with the

challenges that she faced. However, she felt uncomfortable and guilty about having any negative reactions or emotions that she needed to work through:

But you always kind of battle as a family member—you almost feel guilty about any feelings that you would be having about it, because it didn't happen to you. And so, sometimes you don't deal with it as much as maybe you should because you feel like you're out of line.

Relationship Between Mother and Grandmother

Naomi and Lydia shared a unique bond due to both of them being mothers of a premature baby. As Lydia explained, "once you go through premature birth . . . you become a member of an elite membership." For Lydia, this made her feel more competent and "qualified to answer" any questions that Naomi had, although she admitted, "I don't think she had all that many questions." Lydia did not think that their relationship was affected by the event: "My feelings for her and with her have always been the same." The only change was "it's changed in me seeing her as a grown woman and a mother rather than my child, so much as my little girl. It was—I think it was probably a growing experience for us as my girls have become mothers." This change, however, is unrelated to the premature birth and instead is likely experienced by many mother-daughter pairs.

Naomi, on the other hand, reported more conflict in her relationship with her mother. First, she wished that she would have been informed of her family history of preeclampsia before she was already pregnant: "So there's a family history there that of course nobody even bothers to tell you until you're already pregnant. Like, seriously? Because I would have started sooner or just not had a child." Naomi also felt that Lydia did not understand the differences between their two premie situations and thus held

unreasonable expectations of her. She recounted a scenario which illustrates the tension between them during Ella's hospitalization:

I remember after I got home and we went to go the next day to the hospital, we were all going to go together, but like I was riding in the back seat, um, and you know after surgery, it was—I was just like, "I can't, I can't make this hour drive. Like I'm gonna be sick." And so then I put the little wrap on and my husband drove me out after everybody else in the front seat. And like it was weird, because I think that my mom was pretty mad at me because I didn't want to go. But it was like, I made it halfway down the road and I was going to be sick. You know I still had—it was just a lot because my mom had had a premie, and I had a premie, and I think we reacted a little differently. Um, she was just kind of like—which I totally admire—and I, you know, she was just kind of like, whatever I have to do, and I'm gonna be at my child's side the whole time, and—but you know, it was a different situation. Like, she was a housewife, um, so she could do that. She, my sister, was far enough along she got to see her pretty quickly. Um, my sister was far enough along she could touch her and hold her. I—you know, it was weird. I think she got pretty mad at me a couple times about like being weird about "No, I can't make this drive, cause I'm gonna be sick, like recovering from surgery." "Well, you need to suck it up and go." You know, like it was that kind of stuff with my mom I think. Um, which was weird. Because like, there's not a lot I could do for Ella or with Ella, like, and I didn't have the option to just go sit at the hospital. So I think that I was a little bit resentful of my mom a few times. And she was a little bit mad at me a few times. Um, it was a little tension there.

Interestingly, Lydia did not relate any of these tensions. The only hint of any strain from Lydia was her admission that:

I've always had to be a little stern with Naomi from time to time. She knows that. Naomi is very strong-willed and very stubborn. She was always difficult for me. . . . I'm pretty mellow. So we butt heads from time to time, but not too bad.

Despite the tension that Naomi felt, she relied on her mother as a source of support. She said that Lydia stayed in town for a month, helped take care of the household tasks, and visited Ella during the day when Naomi and Brent had to be at work, all of which Naomi described as "a big help." Interestingly, though, the majority of the support that Naomi describes receiving from her mother was instrumental support rather than emotional support. While Lydia said, "I just tried to be there for her if she needed to talk or

anything, but she—I'm trying to think back now—I don't think she had all that many questions." Although her mother was open and available for emotional support, it seemed that Naomi did not choose to talk through things with her.

Relationship Between Mother and Aunt

Naomi was older than Abby by five years, and the two sisters were the only children in the family. Both sisters reported a similar relationship, although Naomi brought up more arguing and conflicts, while Abby painted a more rosy picture of their relationship. Abby said, "we have been close our whole lives, except when one of us was a teenager, you know, we fought a whole lot. . . . I mean, we're—we're extremely close. We're pretty much the same person in different bodies." Naomi, although she also said that they shared a close relationship, emphasized their differences more than Abby did:

Um, we, you know, since we've been adults we've been fairly close. I mean, we argue. And we are, like, politically, we are very different. I mean, so we argue about that and stuff, but we've always—we've been pretty close.

During their pregnancies, their relationship was complicated by "fundamentally different views about pregnancy" which, along with their raging hormones, caused the sisters to argue a lot, as Naomi pointed out:

. . . she definitely wanted to have him normally, vaginally. And I was very much like, can you knock me out and just take the baby? 'Cause the end result for me is the baby. And for her, I think being pregnant was part of the journey for her. For me, it was like no, I just, no I just, just knock me out and take the baby out, that's fine. We had very fundamental differences, and she argued—we got—especially in that first trimester where we were both sick and very grumpy, all the time, um, we got in a lot of arguments, very like—I mean, looking back, not that hurtful, but in the moment, pretty hurtful arguments.

After the first trimester passed, though, Naomi said that most of those arguments faded away:

And we both felt a little bit better, we just had a lot of fun, and we would—you know, we started to look pregnant, it was fun, and sonogram pictures, and sharing those, I mean it was just—we really—as much as I was ever going to enjoy being pregnant, I enjoyed being pregnant with my sister.

Then after Ella's birth, Naomi said that their relationship was tense, but it was a short-lived kind of tenseness while Ella's situation was still uncertain:

Um, at first it was like walking on—I know she—we were all kind of walking on eggshells around each other . . . but after that, like once it was going—it was pretty clear that Ella was going to be fine, and that everything was—she was developing normally and everything was good, we kind of got back to normal.

Abby was very intent on being there for her sister during the process, but she did not know what to do or say:

As her sister, it was just really difficult because there's absolutely nothing that I could do. I couldn't say anything. You can ask her, I typically have something to say about anything that involves either of our lives, and I could not even think, I had nothing to say.

Abby felt that her communication with Naomi was not adequate and she had many unanswered questions about how she could best support and help her sister:

Like, um, do I stay at the hospital all the time with her? Do I go on about my life? Does she need me? Does she not? Would she rather me just leave? Would she rather me not talk about it? Would she rather me say something when I can't say anything? Does she want me down there in the NICU while she's still in the hospital and can't be very much? Or does she feel like I'm taking something away from her? What can I do for Brent? A big challenge was just trying to realize how I fit into that picture at all, because it was so chaotic.

When I asked her if she felt able to communicate those concerns to Naomi and Brent,

Abby said:

I was kind of just stabbing in the dark. Whenever we would communicate, you know, Naomi and Brent were both awesome at being like, "No, you're doing fine. I could use a change of clothes." . . . we would communicate about it sometimes. Sometimes I was just like, sitting in the vicinity, in complete shock of not knowing what to do.

Despite these doubts, Abby did feel like she was able to offer support to Naomi "just by—just by being there." Because she was the only family member who lived in close proximity, she was able to be at the hospital a lot, and she felt that this was an important way of offering her support:

I feel like that was probably the best support, because while maybe sometimes parents wanna be alone, there's times that they really don't. There's times maybe they wanna get away from the hospital and not have to feel guilty about that, and have some sense of normalcy, and I feel like being someone who was able to be there a lot, I could provide that to them.

The other way Abby thought that she helped Naomi and Brent was by bringing in a fresh perspective and outlook to them that allowed them to mentally escape from the turmoil briefly. She explained:

Whenever you are in the hospital and with a situation like that, every day, the things that come up, all the procedures, all of the chaos of what's going on with your baby, because it's a lot, all the time, maybe you need the outlook of being able to see that these things do happen, it's going to be okay, here's what's going on, this sports team did—you know, just being able to bring something else to it that is no one hundred percent hospital life, because it's a long road of a lot of that.

Abby and Naomi's relationship, however, was impacted in a large way by a sense of guilt that Abby felt because she was able to carry her baby to term, but Naomi wasn't:

Um, there was a period of time where I felt like I needed to distance myself just because I felt guilty that I was still pregnant, um, and I didn't ever want—I don't know, I feel like it made our relationship of "we're pregnant together," it changed that. I feel like it made us a little farther apart in that way, just because you feel guilty. Um, I didn't want to be overly excited when I had my son, because I did have him before Ella got to come home from the hospital. He got to come home with me. And I would never want her to feel badly about that, and so there was kind of this period of new motherhood where I feel like, when we were looking for that bond to bring us so much closer, it didn't because of circumstances.

Abby's guilt was exacerbated when she experienced serious post-partum depression after the birth of her son: "And that made me feel even worse, because there I was depressed

about my baby, and just really emotional, and all of those things, and she couldn't even experience that, which made me feel really bad." While Abby tried to protect Naomi and was careful not to be overly excited or ask too much of her, Naomi, quite to the contrary, wanted to be as much a part of Abby's birth experience as possible:

Um, I remember really, really wanting to be as much a part of that as I could, because, uh [pause], it was weird, I didn't feel like the birth of my child was something to celebrate, because it was so hard, and it was so—she was so early [voice shaking, starting to cry], and, you know? So I really wanted to be a part of a normal birth. And um, ended up being able to help my sister a lot. She ended up having to have a C-section, but she pushed for a long time you know, so it was really nice to participate in something that was, you know, normal [voice shaking], I guess.

Abby confirmed what a huge help Naomi was to her in the delivery room, and praised her for being there even though Abby was afraid to ask for her help:

Naomi actually was an awesome partner for me in that situation. My husband was kind of like a deer in headlights whenever I was in labor, and then my sister—in feeling guilty about asking her to be such an active part of that, um, she just did it anyway. I didn't have to ask. I had a rough labor, and she was in there like fanning me, holding my puke bucket [laughing], like all kinds of things, and really stood up. And I was amazed, because she's not the type of person who likes to put herself in those kind of situations, like hospitals, medical, any "there could be blood," you know, and she absolutely pulled through for me."

Abby also said that "if we would talk about it, she was very clear that I should not feel guilty about this, any of it." Abby's labor and delivery seemed to be an equalizing experience that helped to repair the relationship that had been strained by Ella's birth. Although there were difficult periods, both sisters, overall, found that being pregnant together and having families together brought them closer:

But getting through it, seeing our little babies, I mean, Ella is a complete miracle. I feel like I'm ridiculously close to her. And then me and my sister now, I would say it definitely brought us a lot closer . . . she made it through, and here we are. Now we just have these wonderful little kids to raise. (Abby)

I would say we're pretty close, and having families together brought us closer together. We have started lots of traditions, around Christmas and different things, that we might not have started had we not had children at the same time. You know, I feel pretty close to my nephew, and I know she feels pretty close to Ella. Ella and Jack are very close, they're like brother and sister. So I mean just overall, I think we're a lot closer of a family. (Naomi)

Work Environment

Experience of Being a Coworker

Naomi's coworker, Ryan, played a substantial role in Ella's birth. Naomi and Ryan were the two band directors for a small school district and both split time at the middle school and high school. Ryan said that Ella's birth "affected me greatly." When Naomi was in the hospital and on maternity leave, Ryan was left to take on all of her responsibilities by himself:

All of her responsibilities became mine. . . . she did come back, because she actually did her maternity leave differently. She took her maternity leave after Ella came home. So she actually worked through a lot of when Ella was in the NICU, and she'd just drive down to the hospital every night. But you know, it was still me preparing all of the middle school bands and doing basically everything at the middle school, so I was kind of pulling both of our weight during a lot of that time, so uh, it caused a lot of stress on me too. Of course not as much as on them. You know, you gotta look at it in perspective, but it was a stressful situation for me as well. . . . I really was doing the job that previously two people had been doing.

Although Ryan felt additional stress at work, he said that he was not quite sure how he coped with it. He simply took it one day at a time and did what needed to be done, as well as kept things in perspective:

I don't know. I just did it. I mean you—really and truly, you can sit around and complain and feel sorry for yourself all you want, but the bottom line is, it has to get done. So you just do it. So I just buckled down and did it, remembered it wasn't me who had a three month premature baby that as at the hospital. So that kind of puts things in perspective when you're pulling someone else's weight.

Another part of the experience for Ryan was feeling concern for Naomi and her family and constantly fielding questions because he was the one in the district who was most connected to Naomi:

I mean obviously you're concerned about—you know, I was concerned about Naomi and Brent and Ella throughout it, because you know, you only want the best for them. So that was part of it, you know, you're constantly reminded of it, because when I'd walk around anywhere, any of the campuses, my first question would always be, "How is Naomi doing? How is Ella doing? How is the baby?" It's like they—everybody—I was everybody's sounding board with the situation.

Overall, the extra stress that was put on him by the demands of the situation was the predominate experience for Ryan. Interestingly, though, as the interview progressed, he seemed to increasingly downplay the amount of stress he actually experienced. At the beginning of the interview, he said that the birth affected him greatly and that it was very stressful for him. Toward the end, however, he said, "you know, I didn't necessarily look at it as extra stress because I wasn't the one going through that."

Relationship Between Mother and Coworker

Naomi and Ryan's close relationship at the time that Ella was born was evinced by his repeated visits to the hospital while Naomi was hospitalized:

Ryan was there every day. I'm not sure if he was there the day she was born. He might have been, I really, psh, I couldn't tell you. But he was there every other day, checking on us, making sure everything was fine, holding down the fort here [the school].

Naomi admitted that she understood that year was hard on him because he had to do a lot of things by himself that normally she would be there to do: "There was a lot of things that he did—that he had to do on his own, and that wasn't really fair to him." However, Naomi perceived that he took his frustration out on her, contrary to Ryan's account that

he simply did what he had to do and kept in mind that he was not the one with the premature baby:

I mean there's—I couldn't help it, but you know—and he knew I couldn't help it, but he's also not a great person. So you know, he took that out on me a few times, which that year, that specific year, I really tried not to get very upset about, 'cause I mean he kinda had to do this job by himself. . . . And we talked at the end of the school year, like over that summer, and just—about, like hey, let's just start over, like last year was last year, that's all done, you know. But it just was never the same after that, and he was not very pleasant to work with after that.

Naomi reported that their working relationship was significantly damaged, and although she could not be positive that Ella's birth was the causative agent, she thought that it was:

He was very, very critical of me at work. Anytime I would work with the high school kids, it was just to the point where I didn't want to be at work at all. Um, he would do things like . . . he yelled at me in front of the class. That kind of stuff, like all the time, and that didn't happen before. Now, I mean, that could have been a lot of different things. It could have been a lot of reasons, and this may have had nothing to do with it. I just know that from that point forward is when there were problems in our working relationship.

Interestingly, while Naomi thought that "it really affected my and his working relationship in a very negative way," Ryan did not perceive any effect at all: "No. I don't think it did affect our working relationship." Ryan and Naomi, then, reported two completely different experiences of how Ella's birth impacted their working relationship.

Society

The biggest societal impact in the current study was due to financial and economic considerations. Naomi and Brent said that Ella's hospital bills were paid for because she qualified for Social Security and government insurance benefits based on her birth weight. This means that public funds were being used to pay for Ella's hospital bills, which Naomi said were astronomical:

I mean it was like 600, 700 thousand dollars . . . and that was for a child born early that really didn't have any problems. That was for a child born early—and she had—she had to have you know whatever basic tests they do on a regular interval. She did not have to have any special anything, beyond—I mean, as far as—the doctors went on and on about how great she was, and how great she did. That was a pretty uneventful premie hospital stay, and that's how much it was.

Naomi's reminder that Ella's stay was a very basic one is telling of the exorbitant cost burden that premature birth has on our healthcare system.

There was also evidence of a more abstract societal impact of awareness and education about premature birth that spread simply by knowing someone going through the experience. Ryan offered insight about how Naomi's experience had opened his eyes to the phenomenon of premature birth:

I mean I really didn't know anything about premies or any of that kind of stuff before. And then of course, Naomi talks about it all the time, or was talking about it all the time, and uh, she was talking about it all the time like how Ella might be three months old, but you know when she's three months old—or six months old, since she was three months late, she has the development of a three-month-old, and all that stuff, I didn't know anything about. I didn't have any reason to know. So I just kind of, I guess, gained knowledge of it.

Ryan expressed a basic understanding of the concept of adjusted age that he had held onto for three to four years since hearing about it from Naomi. This shows a remarkable capacity for people to learn and retain something that they might not have been previously interested in simply because it is important to someone close to them. This educational component of the experience is an important positive consequence of the birth of a premature child.

CHAPTER FIVE

Discussion and Conclusions

Parents

Marital Relationship

Golish and Powell (2003) described a tendency for couples who already have a strong relationship to become closer through the experience of a premature birth. Couples with a strained marriage, however, tend to experience an exacerbation of their problems when dealing with the crisis of a premature baby. Naomi and Brent both reported that their relationship fell into the first category, and that their already solid relationship was strengthened by going through a difficult experience together. Naomi echoes exactly what Golish and Powell concluded—that a relationship that is already strong prospers from enduring a tough situation together:

It did not shake our relationship in any form or fashion. I—of course I think we came out stronger, because there was a lot of things that we had to deal with that a lot of people don't have to deal with. . . . And we had a good relationship to begin with.

Thus, the current study supports the finding that a couple with a strong relationship is likely to experience a further strengthening of that relationship when enduring a crisis such as premature birth.

Experience of Being a Parent

Attachment. The findings regarding attachment have been inconclusive and contradictory. Many parents report that it is difficult to form an initial bond to their child

due to the circumstances of the hospitalization (von Gontard et al., 1999). Naomi and Brent felt this way, saying that their bonding was delayed or impeded. However, the long-term outcomes of attachment styles between parents and premature children have been debated, with some findings indicating significant adverse effects and some reporting no difference between premature versus full-term parent-infant attachments (Borghini et al., 2006; Brisch et al., 2005; González-Serrano et al., 2012; Hallin et al., 2012; Udry-Jørgensen et al., 2011). Although at the time of the interviews Ella was only four years old and this study did not specifically address attachment styles, Naomi and Brent self-reported that their bond with Ella was not adversely affected, although it was more difficult to establish initially due to her hospitalization. This tends to support the finding that long-term attachment outcomes are not significantly affected by premature birth. However, it is important to note that Ella had had no medical or developmental complications from her prematurity, and it is likely that this lack of complications made the process of bonding and attachment easier for this family.

Emotions. The emotions that Naomi and Brent experienced, including fear, worry, and anger, have been reported by parents in many studies (Blackburn & Lowen, 1986; Golish & Powell, 2003; Jackson et al., 2003; von Gontard et al., 1999). Naomi and Brent also described intensely ambivalent feelings of joy and grief, as previously outlined by Golish and Powell (2003).

However, the feeling of emptiness that Naomi and Brent experienced when they came home from the hospital without their baby is not prevalent in the literature. Naomi, in particular, described a powerful sense of how alone she felt in her own body after the birth, sharply contrasted with the feeling of coexistence with another person who was

growing and moving inside her before the birth. This emptiness may be experienced yet not be commonly captured in studies. This may be because many studies investigate parents' NICU experience in particular rather than how they feel when they are at home (Dudek-Shriber, 2004; Hughes et al., 1994). Even studies that follow families longitudinally tend to use specific time intervals, which may not coincide with milestones such as parents returning home from the hospital (Jackson et al., 2003; von Gontard et al., 1999). It also is possible that this feeling of emptiness is experienced, but simply overshadowed by more distressing feelings that are reported preferentially.

Brent's feeling of resentment also has not been extensively reported. Parents have reported feeling sad because they did not get to have the joyful experience that they anticipated, and jealous of other parents who do (Golish & Powell, 2003), which are similar feelings. It also could be argued that resentment is similar to anger, which is a characteristic emotion for parents. Yet the specific description of resentment is lacking in the literature. It is unlikely that Brent is the only parent to experience this emotion. Perhaps it is being classified into other categories, such as anger and sadness. It is also possible that parents are reluctant to admit to this emotion because it involves a negative connotation of ungratefulness. Although he did admit that he felt resentful, Brent showed signs of being embarrassed and uncomfortable in his admission by pausing before speaking and by minimizing the feeling as he talked about it.

An emotion that is prevalent in the literature but notably absent in this study is guilt. Many mothers describe feeling a personal responsibility for somehow causing the pregnancy to go awry (Golish & Powell, 2003; von Gontard et al., 1999). Naomi, however, did not express this, and even shifted the blame to her family members, who did

not inform her of the family history of preeclampsia before she became pregnant: "So there's a family history there that of course nobody even bothers to tell you until you're already pregnant. Like, seriously? Because I would have started sooner or just not had a child." It is possible that the concrete understanding of why her baby was born prematurely released Naomi from feeling that she had any personal responsibility for the premature birth, while mothers who experience an unexplained premature birth may question themselves about anything and everything they could have done to affect the outcome

Stressors and challenges. The stressors that Naomi and Brent experienced were typical of those that have previously been reported in the literature. Both Naomi and Brent spoke extensively about how sudden, chaotic, and surreal Ella's birth was. They felt *unprepared* for the birth and for the subsequent challenges that it brought with it. The sudden, unexpected nature of the birth is common, and many mothers have expressed bewilderment because they had no indication of the birth, yet they were swept up into the whirlwind of dealing with the emergency situation and the aftermath (Affleck et al., 1991). Thus, Naomi and Brent's experience supports the previous literature which has determined that the frantic and unexpected nature of the birth is distressing to parents.

Naomi and Brent's experience of *not feeling like parents* is also a characteristic challenge that parents of premies face. Naomi's description of her first sight of her child—"cause she's all tangled up and wrapped up in all this stuff and I'm like, is that a child?"—almost exactly echoed a different mother's reaction from Affleck et al.'s (1991) study: "he didn't even look like a person. He was this tiny creature with tubes" (p. 4). This sense of unreality regarding the birth of their child and their newfound roles as

parents made it difficult to smoothly accept their parenthood. The fact that Naomi and Brent could not hold Ella or take a major part in caring for her compounded this feeling. Golish and Powell (2003) previously reported that this inability to physical interact with and care for their baby caused parents to question their roles.

The *uncertainty* that Naomi and Brent faced was a source of much emotion for the parents. This is not abnormal; uncertainty about whether their child will live or have disabilities has plagued many parents, some of whom become intensely fearful and anxious (Affleck et al., 1991; von Gontard et al., 1999). Naomi and Brent's fears, however, seemed to be much more centered around possible disabilities and not so much around her survival, even though she was extremely premature. This apparent lack of concern about Ella's survival could be a result of the amount of time elapsed since the birth.

Another source of stress which Naomi and Brent described was *lack of control*. They expressed great disappointment when doctors told them that they would not be able to have more children, although they had already previously decided that they did not want any more children. Their distress stemmed from their loss of control over the event; they could no longer make that choice for themselves. Their reactions are in line with findings from previous studies (Affleck et al., 1991; Golish & Powell, 2003), which indicate that parents' inability to control the outcome of the pregnancy was upsetting to them. The finding from the current study is particularly interesting, however, because the doctors did not prohibit Naomi and Brent from doing something that they *wanted* to do. While other parents in the literature *wanted* to have a normal, term pregnancy yet they lost control over that outcome, Naomi and Brent did not particularly want to have another

child. However, simply being told that it was not even a possibility made them question their previous convictions. Naomi and Brent expressed a desire to have control over the choice about whether to have further children. They wanted to be the ones to decide. The mere loss of control disturbed and upset them, even though the restriction that was placed upon them was in line with their original desires and plans. This finding should be noted by the NICU staff, as it indicates that giving parents control and choice during the experience of the birth and hospitalization of their child whenever possible could ameliorate a major source of stress.

Coping. Naomi and Brent reported typical coping techniques that have been previously addressed in the literature. Affleck et al. (1991) describe the tendency for parents to use downward comparison in order to cope with the stressful experience of having a premature baby. This involves comparing their situation to others who are worse off. Naomi also engaged in this practice, comparing her baby to another who was born at the same time but had many more complications. The documentation of this coping technique in the literature (Affleck et al., 1991), along with Naomi's use of this technique without any questioning from the researcher about other parents or babies, may indicate that downward comparison is an important psychological mechanism for dealing with stressful situations. In this case, interaction with other families in the NICU may be an important part of the meaning-making process for parents, and should be enabled and encouraged.

Brent predominantly mentioned two types of coping: avoidance and problem-solving. For example, he said that he often just avoided stress by not dwelling on all the details: "You know, just kind of don't really think about it too much." He also

emphasized that during the hospitalization, he simply did what he had to do: "I was just going about everything and making things work, and trying to get things done, you know, trying to lead a normal life as far as, we had to go to work." He said that his personality type encouraged him to "deal with the problems at hand, and whatever comes up will come up and we'll deal with it then." These two techniques are consistent with previous research by Hughes et al. (1994), who found both techniques were commonly used by parents. They also found that the percentage of mothers and fathers who focused on problem-solving was equal, but more mothers tended to use an escape-avoidance coping strategy. It is interesting, then, that the father was the one in the current study who utilized this approach. It is possible that the specific characteristics of the mother-father dyad, rather than merely the sex of the parents individually, helps to determine the methods of coping used by each parent.

Brent and Naomi also found meaning amidst a crisis, which helped them cope with the situation. When Brent described the positive impact that Ella's birth had on his and Naomi's marriage relationship and Naomi said that it was neat to be able to see Ella's development in a way most mothers do not get to, they both found positive things that had come out of their experience. This tendency to find good things that come out of a bad situation is discussed by Affleck et al. (1991). Many couples coped with a premature birth by finding the good things that resulted from it, and one of the most commonly cited positive aspects of dealing with a premature birth is a stronger relationship with their spouse (Affleck et al., 1991). Thus, Naomi's and Brent's meaning-making efforts support the previous observation of this coping technique.

Naomi and Brent both found social support to be an important avenue for successful coping with the birth and subsequent hospitalization. The most important source of this support for Naomi was her husband. She said that she never could have made it through the experience without him. This substantiates Blackburn and Lowen's (1986) finding that spouses were the main source of emotional support for parents experiencing a premature birth. Naomi's extended family and work community also played an important role. Brent similarly reported that "having the outpouring from friends and family and the support there was—I couldn't imagine not having it. It would have been impossible to get through." This is supportive of previous findings which indicate that relying on social support is one of the most common methods of coping for parents (Affleck et al., 1991; Golish & Powell, 2003; Hughes et al., 1994). The replication of this finding in many studies indicates that social support is a vital coping mechanism. The fact that those around the family play such an important role supports the researcher's initial guiding thoughts for this study—that the experience of premature birth is not limited to the nuclear family but is a broad, shared experience which involves many surrounding systems.

Healthcare Team

Experience of Working in the NICU

Nurse. Caroline was very positive about her job and found it to be highly rewarding. When she was asked how caring for premature babies affected her, she repeated several times how rewarding it was, never once saying anything negative about her field. When the researcher specifically asked her if there were any negative ways that

her job impacted her, she responded that there are sometimes parents who are very unreasonable, and as a nurse manager, it is her responsibility to talk to those parents and try to ameliorate the situation. However, she even managed to turn this question around to create a positive outcome; she said that after that crucial conversation took place, the parents realized how over the top they were being and after that, "it was water under the bridge." Caroline's positivity supports Archibald's (2006) finding that nurses were highly satisfied with their job and none in the study had any intentions of changing careers.

Caroline also discussed the close emotional connection with parents and babies that nurses experience: "You get so attached to the babies and the families." As Affleck et al. (1991) pointed out, this is related to the small ratio of nurses to babies under their care. Caroline's testimony is in accordance with Goldberg and DiVitto (1983), who described a nurse being so attached to her primary infant that she cried when it was time for the baby to be discharged. The emotional connection that nurses establish with families also seems to be related in part to their attitude about their career and the reasons for entering it. Caroline reported that many neonatal nurses, herself included, decided on their specialty because "we love babies." This emotional, intrinsic motivation may help nurses foster personal relationships with the babies and families whom they are caring for. This is sharply contrasted by Dr. Williams' reasoning for choosing neonatology: "I knew I wanted critical care." This dichotomy most likely plays a role in the formation of relationships in the NICU setting.

Physician. Dr. Williams overall appeared to be satisfied with his specialty. He mentioned that he was able to form a relationship with parents and that he was working in an environment that suited his personality and his desire to practice medicine in a high-

risk field. However, he did report challenges and stressors, such as being on call and negative patient outcomes. This finding supports a study of neonatologists' job satisfaction and stress experiences which indicated that 75% of neonatologists surveyed were satisfied with their career, but almost all of them experienced stress related to their job (Clarke et al., 1984). Dr. Williams mentioned several of the most common satisfying features of neonatology mentioned by the physicians surveyed, such as patient care, supporting parents, and working in an acute setting. He also reported some of the same stressors, such as the on-call schedule, the stress of patient care, and inadequate equipment. The study by Clarke et al. (1984) is one of the only of its kind and was performed several years ago. Much has changed in healthcare, particularly neonatology, since then. According to the findings of the current study, the experience of neonatologists has remained similar through the years. However, the current study determined the experience of only one physician, and the findings are not generalizable. More current research into the experience of neonatologists would be informative in determining if neonatologists' experiences have changed with the evolution of the field.

Relationship Between Parents and the NICU Staff

In this study, the relationship between the family and the nursing team was a positive one. Naomi and Brent described their confidence in the quality of the hospital and of the NICU, and they described having a good relationship with Ella's nurses. This finding speaks to the hard work that has been done over the years to make the NICU a more family-centered place. Contrary to other studies which have expressed concern about parents feeling left out and uninvolved in their babies' care (Jackson et al., 2003; Feeley, Waitzer, Sherrard, Boisvery, & Zelkowitz, 2012), Naomi and Brent felt that the

nursing staff did a very good job in making them involved in Ella's care. They were able to start off with only touching her, but as time went by, they were able to do more and more. Brent also said the following about the nurses:

They were also encouraging whenever it came time to do things, like okay, now you get to hold them. And it's like, are you serious? She still has tubes coming out of her. I don't think I'm qualified for this. Um, so they were very encouraging. They were great.

Thus, not only did they allow Naomi and Brent to help in Ella's care, but actively encouraged it, even when Naomi and Brent were not feeling confident in their abilities. It has also been reported that many parents feel unprepared to take their infant home and did not perceive that any discharge planning took place (Cooper et al., 2007). Brent and Naomi also reported that bringing Ella home was "unsettling and scary" and "unnerving," respectively. However, the hospital offered them the opportunity to spend the night in the hospital the night before they were to take Ella home. This allowed them to spend one night getting acclimated to taking care of her on their own, while still being in a safe atmosphere and being able to call the nurses for help if they needed it. Brent said that this made them feel more secure than if they had just gone to pick Ella up and taken her home. The implementation of this opportunity to stay in the hospital the night before discharge, then, seems to be a successful response to the concern that parents felt about not having a plan in place for discharge. It is interesting to note, however, that Brent and Naomi still reported feelings of nervousness and insecurity in taking Ella home. This suggests that some nervousness may be a natural response to the transition of bringing a child home and may be an unavoidable and definitional trademark of the experience, no matter how much support NICU staff offer.

The hospital at which Ella was born seems to be successfully implementing a family-centered approach to NICU care, which Caroline appeared to be very proud of. In regard to having previous NICU parents volunteer in the NICU and talk to families, she said, "We're kind of the trend-setters." This hospital works hard to create an experience for families that is as positive as possible, and, according to Naomi and Brent's praises, it seems that it is making a noticeable difference for parents. This finding is in line with that of Cooper et al. (2007), who reported that family-centered care resulted in a positive impact for staff and families, including parents being more informed, less stressed, more confident, and more bonded to their infant. One of the most significant comforts for parents found by Cooper et al. was kangaroo care and being able to hold their babies. However, a mere 8% of practitioners in their study reported that the technique is used on a regular basis at their hospital. Naomi reported engaging in this practice with Ella, further emphasizing this hospital's commitment to supporting parents of premature infants in the NICU.

However, Naomi and Brent described getting very little contact with Ella's doctors during her hospital stay, a concern that has been voiced in the literature for many years (Affleck et al., 1991; Blomqvist, 2011). While many areas of NICU care have improved greatly over time, contact with doctors has remained a complaint. Caroline substantiated this concern, saying that the NICU doctors do not have enough time to "dive a little bit deeper" with families and that the majority of support comes from the nurses. This finding is very concerning. Caroline says that the physician's job is to explain the diagnosis, pathophysiology, and disease process to the parents. However, she then indicated that many parents do not understand what the doctor is explaining to them.

This statement is bolstered by a finding that mothers deemed information from their doctors to be the least helpful in learning about prematurity (Blackburn & Lowen, 1986). It seems that the problem is two-fold: a) doctors do not spend enough time with each family, whether due to choice or inability, and b) when doctors do communicate with families, they are not communicating effectively so that parents can understand. Of even more concern is the fact that some doctors apparently are not aware of the inadequacy of their communication with parents. When Dr. Williams was asked how much time he is able to see and interact with families, he replied, "We spend a long time interacting with them. Probably per family, probably, at least probably 15-20 minutes per parent." While Naomi, Brent, and Caroline all agreed that physicians do not spend very much time with parents, Dr. Williams thought that the time he spends is not only adequate, but "long." This presents a startling disconnect between parents and healthcare providers, and even between members of the same healthcare team.

Extended Family

Experience of Being a Grandmother

Lydia's experience as Ella's grandmother was particularly interesting, although unusual, because she experienced premature birth as both a mother and a grandmother. Lydia gave a first-hand account of the tremendous advances in the NICU environment over time, from a large, bright, noisy room, to dim, cozy, quiet isolettes. Much research over the last decades has allowed for developments in the understanding of what premature babies need, which have led to the changes we see in the NICU, some of which Lydia illustrated (Healy & Fallon, 2014).

Lydia's sense of awe at the NICU environment and her grandchild is consistent with what has been documented in studies of other grandparents (Blackburn & Lowen, 1986; Hall, 2004a, 2004b). A grandmother in one study portrayed her granddaughter as "just perfect all over" (Hall, 2004b, p. 64), and Lydia echoed this sentiment, stating that Ella was "so precious and "so perfect." Other grandparents also express confidence in the staff caring for their grandchild (Frisman et al., 2012), just as Lydia said, "I felt that she was in such good hands where she was." This set of positive reactions to the situation seems to be characteristic of grandparents, possibly because they do not experience the same level of stress that a parent does and thus can focus on more positive aspects.

However, grandparents also experience negative emotions that temper their joy, as do parents (Golish & Powell, 2003), leading to ambivalent and contradictory feelings about the birth (Hall, 2004b). Lydia described the situation as "difficult," saying that "you just want everything to be perfect, and it just wasn't." Lydia experienced a phenomenon described by Hall (2004a, 2004b) as double concern, in which the grandparent worries about both their child and grandchild. Lydia said, "I was worried, I was concerned" about Ella, though not for too long since her health status seemed to soon stabilize. She was more concerned for Naomi, and this is common for grandmothers (Hall, 2004b), while grandfathers tend to put their concerns for the grandchild first (Hall, 2004a).

Experience of Being an Aunt

The findings of what it is like to be the aunt of a premature child are the preliminary, exploratory findings on this topic. The literature has not explored the experience of extended family members outside of grandparents. The current study

found that Abby was one of the most, if not the most, emotionally distressed participants. She was shocked and terrified by the experience, as well as concerned about Ella and whether she would make it. She used the word "terrifying" six times during the interview, and the word "scary" or "scared" nine times. She reported feeling helpless and unsure about how to be a part of the situation. Abby also felt guilty about the fact that she had a normal, full-term pregnancy when Naomi was not able to, and about her negative emotions when the birth did not actually happen to her, but to Naomi. These intense emotions that Abby described—fear, worry, shock, helplessness, and guilt—are often experienced by parents (Affleck et al., 1991; Blackburn & Lowen, 1986; Golish & Powell, 2003; von Gontard et al., 1999). This indicates that the impact of the premature birth on Abby was substantial, perhaps even similar to the impact on a parent. Although, as Abby points out: "I think our situation is a little bit different because I was also expecting." This could have skewed the results and made Abby more sensitive to the premature birth than she otherwise would have been. However, it is still notable that Abby experienced such powerful emotions as a result of this event. Further, Lydia made a comment that supported the idea that many members of the extended family can be affected by a premature birth: "It's hard on the whole rest of the family. My grandmother took it hard, who was Abbyantha's great-grandmother. It was just amazing at how it affected the extended family, and it affected everyone." How widely premature birth affects the family is likely underestimated. Further research is needed to better understand the impact on extended family members like aunts.

Relationship Between Mother and Grandmother

The relationship between Naomi and her mother was unique because they had both experienced a premature birth, although nearly thirty years separated in time. Research in the last decade has increasingly focused on grandparents' experiences of premature birth and on how grandparents interact with and offer support to their children (Frisman et al., 2012; Hall, 2004a, 2004b). Naomi reported that her mother was a significant source of practical support and that she did laundry, cooked, and kept up with other household tasks, which is an important role that grandmothers reported taking on in other studies (Frisman et al., 2012; Hall, 2004b). However, Naomi did not accept the emotional support that Lydia offered, which studies have also described as a hallmark of the grandmother's role in a premature birth (Frisman et al., 2012; Hall, 2004b). This could be because Naomi felt tension related to her perception of judgment, disapproval, and anger from Lydia, "which was weird" for her. This tension may have emotionally distanced Naomi enough that she did not want to accept emotional support from her mother. If that was the case, then the confidence, authority, and ability to be a help and an emotional resource that Lydia felt due to her previous experience with premature birth was underutilized. The potential positive effect was overshadowed by the negative impact on her relationship with her daughter, stemming from her preconceived notion of how the mother of a premature baby should act and her inability to understand the nuances that made their experiences different from one another. This finding indicates that although prior knowledge and experience of premature birth can be advantageous, too much personal experience may cloud the perception of a potential source of support

so that he or she cannot retain a general, unbiased understanding of the experience and can no longer offer helpful emotional support.

Relationship Between Mother and Aunt

Naomi and Abby's relationship was complicated by the fact that they were pregnant at the same time. This brings to light the importance of context in determining the nature of an experience, and validates the theoretical framework of ecological systems theory in this study, as ecological systems theory espouses the importance of the environment and social relationships in human processes. In different circumstances, the experience of Ella's birth most likely would have been different for both sisters. Even though their situation was unique because they were both pregnant at the same time, Naomi and Abby still described a complex, variable relationship through the progression of Ella's birth, hospitalization, and homecoming that warrants further investigation. Both sisters indicated that Abby was an important player in the experience, and it is possible and perhaps likely that other siblings of parents of premature infants, as well as other extended family members, also play a significant role that is, as yet, not depicted in the literature.

Work Environment

To the researcher's knowledge, there has been no research published on the impact that a premature birth has on a parent's coworkers or work environment or the relationship between the parents and those coworkers. The finding that Ryan was put under a great deal of extra stress at work due to Naomi's absence indicates that coworkers can be greatly affected by a premature birth. Interestingly, Ryan seemed to progressively

minimize the stress that he reportedly experienced as the interview went on. He said the experience affected him greatly and caused him a great deal of stress at the beginning of the interview, but by the end, his reported stress was reduced to almost nothing: "you know, I didn't necessarily look at it as extra stress because I wasn't the one going through that." His contradictory responses may indicate that as Ryan attempted to rationalize and process the stressful experience and became further removed from it, the way he remembered it changed over time. There also may have been a social perception bias which caused him to adjust his initial response to appear that he was a more understanding person than he actually was at the time. Also, the collapse of Naomi and Ryan's working relationship, at least from Naomi's perspective, shows that a premature birth can have a significant effect on the relationship between a parent and a coworker. It is interesting to note, however, that the experience was not reciprocally equivalent. Ryan felt no impact on their working relationship, yet Naomi felt that it was at least damaged, if not destroyed. This brings up the question: how can two people going through the same experience see it completely differently? Is this finding related to gender, to parenthood, to stress, to elapse of time, or something else? This dichotomy of experiences requires further exploration to understand why Naomi and Ryan's perceptions were so at odds. The findings from this study show that the literature on premature birth is lacking an important element and could benefit from further investigation into the impact in the workplace.

Society

The extraordinary cost of even an uncomplicated NICU stay, which Naomi quantified, is an indicator of how much of an economic burden this phenomenon places

on society. Although Ella did not have further complications and thus did not require additional funds on top of her hospitalization, some premature babies can have lifelong complications that require even greater use of social resources (Petrou, 2003; Petrou et al., 2001). It is important, then, to attempt to reduce the burden. One way that costs can be controlled is to simply reduce the incidence of premature birth, or at least slow down the increasing rates (WHO, 2012). Also, cost-benefit analyses attempt to discover whether the benefits of a particular treatment outweigh the costs of performing it. Healthcare professionals can use this information to inform their clinical practice and make the most efficient use of resources (Petrou, 2003).

The finding that Ryan, who reported having no reason to know about premature birth before Ella's birth, learned about important concepts within neonatology simply by interacting with and listening to his coworker is indicative of a broad impact that one family's experience of premature birth can have on education and awareness of the phenomenon as a whole. Everyone that comes into contact with the parents of a premature child has the potential to become more aware of issues related to premature birth, and even to become interested in and passionate about the phenomenon. Increased awareness can then lead to further research, increased social support for parents encountering premature birth, and better outcomes for families and children.

Implications

Several major issues arose from the data in this study. First, families are lacking the tools to be able to communicate effectively with each other. Abby said that the single biggest challenge she faced was not knowing how to be part of the situation, and even when she tried to communicate with Naomi and Brent, she felt that they did not give her

any concrete ways that she could be helpful to them. Creating and giving families tools to develop effective communication could reduce the stress for parents and extended family alike. For example, blogging might be an area to pursue because it allows the parents to communicate the situation and what they are feeling and needing to many family members at once, allowing them to spend more time with their baby and less time individually updating family members.

Next, the findings from this study show that extended family members, even those relatively removed from the nuclear family such as a great-grandmother, experience an effect from the premature birth of a child. These family members are usually considered to be sources of the support for parents, but formal support is not offered to them in return to help them deal with the premature birth. In a study of how grandmothers experience premature birth, some grandmothers reported that no one had ever asked them about their experience and how the premature birth made them feel (Frisman et al., 2012). Extended family members can be significantly affected by the premature birth, and there is a need for support that is tailored toward these family members. Simply offering the same educational material to extended family members that are already offered to parents, perhaps by putting these materials online, could be a method of making extended family feel more included and informed.

Lastly, a glaring problem in parents' communication with their doctors was identified in this study. For years, this same problem has been reported in the literature with no corresponding change in practice. Both the NICU staff and the parents in the current study reported a noticeable lack of communication from doctors to parents. More communication could reduce parents' stress and help make them more confident in their

baby's care. Hospitals need to make it a priority to ensure that doctors improve either the quantity or quality of their communication with parents in the NICU (or preferably both, although doctors' time is a serious constraint). This may entail hiring more neonatologists so that each one is responsible for fewer babies and can give more individualized attention to the families. It is possible that the problem could stem from the doctors' source of motivation for entering the field of neonatology. There is some evidence of this in the current study; Caroline reported an intrinsic, selfless motivation for going into neonatal nursing because she loves babies, yet Dr. Williams's reason for choosing neonatology was because he wanted to practice some kind of critical care. An interest in children and families was not present in Dr. Williams's case. It may be necessary for medical schools, pediatric residency programs, and neonatology fellowship programs to more carefully screen for the underlying motivation of students wanting to enter neonatology.

Suggestions for Future Research

Future research is desperately needed in the areas of the extended family and parents' work environments to determine the impact of premature birth on members of these groups and how to best support them. The current study was merely an initial exploration of the impact on these groups using only one family, and the findings cannot be generalized. However, the findings do indicate that the impact on these groups is, as of yet, underrepresented in the research on premature birth and is most likely underestimated. Among extended family members, the research about the experience of grandparents is the most extensive, but more questions remain to be answered. Most of the studies about grandparents use small, relatively homogenous samples (Hall, 2004a,

2004b), and our understanding could be bolstered by studies of a larger, more heterogeneous group of grandparents. Further research could explore potential differences between maternal versus paternal grandparents. Initiatives to support grandparents should be undertaken and implemented in the NICU, and research is needed to evaluate these potential initiatives.

Conclusion

The current exploratory study determined, using an ecological systems theory model and a case study design, that the impact of a premature birth is likely broader and more pervasive than the previous literature has indicated. The experience of a premature birth is context-dependent and is very much influenced by a person's environment and social relationships. Impact from the birth can radiate through many interacting systems and has society-wide implications. Further study is needed to understand the nature of the experience from the perspective of relatives, coworkers, and others who are affected by the birth through their interactions with the family. This direction of study has important implications for healthcare professionals who can improve outcomes for infants and families by understanding how widely the impact of a premature birth can spread and by offering appropriate support to affected members of the family systems.

REFERENCES

- Abbott Laboratories, Inc. (2011). *Your late preterm infant: A parent's guide*. USA.
- Affleck, G., Tennen, H., & Rowe, J. (1991). *Infants in crisis: How parents cope with newborn intensive care and its aftermath*. New York: Springer-Verlag.
- Alexander, G. R., & Slay, M. (2002). Prematurity at birth: Trends, racial disparities, and epidemiology. *Mental Retardation & Developmental Disabilities Research Reviews*, 8(4), 215–220.
- Arad, I., Braunstein, R., & Netzer, D. (2008). Parental religious affiliation and survival of premature infants with severe intraventricular hemorrhage. *Journal of Perinatology*, 28(5), 361–367.
- Archibald, C. (2006). Job Satisfaction Among Neonatal Nurses. *Pediatric Nursing*, 32(2), 176-162.
- Balakrishnan, A., Stephens, B. E., Burke, R. T., Yatchmink, Y., Alksninis, B. L., Tucker, R., ... Vohr, B. R. (2011). Impact of very low birth weight infants on the family at 3months corrected age. *Early Human Development*, 87(1), 31–35.
- Berk, L. E. & Roberts, W. (2009). *Child development* (3rd Canadian ed.). Toronto, ON: Pearson Education Canada.
- Blackburn, S. & Lowen, L. (1986). Impact of an infant's premature birth on the grandparents and parents. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 15(2), 173-178.
- Blomqvist, Y., Rubertsson, C., Kylberg, E., Jöreskog, K., & Nyqvist, K. (2012). Kangaroo Mother Care helps fathers of preterm infants gain confidence in the paternal role. *Journal Of Advanced Nursing*, 68(9), 1988-1996.
- Borghini, A., Pierrehumbert, B., Miljkovitch, R., Muller-Nix, C., Forcada-Guex, M., & Ansermet, F. (2006). Mother's attachment representations of their premature infant at 6 and 18 months after birth. *Infant Mental Health Journal*, 27(5), 494–508.
- Brisch, K., Bechinger, D., Betzler, S., Heinemann, H., Kachele, H., Pohlandt, F., & ... Buchheim, A. (2005). Attachment Quality in Very Low-Birthweight Premature Infants in Relation to Maternal Attachment Representations and Neurological Development. *Parenting: Science & Practice*, 5(4), 311-331.

- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32(7), 513-531.
- Centers for Disease Control and Prevention (2012a). *Morbidity frequency measures*. Retrieved from http://www.cdc.gov/osels/scientific_edu/ss1978/lesson3/Section2.html
- Centers for Disease Control and Prevention. (2012b). *Mortality frequency measures*. Retrieved from http://www.cdc.gov/osels/scientific_edu/ss1978/lesson3/Section3.html
- Chesney, A. R., & Champion, P. R. (2008). Understanding the dynamics between preterm infants and their families. *Support For Learning*, 23(3), 144-151.
- Clarke, T. A., Maniscalco, W. M., Taylor-Brown, S., Roghmann, K. J., Shapiro, D. L., & Harmon-Johnson, C. (1984). Job Satisfaction and Stress Among Neonatologists. *Pediatrics*, 74(1), 52.
- Cleveland Clinic. (2014). *Necrotizing enterocolitis*. Retrieved from <http://my.clevelandclinic.org/childrens-hospital/health-info/diseases-conditions/digestive-disorders/hic-Necrotizing-Enterocolitis.aspx>
- Collyns, O., Gillett, G., & Darlow, B. (2009). Overlap of premature birth and permissible abortion. *Journal of Medical Ethics*, 35(6), 343-347.
- Committee Report: American Pediatrics: Milestones at the Millennium. (2001). *Pediatrics*, 107(6), 1482.
- Cooper, L. G., Gooding, J. S., Gallagher, J., Sternesky, L., Ledsky, R., & Berns, S. D. (2007). Impact of a family-centered care initiative on NICU care, staff and families. *Journal of Perinatology*, 27, S32-S37.
- Davis, L., Edwards, H., Mohay, H., & Wollin, J. (2003). The impact of very premature birth on the psychological health of mothers. *Early Human Development*, 73(1/2), 61.
- Dudek-Shriber, L. (2004). Parent stress in the neonatal intensive care unit and the influence of parent and infant characteristics. *AJOT: American Journal of Occupational Therapy*, 58(5), 509-520.
- Feeley, N., Waitzer, E., Sherrard, K., Boisvert, L., & Zelkowitz, P. (2013). Fathers' perceptions of the barriers and facilitators to their involvement with their newborn hospitalised in the neonatal intensive care unit. *Journal of Clinical Nursing*, 22(3/4), 521-530.

- Feltman, D., Du, H., & Leuthner, S. (2012). Survey of neonatologists' attitudes toward limiting life-sustaining treatments in the neonatal intensive care unit. *Journal Of Perinatology*, 32(11), 886-892
- Ford, R. M., Neulinger, K., O'Callaghan, M., Mohay, H., Gray, P., & Shum, D. (2011). Executive Function in 7–9-Year-Old Children Born Extremely Preterm or with Extremely Low Birth Weight: Effects of Biomedical History, Age at Assessment, and Socioeconomic Status. *Archives of Clinical Neuropsychology*, 26(7), 632–644.
- Frisman, G. H., Eriksson, C., Pernehed, S., & Mörelius, E. (2012). The experience of becoming a grandmother to a premature infant - a balancing act, influenced by ambivalent feelings. *Journal of Clinical Nursing*, 21(21/22), 3297–3305.
- Gallagher, K., Marlow, N., Edgley, A., & Porock, D. (2012). The attitudes of neonatal nurses towards extremely preterm infants. *Journal Of Advanced Nursing*, 68(8), 1768-1779.
- Golish, T. D., & Powell, K. A. (2003). “Ambiguous loss”: Managing the dialectics of grief associated with premature birth. *Journal of Social & Personal Relationships*, 20(3), 309.
- González-Serrano, F., Lasa, A., Hernanz, M., Tapia, X., Torres, M., Castro, C., & Ibañez, B. (2012). Maternal attachment representations and the development of very low birth weight premature infants at two years of age. *Infant Mental Health Journal*, 33(5), 477-488.
- Gross, D. (2011). *Infancy: Development from birth to age 3* (2nd ed.). Boston, MA: Pearson.
- Guinsburg, R., Branco De Almeida, M., Dos Santos Rodrigues Sadeck, L., Marba, S., Suppo De Souza Rugolo, L., Luz, J., & ... Procianoy, R. (2012). Proactive management of extreme prematurity: Disagreement between obstetricians and neonatologists. *Journal Of Perinatology*, 32(12), 913-919.
- Hall, E. (2004a). A double concern: Danish grandfathers' experiences when a small grandchild is critically ill. *Intensive and Critical Care Nursing*, 20(1), 14-21.
- Hall, E. (2004b). A double concern: Grandmothers' experiences when a small grandchild is critically ill. *Journal of Pediatric Nursing*, 19(1), 61-69.
- Hallin, A. L., Bengtsson, H. H., Frostell, A. S., & Stjernqvist, K. K. (2012). The effect of extremely preterm birth on attachment organization in late adolescence. *Child: Care, Health & Development*, 38(2), 196-203.

- Haward, M. F., John, L. K., Lorenz, J. M., & Fischhoff, B. (2012). Effects of description of options on parental perinatal decision-making. *Pediatrics*, *129*(5), 891-902.
- Healy, P., & Fallon, A. (2014). Developments in neonatal care and nursing responses. *British Journal Of Nursing*, *23*(1), 21-24.
- Hughes, M., McCollum, J., Sheftel, D., & Sanchez, G. (1994). How parents cope with the experience of neonatal intensive care. *Children's Health Care*, *23*(1), 1-14.
- Jackson, K., Ternstedt, B.-M., & Schollin, J. (2003). From alienation to familiarity: experiences of mothers and fathers of preterm infants. *Journal of Advanced Nursing*, *43*(2), 120–129.
- Kabir, Z. Z., Clarke, V. V., Conroy, R. R., McNamee, E. E., Daly, S. S., & Clancy, L. L. (2009). Low birthweight and preterm birth rates 1 year before and after the Irish workplace smoking ban. *BJOG: An International Journal Of Obstetrics & Gynaecology*, *116*(13), 1782-1787.
- Lam, H., Wong, S., Liu, F., Wong, H., Fok, T., & Ng, P. (2009). Attitudes toward neonatal intensive care treatment of preterm infants with a high risk of developing long-term disabilities. *Pediatrics*, *123*(6), 1501-1508.
- March of Dimes Foundation. (2009). *NICU: A guide & glossary*. White Plains, NY.
- March of Dimes. (2014a). *Improving the treatment of premature babies*. Retrieved from <http://www.marchofdimes.com/research/improving-the-treatment-of-premature-babies.aspx>
- March of Dimes. (2014b). *Low birthweight*. Retrieved from <http://www.marchofdimes.com/baby/low-birthweight.aspx>
- March of Dimes. (2014c). *Premature babies*. Retrieved from <http://www.marchofdimes.com/baby/premature-babies.aspx>
- Marshall, C. & Rossman, G. B. (2006). *Designing qualitative research*. Thousand Oaks, CA: Sage Publications.
- Mayo Clinic. (2012). *Postpartum depression*. Retrieved from <http://www.mayoclinic.org/diseases-conditions/postpartum-depression/basics/definition/con-20029130>
- McManus, B. M., & Poehlmann, J. (2012). Maternal depression and perceived social support as predictors of cognitive function trajectories during the first 3 years of life for preterm infants in Wisconsin. *Child: Care, Health & Development*, *38*(3), 425–434.

- Meyer, J. D., Nichols, G. H., Warren, N., & Reisine, S. (2008). Maternal Occupation and Risk for Low Birth Weight Delivery: Assessment Using State Birth Registry Data. *Journal Of Occupational & Environmental Medicine*, 50(3), 306-315.
- National Heart, Lung, and Blood Institute. (2012a). *What causes respiratory distress syndrome?* Retrieved from <http://www.nhlbi.nih.gov/health/health-topics/topics/rds/causes.html>
- National Heart, Lung, and Blood Institute. (2012b). *What is respiratory distress syndrome?* Retrieved from <http://www.nhlbi.nih.gov/health/health-topics/topics/rds/>
- National Institutes of Health. (2014). *Neonatal respiratory distress syndrome*. Retrieved from <http://www.nlm.nih.gov/medlineplus/ency/article/001563.htm>
- O'Brien, M., Asay, J. H., & McCluskey-Fawcett, K. (1999). Family functioning and maternal depression following premature birth. *Journal of Reproductive & Infant Psychology*, 17(2), 175.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Newbury Park, California: Sage Publications.
- Petrou, S. (2003). Economic consequences of preterm birth and low birthweight. *BJOG: An International Journal of Obstetrics & Gynaecology*, 110, 17.
- Petrou, S., Petrou, S., Sach, T., & Davidson, L. (2001). The long-term costs of preterm birth and low birth weight: results of a systematic review. *Child: Care, Health & Development*, 27(2), 97-115.
- Pineda, R. G., Stransky, K. E., Rogers, C., Duncan, M. H., Smith, G. C., Neil, J., & Inder, T. (2012). The single-patient room in the NICU: maternal and family effects. *Journal of Perinatology*, 32(7), 545-551.
- Ramsay, S. M., & Santella, R. M. (2011). The Definition of Life: A Survey of Obstetricians and Neonatologists in New York City Hospitals Regarding Extremely Premature Births. *Maternal & Child Health Journal*, 15(4), 446-452.
- Rempusheski, V. (1990). Role of extended family in parenting: a focus on grandparents of preterm infants. *Journal Of Perinatal & Neonatal Nursing*, 4(2), 43-55.
- Rochman, Bonnie. (2012, May 2). The cost of premature birth: for one family, more than \$2 million. *Time*. Retrieved from <http://healthland.time.com/2012/05/02/the-cost-of-premature-birth-for-one-u-s-family-it-was-more-than-2-million/>
- Rossin, M. (2011). The effects of maternity leave on children's birth and infant health outcomes in the United States. *Journal Of Health Economics*, 30(2), 221-239.

- Ruttenberg, W. B., Finello, K. M., & Cordeiro, A. K. (1997). Interactions between depressed and nondepressed Latina mothers and their premature infants. *Infant Mental Health Journal, 18*(4), 364–377.
- Saurel-Cubizolles, M. J., Zeitlin, J. J., Lelong, N. N., Papiernik, E. E., di Renzo, G. C., & Bréart, G. G. (2004). Employment, working conditions, and preterm birth: results from the Europop case-control survey. *Journal Of Epidemiology & Community Health, 58*(5), 395-401.
- Smith, S. R. & Hamon, R. R. (2012). *Exploring family theories*. New York: Oxford University Press.
- Sohr-Preston, S. L., & Scaramella, L. V. (2006). Implications of Timing of Maternal Depressive Symptoms for Early Cognitive and Language Development. *Clinical Child & Family Psychology Review, 9*(1), 65-83.
- Strand, H., Blomqvist, Y., Gradin, M., & Nyqvist, K. (2014). Kangaroo mother care in the neonatal intensive care unit: staff attitudes and beliefs and opportunities for parents. *Acta Paediatrica, 103*(4), 373-378.
- Udry-Jørgensen, L., Pierrehumbert, B., Borghini, A., Habersaat, S., Forcada-Guex, M., Ansermet, F., & Muller-Nix, C. (2011). Quality of attachment, perinatal risk, and mother-infant interaction in a high-risk premature sample. *Infant Mental Health Journal, 32*(3), 305–318.
- von Gontard, A. A., Schwarte, A. A., Kribs, A. A., & Roth, B. B. (1999). Neonatal intensive care and premature birth - maternal perceptions and coping. *Archives Of Women's Mental Health, 2*(1), 29.
- World Health Organization. (2012). *Born too soon: The global action report on preterm birth*. Geneva, Switzerland.