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Discharge Readiness for Families with a Premature Infant Living in Appalachia

A dissertation

presented to

the faculty of the Department of Nursing

East Tennessee State University

In partial fulfillment

of the requirement for the degree

Doctor of Philosophy in Nursing

by

Kathy Zimmerman

December 2017

Dr. Masoud Ghaffari, Chair

Dr. Sharon Loury

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Dr. Carole Kenner

Key words: Discharge, Preparedness, Prematurity, Appalachia, Parents, Infants, Transition,

NICU

ABSTRACT

Discharge Readiness for Families with a Premature Infant Living in Appalachia

by

Kathy Zimmerman

With increased advances in technology, the overall survival rates in the Neonatal Intensive Care Unit (NICU) for premature infants at lower gestational ages have improved. Although premature infants survive at lower gestational ages, they are often discharged to home with unresolved medical issues. While the birth of a new baby for parents is a joyous occasion, they often have difficulty coping and transitioning into a parental role. Premature infants also have ongoing complications such as difficulty with feeding, developmental delays in growth, and long-term eye and respiratory complications. As a result of chronic health sequelae, premature infants require extensive utilization of hospital and community health resources. In addition, hospitals must coordinate between community resources, while preparing parents for specialized discharge teaching. Furthermore, individuals living in rural and underserved areas face unique challenges and barriers to access healthcare resources. An interpretive phenomenology study was conducted to bring insight and develop an understanding into how families perceive discharge readiness, accessing health care resources, and ability to cope at home after discharge from a Level III NICU located in Appalachia. Ten parents total were enrolled in the study and consisted of three couples, three married mothers, and two single mothers. Interviews were conducted over a period of six months and transcript analysis revealed development of major and minor themes. The studies overarching theme was Adapting to a New Family Roles, Finding Normalcy, which described parents experience of being prepared for discharge and their transition to home. Three major themes related to discharge readiness from detailed analysis included; 1) Riding out the

storm, 2) Righting the ship, and 3) Safe port, finding solid ground. Subthemes that supported development of the major these were 1a) having the carpet pulled out from under me, 1b) things I lost, 1c) feel like an outsider, 1d) sink or swim, 2a) quest for knowledge, 2b) caring for me, care for my baby, 2c) customized learning, 3a) getting to know baby, 3b) becoming the expert, 3c) ongoing emotions, and 3d) adjusted parental role. Practice and research implications for discharge readiness include providing customized support for parents as they adjust to a new normal for their family, identify necessary resources, and become self-reliant once home.

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DEDICATION

A dissertation is never completed without help from many sources. It takes a village to be successful and I would not have been able to complete my dissertation without the support and love from my family, friends, and colleagues. I especially want to thank my wonderful and beloved husband, Mike Zimmerman, for his undying love and concern for my welfare throughout this process. He has been the consummate caregiver, taking over all things related to running our household, listening to my frustrations, and being my cheerleader. I am forever grateful and will always appreciate your being there for me. Also I am thankful to my parents, Howard and Maxine Teel for your constant encouragement and always believing in me. Your guidance and care for my upbringing, empowering me with a vision that anything is possible, instilling faith in a higher power, living one's life as a true and humble person, and provided me with the foundation and skills to succeed in this journey.

I also dedicate this dissertation to my family and friends, who supported me all throughout the doctorate journey. Special thanks to Debra Rose Wilson, who first encouraged me to start this process, and often, challenged and inspired me to forge ahead. I want to thank Cheryl Postlewaite, Connie Bauersachs, and Olena Bolyensky for your patience, moral support, and feedback. In addition, all the other family and friends who's encouragement and support kept me grounded, balanced, on task as I completed coursework, conducted research, and while writing my dissertation. You shared in each of my successes, celebrations, struggles, and accomplishments.

Lastly, I would like to thank all the families who allowed me into their home and shared their personal story. You opened up your hearts and shared those tender moments and difficult challenges you experienced. I was honored to have shared a small part of your parenting journey

and this experience has enriched my life in many ways. The love and pride for your new family was evident, and despite struggles and adjustments, each of you maintained a warrior spirit in overcoming obstacles to find your new normal. When working directly in the NICU with parents of premature infant, I always felt that parents were the real heroes and your stories confirmed my belief.

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CHAPTER 1

INTRODUCTION

The Centers for Disease Control and Prevention (CDC) (2015) indicated that approximately 500,000 premature infants are born each year. Premature births occur in 12 percent of births, and the majority of these infants require admission to Neonatal Intensive Care Units (NICU), with seven percent hospitalized for six or more days (Hamilton, Martin, Osterman, & Curtin, 2014). Survivability of lower gestational age has increased 31 percent since the early 1980s and includes the very extreme premature infant born at 23 week gestation (Blencowe et al., 2012; Dusing, Van Drew, & Brown, 2012; Petrou, Sach, & Davidson, 2010). Premature infants born at lower gestational ages are at increased risk of long-term neurodevelopmental complications and prone to extreme disabilities (Johnson et al., 2009). While all newborns are vulnerable, premature infants are at increased risks for long-term and complex health problems (Beck et al., 2010; Newnam & Parrott, 2013). Birth of a premature or medically fragile infant and admission to the NICU is identified as a transition crisis for families (Boykova & Kenner, 2012; Broedsgaard & Wagner, 2005; Enlow et al., 2014; Raffray, Semenic, Galeano, & Marin, 2014; Wong, 1991). Although the NICU environment provides support for these fragile infants, the family structure is adversely affected by the increased stress and anxiety of being in the unfamiliar environment during the infant's hospitalization (Bracht, O'Leary, Lee, & O'Brien, 2013; Erdeve et al., 2008).

The survival rates of premature infants have increased; however, they experience lengthy inpatient hospitalization in the NICU with extended adverse health sequelae after discharge. Throughout the lengthy hospitalization, premature infants require interventions from trained medical staff, who are also preparing parents to care for their infant at home after discharge

(Ballantyne, Stevens, Guttman, Willan, & Rosenbaum, 2012; Bissell & Long, 2003; Broedsgaard & Wagner, 2005; Lee, Garfield, Massey, Chaysinh, & Hassan, 2011; Raffray et al., 2014; Smith, Young, Pursley, McCormick, & Zupancic, 2009; Sneath, 2009). Therefore, parents become the primary caregivers at home despite the fact many do not feel ready or prepared, even for basic infant care tasks (Jeffries, 2014; Weiss et al., 2008).

Parents who are caring for a child with medical complications experience challenges coping daily and are prone to poor mental health outcomes such as grief, anxiety, and Post Traumatic Stress Disorder (PTSD) (Brooten et al., 1988; Feeley et al., 2014; Hughes & McCollum, 1994; Wallander et al., 1989). Infant outcomes are related to overall family wellbeing (Able-Boone & Stevens, 1994; Brazy, Anderson, Becker, & Becker, 2001; Gennaro, 1988; Zelkowitz, Na, Wang, Bardin, & Papageorgiou, 2011). Several studies also report the lack of healthy adaptation to parenthood, limited bonding, perceptions of infant vulnerability, fears of uncertain outcomes, and difficulty transitioning to home can result in negative impact on health outcomes for their infant (Affleck, Tennen, Rowe, Roscher & Walker, 1989; Allen et al., 2004; Brooten et al., 1988; Kenner & Lott, 1990; McKim, 1993).

Statement of the Problem

As premature infants' acute health issues are resolved, they are discharged to home with unresolved medical complications. Current research highlights specific areas in which parents are able to manage their infant's chronic medical issues, including the ability to handle medical equipment and administer medications, knowledge and use of community resources, and development of complex problem-solving skills to maintain physiological stability for their infant; however, little in the literature focuses on the population in the south central and southern region of Appalachia. There is a direct relationship between disparate families living in the

Appalachia and poor health outcomes, particularly related to access to care, socioeconomic status, and medical resources (Halverson, Ma, & Harner, 2004; Marshall et al., 2017). There is a lack of research studies that represent families living in Appalachia and their experiences with caring for their premature infant after discharge from the NICU. There is a paucity of research highlighting discharge readiness and transition to home for NICU families living in Appalachia. In addition, little is known about challenges and barriers families caring for a medically fragile infant at home and who live in Appalachia might experience. Finally, there are gaps in the research that focus on parents' needs and access to care for this population.

A convenience sample of parents with a medically fragile premature infant, also known as a preemie, were recruited at a NICU Follow Up clinic in the south central and southern region of Appalachia (see Figure 1). Particular focus of this study was on high-risk infants, born at 32 week or less gestation, and discharged to home with unresolved medical conditions. These infants are especially vulnerable for long-term health complications, therefore thorough discharge planning and follow up care essential to address health concerns (Lee et al., 2011). Research highlights the ongoing health disparities (Marshall et al., 2017), especially for infant mortality and deficit in life expectancy across Appalachia (Singh, Kogan, & Slifkin, 2017). This research study was conducted to develop an understanding around parents' perceptions of the discharge process, transition to home, and the ability to access health care resources after discharge. The Kenner Model of Transition (Boykova, Kenner, & Ellerbee, 2014) for NICU parents was embedded with in the study, with additional extrapolation from thematic analysis of data. Institutional Review Board (IRB) approval and consent was obtained prior to beginning the study.

Families with an infant discharged from the NICU were recruited from a community health center in rural Tennessee. The clinic is a nurse-managed community health clinic that is a Federally Qualified Health Center serving underserved populations and operated by of East Tennessee State University School of Nursing. Inclusion criteria for the study consisted of families who speak English, live in Appalachia, had a premature infant born at or less than 34 week gestation, and discharged with unresolved medical issues for whom parents manage medications or medical equipment at home.

The study was conducted over a six-month period of time, from May 2016 until November 2016. The principal investigator obtained Internal Review Board (IRB) approval prior to beginning the study. Families were given a flyer (Appendix A) with an explanation of the research study and offered an option to withdraw from the study at any time. Families who agreed to participate in the study signed an informed consent form, filled out a demographic form (see Appendix B), and were given a copy of the consent form to keep. The study consisted of focused interviews that were conducted at parent's residence, via phone, and one at a local restaurant. Privacy was provided for all interviews, particularly the one held at a restaurant.

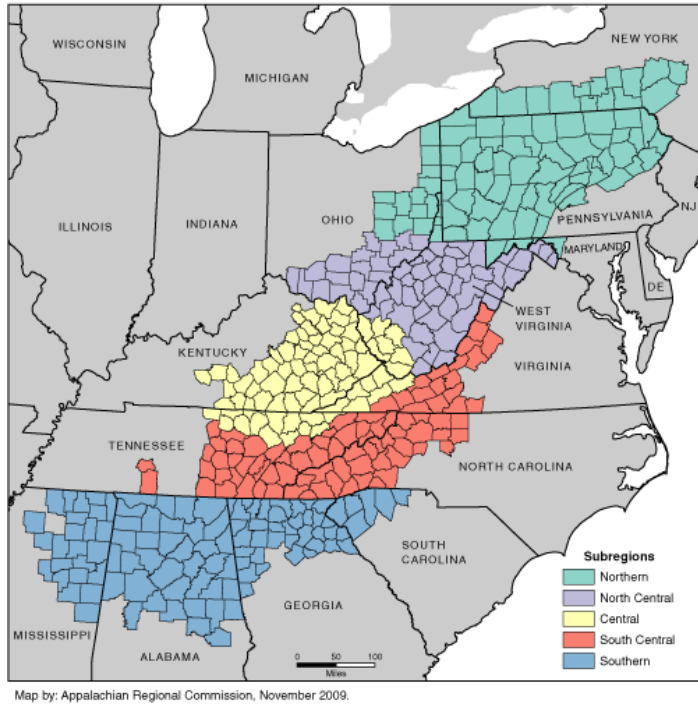


Figure 1: Sub Regions in Appalachia. From "Subregions in Appalachia," by Appalachian Regional Commission, 2009
 (https://www.arc.gov/research/mapsofappalachia.asp?MAP_ID=31). In the public domain.

Purpose of the Study

The purpose of this study was to explore the perceptions of parents who had a premature infant with unresolved issues and who live in Appalachia regarding discharge readiness from the NICU and access to care as they transition to home. Infants' acute health care needs are addressed in the NICU, but they are often discharged to home with continuing medical needs. Discharge readiness and transition to home are important concepts to explore for families taking care of a premature infant with unresolved medical conditions. Parenting skills and understanding how to care for the medical issues of their infant are very different from those parents with a healthy infant. A phenomenological study was conducted to gain an understanding

of discharge readiness, access to care, and the lived experience for families with a premature infant. Parents who had a baby discharged from the NICU and were referred to the regional NICU Follow Up clinic were recruited. The researcher interviewed families who consented to participate in the study. Guiding questions were used to explore and discover parents' perceptions around the discharge experience and ability to care for their infant at home.

Significance of the Study

Research studies highlight the need for effective discharge readiness for patients with acute and chronic health conditions (Weiss et al., 2007; Weiss, Yakusheva, & Bobay, 2010). Much of the research focuses on the discharge process from the hospital as a one-time event; however, those requiring extensive hospitalization, such as premature infants discharged with unresolved medical issues, require complex discharge instructions and preparation extending beyond discharge (Ballantyne et al., 2012; Hummel & Cronin, 2004; Sneath, 2009). Parents must be prepared to care for their infant at home, able to access outpatient resources, and navigate multiple follow up appointments. While parents with a premature infant experience difficulty coping and managing at home, families living in rural areas have additional challenges in caring for their infant at home. Access to care, distance to travel for appointments, lack of professional support, and limited specialization services for premature infants needs all create barriers for families living in rural and underserved areas.

Readiness for discharge involves comprehensive assessment of infant readiness, family readiness, home plan readiness, and outpatient health resources (Bissell & Long, 2003; Weiss et al., 2008). Successful discharge readiness may lead to increased ability to cope, resiliency, and improved infant growth and development. The purpose of this study was to provide insight into concerns families living in Appalachia with a premature infant have after discharge from the

hospital, to determine if families felt discharge teaching was adequate to explore perceptions of parents' discharge preparedness, to determine their understanding of available health resources, and to explore challenges accessing resources and ability to cope at home.

Philosophical Perspectives

Phenomenology philosophy, specifically interpretive perspectives, is imbued within this study. Phenomenology focuses on interpretation and understanding the meaning of the lived experience for a specific phenomenon. Through in depth narrative interviews, the researcher highlights the lived experience around discharge readiness for parents with a premature infant living in Appalachia, and strives to gain understanding from all text. Understanding comes from thematic analysis of transcripts, field notes, reflective journals, and peer feedback.

Specific Aim of the Study

This study focused on the experiences of families who had a medically fragile infant discharged from the NICU and their perceptions of preparedness in that process. The specific aim was to gain an understanding of parents living in rural settings or areas, experiences around discharge, identify any challenges or disparities they might have experienced with access to care and obtaining resources, and their ability to care for their infant once home. Themes that emerged from the data rich interviews were used to identify parental level of preparedness and highlighted potential gaps around discharge readiness. Implications for practice, theory, research, and policy were identified from data analysis. The overall aim of this study was to highlight areas that will enhance the discharge process and improve outcomes for infants and family process. This research study focused on addressing the questions that follow.

Research Questions

1. How do families perceive their level of preparedness in taking care of their premature infant at home after discharge?
2. What, if any, challenges do families with a premature child face in attempting to access medical resources after discharge from the hospital?
3. What, if any, types of medical and social resources are families with a chronically ill child utilizing?
4. What, if any, concerns do families have related to taking care of their premature infant at home after discharge?
5. What, if any, types of challenges do families have while caring for their premature infant?
6. What, if any, specific information related to the infant's unique needs was provided during discharge teaching?
7. How do parents view the overall outcome for their infant?

Summary

The advent of increased medical interventions and technology has resulted in infants being born earlier, however they are also being discharged with unresolved medical conditions, and parents are required to manage their babies' health. Training for parents is essential to be prepared for independent parental tasks, while also collaborating with community providers, and ability to utilize resources. Access to care and qualified professionals can also present challenges for parents, particularly those living in rural areas. This study shed light on parents experiences as they adapted to their new family, identified barriers to discharge readiness, and areas that provided support and facilitated parent's transition to home.

CHAPTER 2

REVIEW OF THE LITERATURE

This chapter reviews significant literature related to the experience of having a premature infant in the NICU, transition in parental roles toward independent caregiver, and discharge readiness as an embedded aspect of transition for families. Premature birth is a complex medical issue that challenges the family bonding process. Successful outcomes depend upon societal support to sustain health and wellness, which provide opportunities for further discussion and analysis. The overarching feature of this study focused on discharge readiness and transition for families with a premature infant living in rural areas of south central and southern Appalachia, who faced adversity in accessing material and social support.

Premature Birth

With the advancement of technology, antenatal steroids, and other lifesaving measures, infant age of viability has lowered significantly in the last 30 years. Although age of viability has lowered, the incidence of premature birth, has increased 30 percent from 1981 to 1997, to a rate of 12 percent of all births in the United States (Hogue & Vasquez, 2002). Higher mortality rates occur in the United States than other countries, ranking 27th in 2002, globally (Hogue & Vasquez, 2002). In 2003, 67 percent of infants born below 24 week gestation and 82 percent at 24 week gestation survived, whereas in the mid-1990s infants born below 24 week had a 10 to 50 percent chance of survival, and those born at 24 week gestation had a 60 to 89 percent chance of survival (El-Metwally, Vohr, & Tucker, 2000; Herber-Jonat et al., 2006). Ethnic and racial minorities share a disproportionately higher incidence of premature births nationwide (CDC, 2011). Some states, including Tennessee, Kentucky, and Virginia, experience rates of premature births higher than the national average, upwards of 13 percent (March of Dimes, 2013).

Premature infants admitted to the NICU experience physiological complications such as respiratory distress syndrome, intrauterine growth restriction, intraventricular hemorrhage, and bronchopulmonary dysplasia (Burnham, Feeley, & Sherrard, 2013). Medical interventions and treatments include mechanical ventilation, nasal cannula high flow oxygen, intravenous line, chest tube, gavage feeding, and other surgical procedures (Burnham et al., 2013). There is an inverse relation between gestational age and need for technological support, morbidity and mortality, and the magnitude of health risk related to long-term disabilities (Blencowe et al., 2012; Purdy & Melwak, 2012; Zimmerman & Bauersachs, 2012).

Additionally, the American Academy of Pediatrics Council on Children with Disabilities (AAPCCD, 2005) identified premature infants and those with low birth weight (LBW) as high risk for medical complications who potentially require substantial health care support and may become technology-dependent. Infants with LBW, weighing less than 2,500 grams, and especially those with very low birth weight (VLBW), weighing less than 1,500 grams, have the highest risk for health complications, reduced viability, and longer hospital stays (Escobar et al., 1999; Kim, Garfield, & Lee, 2015; Underwood Danielsen, & Gilbert, 2007). These infants have one or more unresolved medical conditions, highlighting the need to prevent further adverse health outcomes or re-hospitalization (AAPCCD, 2005). Premature infants experience developmental delays, cerebral palsy, respiratory complications, heart disease, and hearing and vision problems. Cho et al. (2012) highlighted the most common concerns parents with a premature infant experience: feeding and developmental delays. Infants born with lower birthweight and gestational age are at highest risk of disabilities and long-term neurological complications (Brisch et al., 2005; Finnström et al., 1998; Hack, Klein, & Taylor, 2005; Moster, Lie, & Markestad, 2008).

Health Disparities

Research has demonstrated increased levels of that health disparities exist among individuals experiencing poverty and homelessness, racial and ethnic minorities, individuals facing chronic mental and physical illness or substance abuse, immigrants, refugees, individuals experiencing family abuse, and high-risk mothers and infants (Aday, 1994; de Chesnay & Anderson, 2016). While vulnerability may be a group or individual concept, practitioners and researchers focus on identifying areas with health disparities and developing methods to improve health and wellness as a society. De Chesnay and Anderson (2016) highlight the disparate impact living in rural areas has on health and wellness for individuals.

Rural

Despite lifesaving measures to save premature infants at younger gestational age challenges families must deal with caring for their infants, families who live in a rural community are further burdened by limited access to health care resources (Doherty, 2007). MacDowell, Glasser, Fitte, Fratzke, and Peters (2009) stressed the shortage of health care professionals and resources in rural locations. This is especially true for specialty and subspecialty providers such as those needed to care for a medically fragile infant. According to Meit et al. (2014), disparities exist for children in rural areas due to the lack of pediatricians and living a considerable distance from health resources. Medically underserved regions present significant barriers and access to care for families with a special needs child (Marcin et al., 2004). Marcin et al. (2004) conducted a telemedicine medical needs assessment in rural northern California and identified barriers to care such as increased travel time to medical facilities, missing work for appointments, parental self-regulation of children's medication, and increased reliance on emergency medical services.

Complications of prematurity discussed above continue long after discharge. Bruder and Cole (1991) highlighted the need for careful discharge instructions; however, fewer resources are available in rural communities. Miles, Holditch-Davis, Thoyre, and Beeber (2005) revealed in a qualitative study of African American mothers in the rural southeast the lack of provider understanding needs of premature infants' care. Findings of parental concerns were similar to other studies; but the impact of lower socioeconomic status and limited access to resources created additional barriers to care (Miles et al., 2005). Early treatment and intervention are keys to identifying early developmental needs; however, infants living in rural areas are further challenged by limited access to early intervention and therapeutic services.

Contrary to statistics highlighting increase in premature birth over the past 30 years due to medical advances, Kent, McClure, Zaitchik, and Gohike (2013) described a slight recent decrease in preterm birth and low birth weight infants in both urban and rural areas. Despite this overall decrease, there continues to be significant increases in adverse outcomes for infants living in rural areas. Kent et al. (2013) posited contributing factors for continual poor outcomes in rural areas include fewer providers, even fewer specialists, an increase in maternal smoking, and an overall increase in distance to health resources or "time to care" (p. 6). Samra et al. (2013) explored the relationship between perceived infant outcomes of parents, perceived infant vulnerability using the Vulnerable Baby Scale and distance from health care facility and revealed parental perception of poor outcome and higher risk were six times higher for each additional hour of travel to a medical center in rural Midwest.

Nesbitt, Connell, Hart, and Rosenblatt (1990) studied rural birth outcomes in Washington State and identified that rural areas have fewer health providers and even less specialists per capita than urban areas. Marginal income, lack of sufficient transportation, and length of travel to

health services place patients at risk for adverse outcomes. Additionally, women who deliver outside their community are more susceptible to poor perinatal outcomes than those who deliver within their own community and face additional barriers (Nesbitt et al., 1990). In contrast Wakely, Rae, and Cooper (2010) conducted a study focusing on rurality and identified several themes related to family resiliency: strength to cope, optimism, search for normalcy, and maintenance of “stoic survival” for families living in rural areas of Australia (p. 2).

Appalachia

Research has demonstrated that Appalachia has significant deficits as compared to other areas of the United States and poorer health outcomes that correlate with adverse socioeconomic factors than non-Appalachian areas (Halverson et al., 2004; Marshall et al., 2017). Furthermore, these disparities especially for infant mortality and life expectancy, increased between 2009 and 2013 (Singh et al., 2017). A goal of Healthy People 2020 (2017) is to reduce health disparities across the United States, particularly along the demographic region of Appalachia (Marshall et al., 2017). Appalachia is distributed along urban and rural areas, consisting of 410 counties and extends from the southern area of New York, along the Eastern States, and to the northeastern portion of Mississippi. While there are subgroups within the Appalachia area, significant disparities, high levels of poverty (Figure 2), and mortality measures are reported in the Eastern Tennessee, West Virginia, Virginia, North Eastern North Carolina, and eastern Kentucky (Halverson et al., 2004).

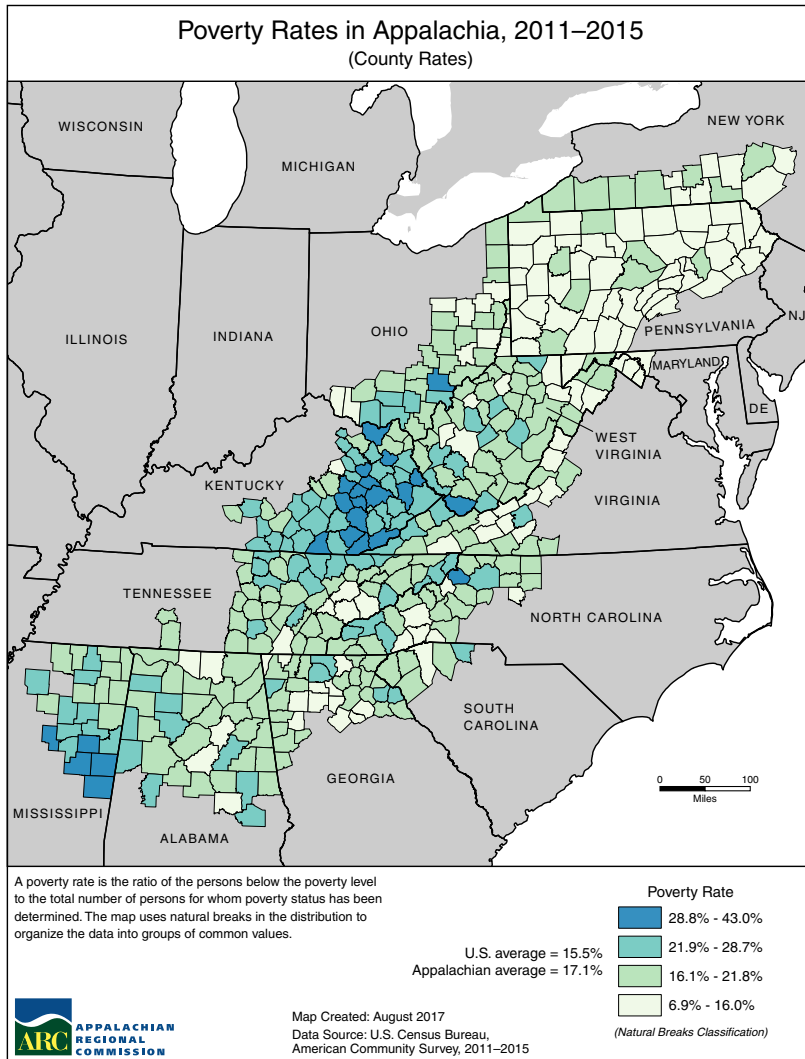


Figure 2: Poverty Rates in Appalachia, 2011–2015. From "Poverty Rates in Appalachia," by Appalachian Regional Commission, 2017 (https://www.arc.gov/research/mapsofappalachia.asp?MAP_ID=128). Available in the public domain.

Very few studies are specific to the needs of families with a premature infant that live in Appalachia. Bailey and Cole (2009) conducted a longitudinal study of 4,144 births in rural southern Appalachia. Infants were at risk of being born with lower weight (770 grams), were 1.5 inches shorter, born over three weeks earlier than infants born in non-rural areas, and were four

times more likely to be born premature and five times more likely to be admitted to NICU (Bailey & Cole, 2009). Recommendations included increasing access to care, increasing health providers specializing in caring for premature infants, and improving transportation and employment (Bailey & Cole, 2009).

There is an association between adverse socioeconomic factors and adverse health outcomes (Halverson et al., 2004; Marshall et al., 2017). Access to adequate medical resources and health professionals is critical for health and wellness; however Appalachian rural counties, especially in eastern Tennessee, northwest North Carolina, central West Virginia, and eastern Kentucky, include significant shortage areas, with few to no resources in some counties. Families and community leaders could offer insight into how to best meet their health needs and address barriers to health care.

Vulnerable Populations

Vulnerable populations are identified as those who are more susceptible to developing illness and health problems than the rest of society (Aday, 1994). Groups considered to be vulnerable are at increased risk of having poorer physical, mental, and social health outcomes (Flaskerud & Winslow, 1998). Vulnerable individuals are often underserved as they deal with increased challenges related to access and quality of care. Underserved populations, especially those living in Appalachia, typically have lower socioeconomic status, experience stigma and discrimination, and are at risk for being marginalized and disenfranchised (Flaskerud & Winslow, 1998).

Transition

Transition is a complex process consisting of relationships, health, and environment. Transition involves integrating new knowledge and results in a change in action and outcomes

(Meleis et al., 2010). The process includes identification of new roles, relationships, and patterns of behavior (Meleis et al., 2010). Events such as birth of a premature infant begins the process of change for parents and is described as a state of transition, moving through crisis, uncertainty, and powerlessness (Watson, 2010) as parents transition to parenting a hospitalized infant, gradual caregiving, and finally, an independent role at home.

Transition for parents with a term or healthy newborn is very different from those with medical complexities (Odom & Chandler, 1990). Having a premature infant poses an additional crisis in transition in which parents face five basic interrelated categories of needs: Informational needs are prevalent and influence all other categories; stress and coping influence parent-child role development; grief influences parent-child role development; and both stress and coping influence social interactions between the parent and child (Boykova & Kenner, 2012; Flandermeyer, Kenner, Spaite, & Hostiuck, 1992). The transition from hospital to home for these families also presents unique challenges (Boykova & Kenner, 2012), whereas continuity of care is essential in overcoming these challenges (Merritt, Pillers, & Prows, 2003; Mills, Sims, & Jacob, 2006; Sims, Jacob, Mills, Fett, & Novak, 2006).

Hutchinson, Spillett, and Cronin (2012) identified four phases parents experience as they transition from NICU to home: “premature parental onset, parental incompleteness, parental involvement, and completion” (p. 13). Bruder and Walker (1990) summarized in a literature review the families’ transition from hospital to community services is impacted by communication between health care services, both in hospital and community providers.

However, patients within the process are more vulnerable to risks that may have an adverse effect on health (Meleis, 2010). Contrary to Hutchinson et al.’s (2012) four phases of transition, Boykova and Kenner (2012) discussed two transition periods using the Kenner Model of

Transition for NICU parents, one transition to parenthood and finally the transition to caregiver of their infant at home. Boykova (2015) added a third transition point, the transition to primary care to meet the health care needs of infants. This is important to link the needs of parents by determining level of discharge readiness and successful transition to home for parents.

Role Adaptation

Parents of premature infants experience difficulty in managing the parent role while caring for their infant (Bissel & Long, 2003; Gennaro, 1988; Holditch-Davis, Miles, Burchinal, & Goldman, 2011; Pridham, Lin, & Brown, 2001). Extended hospitalization and separation alters the transition to parenthood (Bernstein et al., 2007; Broedsgaard & Wagner, 2005; Brooten et al., 1988; Odom & Chandler, 1990) and may result in role confusion (Affonso et al., 1992; Rikli, 1996; Scharer & Brooks, 1994). Although some researchers identified the relationship between maternal role identity and affective perception of their infant was similar in term and preterm infants (Flacking, Ewald, & Starrin, 2007; Griffin & Pickler, 2011; Hutchinson et al., 2012), some preterm mothers experienced a delay in identifying their maternal role (Zabielski, 1994).

Parents of premature infants also experience less confidence (Gennaro, 1988), and feelings of inadequacy as a parent (Affonso et al., 1992) and need more support (Coppola, Cassibba, & Costantini, 2007; Jones, Rowe, & Becker, 2009). Researchers have discovered there is a lack of identifying as a parent (Flacking et al., 2007; Griffin & Pickler, 2011; Hutchinson et al., 2012) and experiencing less self-confidence (Gross, Rocissano, & Roncoli, 1989; Holditch-Davis, Bartlett, Blickman, & Miles, 2003; Raines & Brustad, 2012). Olafsen et al. (2007) also revealed a correlation between stress and confidence in mothers of premature infants.

In addition to altered role identity, parents of premature infants often experience delayed or distorted attachment (Forcada-Guex, Pierrehumbert, Borghini, Moessinger, & Muller-Nix 2006; Huhtala et al., 2012; McManus & Poehlmann, 2011; Reed & Bramwell, 2003; Shah, Clements, & Poehlmann, 2011; Watson, 2010; Zelkowitz et al., 2011). Parents also reported feeling inadequate and seeking normalcy (May, 1997; Murdoch & Franck, 2011). Bonding is also affected from less contact with infants in the beginning of their hospitalization and a premature infant's limited response to comfort cues (Brachfeld, Goldberg, & Sloman, 1980; Coppola et al., 2007; Davis, Edwards, & Mohay, 2003; Weiss & Chen, 2002; Zabielski, 1994). While Hall et al. (2014) found no differences between full-term and preterm infants when comparing parental attachment and infant responsiveness, Amankwaa, Pickler, and Boonmee (2007) revealed social support and maternal self-esteem had a "significant relationship with maternal responsiveness" (p. 25).

Birth of a premature infant is often unexpected, and parents experience uncertainty and unforeseen challenges. Parents are faced with multiple mental health concerns with separation and uncertainty with the birth of their premature infant (Bakewell-Sachs & Gennaro, 2004; Doering, Moser, & Dracup, 2000; Griffin, & Pickler, 2011; McManus, & Poehlmann, 2011; Meyer et al., 1995; Miles & Holditch-Davis, 1997; O'Brien, Asay, & McCluskey-Fawcett, 1999).

In an early study, McCubbin et al. (1983) identified high levels of stress among parents at home coping with caring for a chronically ill child. While Boykova and Kenner (2012) detailed family stress and coping at home post discharge, there is little research to describe the relationships between preparedness, stress, and readmission rates. Rabelo, Chaves, Cardoso, and Sherlock (2007) conducted a qualitative study of 11 mothers in a Brazilian NICU to explore feelings and expectations at discharge. Rabelo et al. (2007) analyzed data from interviews into

the following themes: moment of discharge, instruction and preparation for discharge, and maternal questions and doubts. Despite feeling excited and happy at discharge, mothers were anxious and insecure about caring for their infant at home (Rabelo et al., 2007). Rabelo et al. (2007) also highlighted the impediment of bonding and normal parenthood roles in the NICU; therefore, it is essential to involve parents in care to “reestablish affective bonding” (p. 337). Parents can participate in care, gain support, and learn knowledge and skills required to safely care for their infant, which ultimately will increase their confidence in caring for their infant.

Coping

Parents with a premature infant often experience altered levels of coping (Gennaro, 1988; Ray & Ritchie, 1993; Teague et al., 1993). In addition to having feelings of powerlessness and helplessness (Kenner & Lott, 1990), parents are susceptible to caregiver burnout (Garel, Dardennes, & Blondel, 2007; Lagatta, Clark, Brousseau, Hoffmann, & Spitze, 2013). Parents with medically fragile infants face increased levels of stress, anxiety, grief, and also experience PTSD (Boykova, 2008; Flacking et al., 2007; Garel et al., 2007; Kenner et al., 1993; Lee, Norr, & Oh, 2005; Whittingham, Boyd, Sanders, & Colditz, 2014). Depression and PTSD symptoms occur with admission but also continue post discharge from the NICU (Ahlund, Clarke, Hill, & Thalange, 2009; Holditch-Davis et al., 2003; Hynan, Mounts, & Vanderbilt, 2013; Lefkowitz, Baxt, & Evans, 2010; Pritchard et al., 2012; Vigod, Villegas, Dennis, & Ross, 2010). In addition, mothers with previous chronic illness or trauma are at higher risk of developing PTSD (Theroux, 2009). Stress in parents of premature infants is often related to uncertain outcomes (Gambina et al., 2011; Kersting et al., 2004; Padovani, Carvalho, Duarte, Martinez, & Linhares, 2009) and research correlates a link between high maternal levels of stress and poor infant outcomes (Howland, Pickler, McCain, Galser, & Lewis, 2011; Zimmerman & Bauersachs, 2012).

Stress, Anxiety, and Depression

Parents of preterm infants express increased levels of anxiety, worry, and concern (Affleck et al., 1989; Brooten et al., 1988; Kenner & Lott, 1990; McKim, 1993; Padovani et al., 2009; Rogers, Kidokoro, Wallendorf, & Inder, 2013). Maternal anxiety has found to be associated with less interaction and play with their infant at 24 months of age (Zelkowitz, Bardin, & Papageorgiou, 2009). As time goes on, parents become more familiar with infant care and feel less alienated. Jackson, Ternstedt, and Schollin (2003) identified that parents become more organized; confident, and familiar with care from 2 to 18 months post discharge from the NICU. In addition, some studies dispute that parents of preterm infants experience high levels of stress and difficulty coping (Davis et al., 2003; Jones et al., 2009).

There is a correlation between depression and stress; however, the longer the infant is at home, depression symptoms lessen (Gennaro, Zukowsky, Brooten, Lowell, & Visco, 1990; Mew, Holditch-Davis, Belyea, Miles, & Fishel, 2003; Miles, Holditch-Davis, Burchinal, & Nelson, 1999; O'Brien et al., 1999). Additionally, some studies contradict findings of increased stress (Jones et al., 2009; Pridham et al., 2001) and describe how stress decreases over time (Gennaro, 1988). Postpartum depression can occur in women with a normal term delivery; however, mothers with a premature birth are at higher risk (Pritchard et al., 2012): Even mothers who have a late preterm infant experience more stress, depression, and anxiety (Gambina et al., 2011). Poor mental health symptoms in parents are associated with increase of dysregulation in preterm infants measured at 2 years of age (Treyvaud et al., 2010).

Grief

Parents also often experience grief, described by Golish and Powell (2003) as ambiguous loss, while managing the crisis of a premature birth and mourning the loss of a normal full term

pregnancy (Boykova 2008; Flacking et al., 2007; Garel et al., 2007; Kenner et al., 1993; Lee et al., 2005; Shah et al., 2011; Whittingham et al., 2014). Parents face a dichotomy between feelings of pleasure and celebration for their newborn child and feelings of sadness, shock, anger, and grief. Parents who have difficulty expressing feelings of grief and guilt also experience increased levels of stress (Golish & Powell, 2003; Lee et al., 2005; Shah et al., 2011). These feelings of grief are ongoing and may result in chronic sorrow. Chronic sorrow occurs from experiencing grief as a result in loss of normalcy, ongoing uncertainty in current and future outcomes, and recurrent triggers of these feelings (Fraley, 1986). Fraley (1986) first identified chronic sorrow as the cyclical pattern of grief and sorrow for parents of premature infants.

This ongoing grief and loss can also impact parental and infant attachment (Shah et al., 2011). Conducting a longitudinal study ($N=74$), Shah et al. (2011) found a correlation between grief resolution and increased attachment in high-risk infants and their mothers. Although the process of grief resolution has implications for improved infant outcomes, Shah et al. (2011) also discovered the level of medical complexity for infants did not necessarily correlate to resolved grief. Birth of a premature infant has a lasting impact on parents, affects overall quality of maternal and infant interactions, and can lead to feelings of child vulnerability (Muller-Nix et al., 2004).

Vulnerable Child Syndrome

Green and Solnit (1964) identified Vulnerable Child Syndrome (VCS) in their foundational work on parental maladaptation and reaction to potential or real illness for their infant. Parents of premature infants have overwhelming feelings ranging from fear to grief, depression, and anxiety (Affleck et al., 1989; Brooten et al., 1988; Culley, Perrin, & Chaberski, 1989; Kenner & Lott, 1990; McKim, 1993). In addition, Chambers, Mahabee-Gittens, and Leonard (2011) revealed

that parental perception of vulnerability as measured by parental perception of child vulnerability correlated to increase use of health resources, emergency department visits, hospital admissions, parent and child mental health complications, and child developmental problems. In addition, parental compensation occurs with the perception of having a vulnerable child (Miles & Holditch-Davis, 1997).

Directly related to parental adaptation and transition to parenthood, the concept of vulnerability also has an impact on health outcomes for premature infants (Allen et al., 2004; Perrin, West, & Culley, 2001). Higher parental anxiety is related to higher child perception of vulnerability (Allen et al., 2004) and lower psychological developmental levels in infants (Stern, Karraker, McIntosh, Moritzen, & Olexa, 2006). Research highlights the negative impact on physiological and behavioral development outcomes for premature infants when parents have a distorted and heightened view of their child's health vulnerability (Allen et al., 2004; Lipstein, 2006; Perrin et al., 2001; Stern et al., 2006). Additionally, after discharge, VCS is directly related to increased parental usage of health care resources for their infant (Allen et al., 2004; Lipstein, 2006). Factors that increase the risk of parental perception of VCS include previous loss, history of infertility, low self-esteem, history of mental illness such as anxiety or somatization disorders, and lack of social support (Teti, Reiner, & O'Connell, 2005). Parental and infant attachment is altered with the unexpected birth of a premature infant. In addition, lack of time to develop bonding and normal relationships is hindered with premature delivery, thus placing the infant at a further disadvantage and vulnerability.

Discharge Readiness

Feeding, diapering, bonding, nurturing, hygiene, and safety are fundamental to basic baby care; however, the high risk NICU infants being discharged to home with unresolved medical

issues require much more complex teaching to prepare parents for independent caregiving and transition to home. Given that technological advancements have improved survivability, care for the high-risk infant currently has different meaning and implications than in the past. Studies identifying discharge readiness for the high-risk infant and extreme prematurity is limited. For example, Goodman and Sauve (1985) studied maternal concerns in the high-risk infant; however, they identified 33 week gestation as inclusion in the study. It is also worthwhile to note the previous study is 32 years old and that there may have been significant advances in technology since. Early studies (e.g., Cagan & Meier, 1983) described discharge readiness for parents with high-risk infants, although many are not explicit regarding level of medical complexity and parental education needs. Additionally, Lee et al. (2011) denoted the lack of studies that examine parents' needs to care for their VLBW infant.

Shieh et al. (2010) measured maternal confidence at discharge and included infant gestational age, length of stay, and infant birth weight. Smith, Dukhovny, Zupancic, Gates, and Pursley (2012) and Smith et al. (2009) included birth weight and medical complexity in the comparison of parents who reported being prepared for discharge, and those who were unprepared. Medical complexity for infant characteristics included gastrostomy tube, central line, ventriculoperitoneal shunt, tracheostomy, feeding tube, colostomy, oxygen, and home monitoring equipment (Smith et al., 2009). Tearl and Hertzog (2007) specifically focused on parents and caregivers who had an infant with a tracheostomy or whose infants were ventilator-dependent.

In one qualitative study, Lee et al. (2011) conducted interviews at three time points, just prior to discharge, within the first few days after discharge, and several weeks after that. Lee et al. (2011) studied a convenience sample of parents with a VLBW infant who had an average

gestational age of 29.5 week gestation and a NICU stay greater than two months. Enlow et al. (2014) included infant characteristics such as gestational age, birth weight, and co-morbidities. Kim et al. (2015) described inclusion of families with at least one VLBW infant who survived and transitioned to home. Miquel-Verges and Donohue (2011) assessed the discharge preparedness in an immigrant Latino population but did not indicate any information on specific infant conditions. Since there was no control group, Miquel-Verges & Donohue (2011) compared results from a subset of English speaking parents with VLBW infants hospitalized in the same NICU but who had participated in a different study.

Despite the complexities of needs and information to focus on, Cagan and Meier (1983) concluded that discharge is the most important event in hospitalization from a parent's perspective. Even though parents report feeling prepared for discharge, the realities and challenges at home for both new parents and those with little experience taking care of a fragile infant can be overwhelming (Griffin & Pickler, 2011; Hess, Teti, & Hussey-Gardner, 2004; Reyna, Pickler, & Thompson, 2006). Parents of premature infants report inconsistent information from caregivers, lack of understanding in instructions, and receiving discharge teaching in a rushed manner (Bernstein et al., 2007; Kenner & Lott, 1990). This is also true for later preterm infants (Premji, Young, Rogers, & Reily, 2012).

Inconsistency with discharge teaching is evident in the literature. Aris et al. (2006) described in a two phase study development of a survey questionnaire from content and practicing experts and final implementation of the survey on nurses' discharge education and knowledge of best practice for infant sleep positions and prevention of Sudden Infant Death Syndrome. A regression analysis of the final questionnaire on a convenience sample of 252

NICU parents revealed inconsistencies in discharge teaching for parents of sleep positions and modeling behavior in the clinical setting (Aris et al., 2006).

Discharge preparation may be complicated by the limited ability of parents to visit due to work and family obligations (Griffin & Abraham, 2006). Along with Griffin and Abraham (2006), Weiss et al. (2008) denoted that parents and family who visited more often reported increased satisfaction with the discharge process. This supported Steeples' (1999) earlier claim that mothers who roomed in report an increase in preparedness, where they have increased access to resources, support, and discharge instructions.

Weiss et al. (2008) conducted a quasi-experimental correlational study on discharge readiness for 135 parents with a hospitalized child. The relationships between four indicators were examined: specific characteristics between parent, child, and hospitalization with readiness for discharge; discharge teaching and care coordination by nursing staff and discharge readiness; parental readiness for discharge and post discharge coping; and parental readiness for discharge and post discharge resource utilization (Weiss et al., 2008). The significance in this study was the delivery method for discharge teaching was dependent on skill level of the nurse. Weiss et al. (2008) identified quality discharge teaching includes listening, sensitivity and understanding, timing, consistency, reduction of anxiety, and improved confidence.

In a qualitative descriptive correlational study with 40 nurses and 45 parents, Sheikh, O'Brien, and McCluskey-Fawcett (1993) identified parents' perceptions and ranked importance of information imparted from NICU staff about discharge preparation. The questionnaire was very thorough and covered topics such as feeding, bathing, sleeping, crying, monitoring and managing infant health, specifics on prematurity, handling and holding, and visits with friends and family (Sheikh et al., 1993). Sheikh et al. highlighted a significant difference between staff

perceptions of the discharge process and preparation and parental perception. While Sheikh et al. did not measure preparedness, Sheikh et al. did highlight that nursing staff and parents ranked similar items in level of importance; however, staff believed parents were receiving more information than reported by parents. NICU nurses reported the percentage of a specific topic being discussed higher than parents who recalled the information about the topic at a later date (Sheikh et al., 1993). This discrepancy reveals the need to measure at what level parents are able to understand and comprehend discharge instructions. Research has identified parents' lack of knowledge about infants' development as crucial in understanding instruction and care needs (De Rouck & Leys, 2011; Hess et al., 2004; Penticuff & Arheart, 2005).

Providing discharge instructions and support while in the NICU include important nursing interventions to enhance parents' perception of preparedness (Broedsgaard & Wagner, 2005). Broedsgaard and Wagner (2005) used a descriptive design to measure parents' perceptions of a discharge consultation and guidance intervention from a designated Registered Nurse health visitor. Out of 37 parents enrolled, 95 percent stated they had received support and guidance from a health visitor to prepare them for discharge and 90 percent reported feeling secure when they returned home (Broedsgaard & Wagner, 2005). Broedsgaard and Wagner (2005) highlighted the connection between discharge teaching, increased parental confidence, and improved infant outcomes.

Raines and Brustad (2012) and Weiss et al. (2010) recognized that gaps in discharge teaching are often not discovered until after discharge, adding to parental stress and lower confidence levels in caring for their child. Additionally, Smith et al. (2012) identified in their study of discharge preparedness that patients reported increased readiness when they were familiar with their nurse; however, in a similar study, nurses often overestimate parents'

readiness for discharge (Smith et al., 2009). Mancini and White (2001) suggested the essential need to determine parents' concerns and needs around discharge prior to discharge.

Advances in technology in the NICU allow infants to survive at earlier ages of development and often require complex medical therapies, interventions, and support to thrive outside the womb (Smith et al., 2012; Sneath, 2009). While the NICU environment provides support for these fragile infants, the family structure is adversely affected by the increased stress of being in the unfamiliar NICU environment during the infant's hospitalization (Bracht et al., 2013; Erdeve et al., 2008). In addition, parents require special instructions throughout their infants' hospitalization to care for their infant and prepare for discharge from the hospital (Bissell & Long, 2003).

Challenges for families include a delay in effective parent and infant bonding, disruption in normal parental roles, and feelings of powerlessness (Mundy, 2010; Olshtain-Mann & Auslander, 2008; Sneath, 2009). Premature infants often experience lengthy hospitalization with support from trained nursing staff; however, parents are expected to assume full responsibility for their infant's care at home after discharge (Ballantyne et al., 2012; Broedsgaard & Wagner, 2005; Sneath, 2009). The American Academy of Pediatrics (AAP) Committee on Fetus and Newborn (2017) has established guidelines for infants to meet for address discharge from the NICU, which include maintaining an increased weight, temperature stability, feeding tolerance, and no episodes of apnea or bradycardia within a specific number of days prior to discharge.

Discharge preparedness and readiness is described as a complex, multifaceted concept and multistage process that provides an approximation of a patient's ability to leave an acute healthcare facility and transition to home (Bernstein et al., 2007; Titler & Pettit, 1995). Bernstein et al. (2007) also defined readiness to include the collaboration agreement of readiness among

mothers, pediatricians, and obstetricians. Additionally Bernstein et al. (2007) defined discharge readiness as a clinical, subjective, and contextual process that measures the perspective of all involved parties.

Discharge readiness is directly related to discharge planning, described by Jeffries (2014) as a comprehensive and organized method to safely and effectively ensure a positive transition from the hospital to home. Discharge readiness occurs from support and facilitates building the bridge between family bonds, parenthood, and transition from NICU to home (Broedsgaard & Wagner, 2005). The AAP Committee on Fetus and Newborn (2017) policy statement describes readiness for infants beginning at admission and includes criteria for infant physiological stability, “family and home environmental readiness, and community and health care system readiness” (p. 464). Sheikh et al. (1993) defined goals for effective discharge planning to include infant maintenance, minimization of illness and re-hospitalization, minimization of stress in transition to home, and increase in parental confidence and competence.

Measuring Discharge Readiness

While discharge teaching and preparedness should begin upon hospital admission, family and caregivers’ physiological and psychosocial preparedness for their infant’s discharge should be determined. Smith et al. (2009) defined discharge readiness using a Likert scale questionnaire, measuring technical expertise of parents and emotional determinants such as coping and confidence. Jeffries (2014) stated that additionally parents should be able to cope independently and have confidence in their ability to care for their infant, recognize illness and respond with appropriate interventions, safely administer medications, provide a safe home environment, and safely transport their infant.

Compared to studies in adult patient populations on discharge preparedness, limited studies have focused on the parents' perspective of discharge planning needs and barriers in the NICU (Bernstein et al., 2007; Smith et al., 2009). Studies that do exist highlight the need for parents to be involved and maintain a consistent presence in their infant's hospital stay in order to prepare for discharge and cope at home (Bain, Findley, & Greig, 2003; Mancini & White, 2001; Peyrovi, Mosayebi, Mohammad-Doost, Mitra-Chehrzad, & Mehran, 2015; Smith et al., 2009). Few studies have conducted a pre- and post-test design to evaluate interventions measuring discharge preparedness (Hager, 2010; Macini & White, 2001; Shieh et al., 2010; Weiss et al., 2008).

Most recently, Peyrovi et al. (2015) studied the effect parental empowerment can have on discharge preparedness. Peyrovi et al. (2015) conducted a study in Iran with use of the discharge preparedness tool by Smith et al. (2009) in a pre- and post-test quasi-experimental design. The experimental group participated in a three-stage empowerment-training program, and the control group had traditional discharge instructions (Peyrovi et al., 2015). At the time of discharge, the experimental group scored higher in technical skills and readiness for both the mothers' and nurses' report; additionally, there was a significant difference between emotional readiness for mothers in the experimental and control group ($p=0.003$) (Peyrovi et al., 2015).

Bernstein et al. (2007) conducted a large ($N=4,300$) prospective cohort study of healthy term infants with mothers, pediatricians, and obstetricians to identify readiness for discharge on day of discharge. Perceptions at time of discharge are different, and needs of the parents or caregivers are unique and individual; therefore, decisions for discharge should be made jointly (Bernstein et al., 2007). While this was a large cohort study, the focus was on healthy newborns and not premature infants or infants with medical complications needing intensive care support.

Bain et al. (2003) evaluated family perception of their preparedness for discharge in a mixed methods descriptive cohort study of NICU ($N=21$) in Scotland. Bain et al. (2003) identified parent satisfaction with discharge preparedness in 374 parents two weeks post discharge where results revealed 86 percent of parents were satisfied with teaching and felt prepared for discharge. Although 86 percent is considered a good indication of successful teaching, parents did report there was a lack of education and advice around feeding (Bain et al., 2003). Only 31 percent reported being able to practice preparing feedings in the hospital, and only 37 percent received information about hunger and increasing feeds for their infant (Bain et al., 2003). The discrepancy existed between breastfeeding instruction on storage and expressing milk (90%), whereas 97 percent felt confident with bottle-feeding versus 80 percent breastfeeding (Bain et al., 2003). Need for information and access to support is linked to improved parents confidence (Gennaro, 1988; Holditch-Davis et al., 2003; Jones et al., 2009; Kenner, 1988; Kenner & Lott, 1990; McKim, 1993; Singer, Davillier, Bruening, Hawkins, & Yamashita, 1996). Parents report higher levels of stress when they receive less information (McKim, 1993); additionally, they report receiving conflicting information (Kenner & Lott, 1990), and conduct their own website searches to obtain information (De Rouck & Leys, 2011).

Smith et al. (2009) conducted a descriptive quantitative study with 867 families who rated their preparedness using a nine point Likert scale discharge preparedness tool. The discharge nurse also rated the families using a similar tool, and both were compared (Smith et al., 2009). Overall, 97 percent of stated they felt ready for discharge; however, 13 percent were unprepared when family and nursing results were combined. This indicated a distinct discrepancy between parents and staff reports on readiness for discharge (Smith et al., 2009, p. 625). Nurses rated discharge preparedness for families at a lower level than the families did;

furthermore, families that reported feeling unprepared, also did not have a long-term relationship with their discharge nurse (Smith et al., 2009). Although results were not statistically significant, Smith et al. (2009) identified that families reported feeling more prepared when also rated by nurses on how familiar they were with the family, highlighting the need for developing relationships with families. Additionally, there was a correlation between families' increased preparedness and confidence in their pediatrician (Smith et al., 2009).

Discharge Planning

Marshall (1987) described discharge planning as a process to “prepare patients for orderly transition from one setting to another” (p 102). Discharge preparedness is a result of organized and effective discharge planning. Kim et al. (2015) denoted that discharge preparedness is directly related to development and implementation of a discharge plan. The key element in discharge preparedness is careful planning from admission through discharge, while extending planning for home caregiver confidence and independence and outpatient access to care (Gaal, Blatz, Dix, & Jennings, 2008). Although the standard of practice is to implement discharge planning from admission, discharge readiness actually becomes the last priority when providing life saving measures to the high-risk infant (Broedsgaard & Wagner, 2005). The literature supports standard of practice use in discharge planning; however, studies also reflect the continual practice of rush to discharge at the last minute.

Parents need familiar and professional support post discharge (Crnic, Greenberg, & Slough, 1986; Leonard, Scott, & Sootsman, 1989; Tien, Peterson, & Shelley, 2002; van der Pal, Alpay, Steenbrugge, & Detmar, 2014; Wong, Butt, Symington, & Pinelli, 2011). Discharge readiness occurs with support and facilitates building the bridge between family bonds, their premature infants, parenthood, and transition from NICU to home (Broedsgaard & Wagner,

2005). Discharge preparedness cannot be appropriately evaluated without having an understanding of parental transition.

As far back as 1983, Cagan and Meier described the need for discharge planning and organization of the process. Cagan and Meier's pilot study compared two different methods of discharge preparation by measuring parent's perception of readiness to care for their high-risk infant with a questionnaire. Cagan and Meier compared two groups: a control group with traditional unstructured discharge teaching ($n=35$) and an experimental group ($n=40$) with use of a planning tool. Parents perceived themselves as more capable and prepared to care for their high-risk infant (Cagan & Meier, 1983).

Sims et al. (2006) identified critical issues in the discharge process related to scarcity of discharge planning from admission to discharge, the majority and large amounts of discharge teaching that occurs just prior to discharge, lack of communication and mutual consent between NICU team members regarding discharge planning, and limited interdisciplinary communication and collaboration used in discharge planning. Sims et al.'s work was a process improvement initiative to develop Potentially Better Practices (PBPs) to improve the discharge process.

Methods for better practice included feedback from content experts, literature review, Neonatal Intensive Care Quality Improvement Collaborative 2002 listserv, feedback from parents, Case Management, and conference attendance every six months (Sims et al., 2006). PBPs were divided into the following five categories: develop a discharge planning tool that is accessible and user friendly; individualize oral and written communication tools for all disciplines which reflect daily process toward discharge; streamline and update educational material and delivery method; implement and use parent and staff satisfaction tools to reflect quality improvement; and increase communication and efficiency with community resources and

providers (Sims et al., 2006). This initiative shed light on several areas unique to NICU discharge and the need for individualized parent discharge planning versus primarily focusing on disease discharge pathways similar to adult populations.

Parental Support and Resources

Despite hospital staff use of extensive checklists and other resources to guide discharge, often the discharge process is hurried at the last minute, and there is limited opportunity for instruction (Ballantyne et al., 2012; Griffin & Pickler, 2011). With the increase in survivability of premature infants, the need for educational resources and support for NICU parents during hospitalization and beyond discharge exists (Bain et al., 2003; Bissell & Long, 2003; Kim et al., 2015). Educational and written resources are vital for parents to have confidence and ability to care for their infant. Several studies, including Bain et al. (2003), Hurst (2006) and Pritchard, Colditz, and Beller (2008), discovered lack of written information and incomplete information in discharge teaching. Broedsgaard and Wagner (2005) also identified the need to repeat educational information for parents who were satisfied with available written information. In a qualitative study on parent's perceptions of discharge readiness, Burnham et al. (2013) identified that parents wanted more information readily available and findings revealed that hands on experience and observation in the NICU of their infant influenced parents' readiness for discharge. Zamanzadeh, Namnabati, Valizadeh, and Badiie (2013) conducted a qualitative study of mothers in Iran and found through interviews that parents wanted formal training in addition to observational learning. Additionally, tailoring information and providing unique experience to meet their needs increased their readiness for discharge (Zamanzadeh et al., 2013).

Burnham et al. (2013) recommended anticipatory guidance for infant's behavior in the NICU and possibility of changes at home. Additional support includes encouraging parents to

participate in infant care, educating parents on signs of changing health status, inquiring in what specific needs parents might have, and providing anticipatory guidance in problem solving potential problems at home (Burnham et al., 2013). Parents have worries and concerns about growth and development for their premature infant (Kenner et al., 1993; Minde, Whitelaw, Brown, & Fitzhardinge, 1983; Spiegler et al., 2013; Vasquez, 1995; Veddovi, Gibson, Kenny, Bowen, & Starte, 2004). McKim's (1993) study revealed parents want more information on recognizing illness in their baby and determining normal bowel movements. Signs such as lack of eating, difficulty breathing, and changes in skin color were identified as essential for parent discharge teaching (McKim, 1993). Additionally, parents need information on normal behavior for a premature infant versus a full term baby. Developing an understanding of the differences in patterns such as sleep, eating, and fussiness help mothers cope with challenges of these behaviors (McKim, 1993).

Kim et al. (2015) conducted a qualitative grounded theory research study with 25 parents, which included 15 mothers and 10 fathers, who had VLBW infants discharged from the hospital. Kim et al. examined technology use for parents who had a VLBW infant who were seeking support and information on how to care for their infants. Kim et al. revealed that "mothers are primary information seekers in the family, both parents were concerned with online privacy issues" (p. 46), parents sought out others who had similar experiences, mothers relied on fathers for learning technology, and mothers were the primary parent to choose a health care provider (p. 46).

Mancini and White (2001) confirmed the need to include parents' perceptions and opinions for developing and improving discharge teaching in NICU parents. Mancini and White (2001) conducted semi structured interviews with 16 parents at two days prior to and six weeks

after discharge. The researchers focused on parents' views, concerns, helpful resources, and specific information they remembered from discharge teaching at six weeks out. Results revealed parents were overall satisfied with discharge teaching; however, 11 felt education around safety issues for their infant could be improved, and 13 reported hygiene concerns (Mancini & White, 2001).

Steeple (1999) conducted a descriptive correlational study on 75 mothers' perceptions of their preparedness and gathered data on perceived factors affecting preparedness and preferred strategies to gain preparedness. Using a five point Likert scale, Steeple's questionnaire measured five dimensions of caregiving: feeding, hygiene, handling and positioning an infant, developmentally appropriate interaction, and methods to handle a crisis. Participants were assessed at two time points, one at discharge and another one-month post discharge (Steeple, 1999). Infants were given a perinatal risk score using five items: gestational age, birth weight, size for gestational age, length of hospitalization, and severity of medical complications. The total risk score ranged from three (a healthy infant) to 28 (considered high risk and medically fragile infant) (Steeple, 1999). A significant finding in the study included a positive correlation between mothers reporting feeling prepared and infants identified as being medically fragile (Steeple, 1999). Steeple also revealed that mothers felt more prepared one-month post discharge, stating they had more time to care for their infant and summarized that mothers who had previous caregiving experience correlated with increased level of preparedness. Furthermore, support from nursing staff and being able to room in or stay in the hospital was ranked highest in influencing mothers' feelings of preparedness (Steeple, 1999).

Steeple (1999) also evaluated mothers' preferred method of training and who presented the information. The majority preferred a combination of formal and informal training (43%),

use of in person demonstration (54%) but also printed material (19%); nursing staff ranked highest (25%) with doctors and infant developmental specialist (22% & 23% respectively) following, and most preferred individual training (50%) in the NICU (53%) versus other rooms (11%) or at home (12%) (Steeple, 1999). These findings supported Zamanzadeh et al.'s (2013) assertion for the need to focus discharge planning and teaching based on mothers' preferences.

A specific concern of discharge readiness is parents' perceived ability to handle feeding. Adequate nutrition is vital for premature infant growth and development, and parent skill and confidence in feeding their infant is crucial. Feeding an infant is likely to be a new skill for parents, and given the physiological obstacles many premature infants face, parents may be challenged to provide adequate nutrition to their infant (Pridham, Saxe, & Limbo, 2004). According to Pridham et al. (2005), feeding is a transfer of nutrition but also an intimate relationship between infant and parent. Premature infants must coordinate breathing, sucking, and swallowing in order to obtain nutrition from a bottle. It takes a unique approach by the caregiver to help support and maintain physiologic stability of an infant while feeding. In addition, a premature infant does not respond to normal social cues as a normal newborn, also requiring extra parent education in premature development. Results demonstrated greater competencies in mothers with guided participation in feeding support from a home health nurse visit at 1, 4, 8, and 12 months post discharge than mothers in the control group who received no extra guided instruction (Pridham et al., 2005).

Pickler, Reyna, Griffin, Lewis, and Thomason (2012) measured changes in feeding skills between discharge and two weeks post discharge. Given that an infant needs careful assessment prior to discharge, Pickler et al. (2012) examined an assessment tool, Early Feeding Skills Assessment, and determined it was useful for predicting successful feeding post discharge.

Parents not only need to develop skill to feed their infant but also must develop the confidence to feed their infant. Whether choosing breastfeeding or formula bottle, parents are challenged to succeed, though breastfeeding appears to confer additional challenges. Wheeler (2009) conducted a study over six weeks post discharge, in which mothers recorded amount of breastfeeding and reasons for quitting. Reported reasons were maternal or infant illness, lack of sufficient milk, limited time, and mental health concerns such as depression and stress, limited successful latching, swallowing disorders, and lack of support (Wheeler, 2009). In addition to emotional and mental health problems, Flacking et al. (2007) reported shame and grief as barriers to successful breastfeeding. Wooldridge and Hall (2002) identified adequate milk supply related to successful transition from bottle-feeding in the hospital to breastfeeding at home.

Successful breastfeeding post discharge begins in the NICU. Wooldridge and Hall (2002) highlighted the need to establish adequate supply well before discharge. Kavanaugh, Mead, Meier, and Mangurten (1995) also identified mothers' concerns post discharge. Key findings revealed mothers of premature infants were not able to respond to normal infant cues when feeding, resulting in inadequate milk supply and volume (Kavanaugh et al., 1995).

Medication Safety

As more infants are discharged from NICU with unresolved medical issues and are technology dependent, the complexities of discharge teaching for parents have also intensified (Hummel & Cronin, 2004). While the Institute of Medicine (1999) reported that medical errors occur at high rates, with as many as 44,000 to 98,000 individuals in the hospital, the potential for errors at home can result from lack of clear instruction and understanding. Research studies indicate importance in parental measure of medication administration (Bain et al., 2003); however no studies related to outpatient errors as a function of preparedness have been

identified. The Institute of Medicine highlighted the need for health care facilities to develop methods to reduce and prevent medication errors (IOM, 1999). With the increasing discharge of medically fragile infants who are on medication at home, medication error prevention for parents should also take a priority.

Interdisciplinary Support

Raffray et al. (2014) described the value in interdisciplinary collaboration within a facility to determine how application of industry best practices can result in higher quality teaching and meet the needs of parents and caregivers. Weiss et al. (2008) suggested higher quality of discharge teaching correlates to more favorable perception of discharge readiness. This is parallel to Hager's (2010) recommendation that effective planning and interdisciplinary efforts increase patient readiness and satisfaction and reduces overuse of healthcare resources.

Hager (2010) conducted a quasi-experimental study to determine effectiveness of interdisciplinary efforts to develop discharge planning and teaching. Hager compared perceived readiness for discharge and patient satisfaction scores between a control and experimental group. The control group experienced typical discharge teaching, whereas the experimental group was asked to identify goals and barriers to discharge (Hager, 2010). There was a significant difference in the experimental group over the control group related to better understanding of post discharge medical follow up, treatment plan, and ability to perform medical treatments (Hager, 2010). According to Hager (2010) results showed, "at 72 hours post discharge, the control group felt less prepared than the experimental group" (p. 85). Additionally, overall satisfaction was increased in the experimental over the control group, and readmission rates were higher for the control group, 27 percent, whereas the experimental group had no readmissions (Hager, 2010).

Outcomes

Premature infants are at risk for developing a wide range of illnesses and complications such as retinopathy of prematurity, intraventricular hemorrhage, respiratory distress syndrome, necrotizing enterocolitis and patent ductus arteriosus (Behrman & Butler, 2007; Dusing et al., 2012; Moster et al., 2008; Smith et al., 2012). These complications are often unresolved by discharge, have an overall physical, cognitive, and social effect on premature infants, place the infant at risk for further health conditions, and can lead to chronic long-term complications and disease (McGrath, Sullivan, Lester, & Oh, 2000; Smith et al., 2009). Parents have increased levels of anxiety and stress related to infant outcomes (Gambina et al., 2011; Griffin & Pickler, 2011; Jubinville, Newburn-Cook, Hegadoren, & Lacaze-Masmonteil, 2012; Kersting et al., 2004; McCluskey-Fawcett, O'Brien, Robinson, & Asay, 1992; Padovani et al., 2009; Phillips-Pula, Pickler, McGrath, Brown, & Dusing, 2013; Turner, Winefield, & Chur-Hansen, 2013).

Limited studies correlate discharge readiness and patient outcomes (Weiss et al., 2008). Delays and complications in developmental and physiological outcomes are often not seen for many months or years; however, research highlights the importance in early interventions for premature infants. Compared with infants who are born full term, premature infants have increasing rates of respiratory distress, thermoregulation instability, feeding difficulties, periventricular leukomalacia, apnea, hypoglycemia, jaundice, seizures, and weight gain (Beck et al., 2009; Blencowe et al., 2012).

A premature infant requires hemodynamic support to survive; however, these interventions place them at risk for further health complications (Als et al., 1986). Mechanical ventilation causes parenchymal damage in the lungs resulting in bronchopulmonary dysplasia or chronic lung disease (Als et al., 1986). McGrath et al. (2000) described a predictor of poor outcomes in preterm infants

related to birthweight. Conducting a prospective longitudinal study ($n=188$), McGrath et al. examined neurocognitive outcomes and school performance in low birth weight infants and found preterm infants with neurocognitive difficulties were more likely to score lower in cognitive and school performance.

Community Providers

While discharge readiness for the parent includes information on how to access outpatient resources, the skill and knowledge of those providers also needs to be taken into consideration for comprehensive discharge preparedness (Newnam & Parrott, 2013; Peacock, 2014). Much of the research addresses caring for preterm infants; however, information does not adequately cover the complex infant who has been discharged with unresolved medical conditions (Affleck et al., 1989; Brooten et al., 1988; Butts et al., 1988; Drake, 1995; Gennaro et al., 1990; McKim, 1993; Minde et al., 1983; Termini, Brooten, Brown, Gennaro, & York, 1990).

With the increase in survivability of VLBW and extremely low birth weight infants, Newnam and Parrott (2013) highlighted the increasing need for primary health care providers who can address the complex needs of these infants. Browne and Talmi (2012) discussed the lack of training and preparedness from community providers in the developmental and complex needs of premature infants. There is also a lack of referral to outpatient early intervention resources (Barfield et al., 2008; Roberts et al., 2008). The bridge to successful care includes collaboration and communication among services that address infant's unique medical needs (Peacock, 2014). Burnham et al. (2013) also identified the importance in collaboration of service and continual communication between in hospital and community clinics.

Tearl and Hertzog (2007) identified the significant role parents have in managing home medical care and monitoring, especially in light of the critical nationwide shortage of home

healthcare nurses. Therefore, extensive education and skill training for parents prior to discharge is essential. Completing a quasi-experimental study design, Tearl and Hertzog (2007) demonstrated improvements in parents from intervention training with pretest scores 35.3 and post-test scores 91.1 (Wilcoxon signed rank $Z = -3.84, p = 0.001$) given to evaluate parent satisfaction and skill competency.

Prior to initiating the pretest, it was administered to a group of 10 respiratory therapists who were not involved in the training program, to provide feedback and determine an appropriate degree of difficulty and eliminate floor-ceiling effect on overall scoring (Tearl & Hertzog, 2007). Although Tearl and Hertzog (2007) did not include specific measures for individual parental perceptions of preparedness, durable medical equipment company providers who visited families during the first two weeks following discharge and evaluated parents at one month out, reported 100 percent of families demonstrated knowledge and skill competency related to tracheostomy ventilator dependent children. Despite it being a small sample ($n = 20$), the success of Tearl and Hertzog's (2007) model resulted from an assortment of educational formats such as visual aids, handouts with interactive sessions, and interpersonal skills demonstrated by the respiratory therapists.

Broedsgaard and Wagner (2005) described the lack of experienced practitioners in Denmark in a mixed method use of grounded theory and non-experimental descriptive design on implementation of an intervention over two years and evaluation of the intervention the following year. While this study was to improve parents' confidence and independence in caring for their premature infant, it resulted from the lack of experienced caregivers in the community (Broedsgaard & Wagner, 2005). Semi-structured questionnaires were administered and completed by 37 families, whereby the quantitative and qualitative results were analyzed and

guided development of the focus group that included 17 families (Broedsgaard & Wagner, 2005). The main themes reported by Broedsgaard and Wagner (2005) from the focus groups included admission to the hospital at the neonatal unit, rooming in, rooming-home, discharge, and everyday life at home. The focus groups were recorded, transcribed, coded, and analyzed separately but compared with the structured questionnaires (Broedsgaard & Wagner, 2005). The goal of the study was to provide an education program during hospitalization for parents of premature infants, prepare parents for the transition to home, and ensure parents were able to independently care for their infant at home (Broedsgaard & Wagner, 2005).

Infants often go home on oxygen, medications, and tube feedings (Lasby, Newton, & von Platen, 2004) and there is a high caregiver burden related to use of home monitoring equipment, oxygen, feeding pumps, and medication administration (Garel et al., 2007; Lagatta et al., 2013). Broedsgaard and Wagner (2005) highlighted that families with a premature infant feel more vulnerable and rely on increased support and assistance to cope, bond with their child, develop the confidence needed to transition to home, and provide independent care for their infant. Broedsgaard and Wagner discovered the need for collaborating services, both in the hospital and community primary care, providing a bridge to meet the families' needs. Parents also need extensive reassurance in skills (Lutz, Anderson, Pridham, Riesch, & Becker, 2009; Shieh et al., 2010; Tran, Medhurst, & O'Connell, 2009).

Outpatient Utilization

There is an increase in utilization of outpatient resources for premature infants post discharge (Spicer et al., 2008). Although discharge is a long anticipated event for families, the health needs of premature infants continue for long periods of time post discharge (Sneath, 2009). Outpatient caregivers assume responsibility for these medically fragile infants, (Arpino et

al., 2010; Groothuis & Makari, 2012; Gunn, Cartwright, & Gole, 2012; McCormick, Litt, Smith, & Zupancic, 2011; Stephens & Vohr, 2009). Wade et al. (2008) denoted an increase of approximately 20 to 29 outpatient pediatrician visits in the first year post discharge. These complications place the infant at risk for further health problems and can affect their growth and development. Parents must navigate multiple medical resources to meet their infants health needs as greater numbers of infants are being discharged with tracheostomy tubes and home ventilators.

Additionally, a number of studies reveal barriers and gaps in discharge teaching that are not discovered until post discharge (Raines & Brustad, 2012) and may result in increased burden on the healthcare system (Weiss et al., 2010). Measuring parental discharge preparedness by medical staff is essential because infants who are not discharged properly have the potential to cause an increased burden on the healthcare system. A paucity of studies relates discharge preparedness and outcomes (Weiss et al., 2008). Although there was no predictive relationship between discharge readiness and outpatient utilization three weeks post discharge, Weiss et al. (2008) suggested the cumulative effect between qualities of teaching and increased coping has an overall influence on reduced utilization.

Follow up clinics. NICU follow up clinics have become more important in the role of following complex needs of premature infants (Bockli, Andrews, Pellerite, & Meadow, 2014). The AAP Committee on Fetus and Newborn (2017) recommended that premature infants born less than 1,000 grams be seen in a follow up clinic. It is mandated that all level III NICU coordinate with a follow up clinic for all premature infants born less than 1,000 grams (Bockli et al., 2014). This service is crucial to identify ongoing health issues and coordinate early intervention. The NICU follow up clinics are composed of specialists in treating complications a

premature infant may experience such as feeding difficulties and respiratory, cardiac, musculoskeletal, neurological, growth, and developmental issues. Conducting a descriptive correlational study of NICU follow up clinics in both private and public hospitals, Bockli et al. (2014) identified challenges each faced in caring for premature infants, with feeding difficulties reported in academic clinics and both feeding and bronchopulmonary dysplasia were reported as challenges to treat in private clinics. Major challenges for all clinics included limited or lack of funding and high no-show rates and missed appointments, upwards of 20 percent (Bockli et al., 2014).

Hussey-Gardner, Wachtel, and Viscardi (1998) reported in a qualitative study that parents were uncertain for need to attend clinic and lack of preparation in what to expect. Neonatal follow up clinics have increased numbers of cancelled appointments or lack of continuity of visits (Ballantyne et al., 2012). Limited information is often given to parents on long-term concerns for premature infants and the need identify early interventions (Ballantyne et al., 2012; Hussey-Gardner et al., 1998).

Campbell et al. (1993) conducted a retrospective cohort study in Ontario, Canada, of LBW infants ($N=496$), identifying parental factors associated with lack of attendance at the follow up clinic and predictive risk of developing cerebral palsy. Results showed loss to follow up was greatest in mothers under 20 years of age, unmarried mothers, and infants not born in a tertiary hospital (Campbell et al., 1993). Nehra, Pici, Visintainer, and Kase, (2009) also confirmed problems with lack of follow up appointments after discharge included lower maternal age and maternal drug use. Factors that improved compliance included parent-infant contact within a week of discharge and early intervention referral after discharge (Nehra et al., 2009). Ballantyne et al. (2012) also identified studies with high percentages of non-attendance to NICU

follow up programs. Conducting a prospective, two-phase, descriptive cohort study in three follow up programs in Canada ($n=357$ mothers) and evaluating appointments through the first 12 months after discharge, Ballantyne et al. found percentages of non-attendance increased over time, from 16 percent to 26 percent at 12 months. Nine percent never attended (Ballantyne et al., 2012). Infants born premature are eligible for early intervention services, consisting of a multidisciplinary team approach and from providers who specialize in the complex health needs of premature infants (Bockli et al., 2014).

Even with high rates of non-attendance at NICU follow up clinics; overall, parents are satisfied with care provided. However, Wong et al. (2011) discovered correlation in parent satisfaction of care at a follow up clinic in Canada and level of neurodevelopmental complication of infants. Parents with an infant who experienced poor neurodevelopmental complications were less satisfied with care at a follow up clinic (Wong et al., 2011).

Medical Resources

There is limited information on parental resources available in the outpatient setting (Barton, Roman, Fitzgerald, & McKinney, 2002; Tien et al., 2002). It is evident there is higher usage of outpatient resources for parents with a VLBW than term infants, 38.7 versus 17.4 respectively, for total healthcare contacts (Jackson, Schollin, Bodin, & Ternstedt, 2001). Comprehensive discharge plans are essential to assure that each child remains healthy and thrives at home, and maintain optimal developmental support (Robinson et al., 2000; Sneath, 2009). Parents need both family and professional support post discharge (Crnic et al., 1986; Leonard et al., 1989; Tien et al., 2002; van der Pal et al., 2014; Wong et al., 2011). Higher levels of support reflect in improved maternal health status; however, birth of a preterm infant may

result in individuals unsure of support role, adding to stress and feelings of stigmatization for parents (Zarling, Hirsch, & Laundry, 1988).

Readmission

Lack of coordination and communication among hospital staff, families, and primary care providers may limit families' preparation to go home and result in the infant's readmission to the hospital (Ambalavanan et al., 2011; Erdeve et al., 2008; Lagatta et al., 2013; Lorch et al., 2010; Ralser et al., 2012; Wade et al., 2008). Readmission rates can be as high as 50 percent for premature infants (Amabalavanan et al., 2011; Bird et al., 2010; Ralser et al., 2012; Underwood et al., 2007). Hospital readmissions for premature infants include a wide variety of diagnoses, although respiratory distress surgery, sepsis, and gastrointestinal conditions are most frequently recorded (Boykova & Kenner, 2012; Brooten et al., 1996; Joffe, Escobar, Black, Armstrong, & Lieu, 1999). Approximately 15 percent of hospital readmissions after discharge are related to feeding problems (Escobar et al., 1999). VLBW infants are at even increasing risk of re-hospitalization, particularly those with chronic lung disease (Chien, Tsao, Chou, Tang, & Tsou, 2002; Tseng et al., 2010).

Overall costs for premature birth are variable, and an inverse relationship exists between gestational age, initial hospitalization, re-hospitalization, and acute care visits in the first year of life (Cuevas, Silver, Brooten, Youngblut, & Bobo, 2005; McLaurin, Hall, Jackson, Owens, & Mahadevia, 2009; Petrou et al., 2000; Ray, Escobar, & Lorch, 2010). Additionally, those with medical complexities, such as premature infants, have high overall healthcare usage, and hospital readmissions are higher, 8.8%, nationwide (Hudson, 2013; Jain & Cheng, 2006). Gay, Hain, Grantham, and Saville (2011) conducted a retrospective correlational study to identify readmission rates within 15 days of discharge in a large tertiary children's hospital in Middle

Tennessee. Out of the total children's hospital annual admissions, 8.4% were readmitted within 15 days of discharge (Gay et al., 2011). Readmission rates for premature infants are inversely related to gestational age at birth: the younger the gestational age of an infant at birth, the greater his or her chance for physiological comorbidities necessitating hospital readmission post discharge (Erdeve et al., 2008). Weiss et al. (2008) indicated insufficient information and limited studies that compare readiness for discharge to outcomes exist.

Readmission rates are an important quality indicator of care for hospitals and focus attention on the transitional needs between inpatient and outpatient phases of treatment (Goldfield et al., 2008). Hospitals currently face major challenges to control costs in light of reduced payments for reimbursement as a result of health care reform. Underwood et al. (2007) reported the average costs of each readmission to be \$8,468. Criteria for quality improvement measures identified in the Affordable Care Act include a reduction in hospital readmission rates, especially within 30 days of discharge (Centers for Medicare & Medicaid Services, 2013). Gay et al. (2011) denoted lack of data to identify reasons for hospital readmissions, particularly in the pediatric population.

Education and Staff Training

Conducting a qualitative study to explore NICU healthcare provider's perceptions of the discharge process, Raffray et al. (2014) discussed specific findings related to discharge readiness for healthcare workers perspectives. Raffray et al. included 15 healthcare providers from different disciplines such as nursing medicine, pediatric surgery, psychiatry, speech therapists, social workers, and nutritionists. Raffray et al. conducted interviews with the healthcare providers who identified three primary parental challenges for discharge: establishment of parent and infant bond, acquisition of parenting skills, and discharge day and follow up post discharge.

While Raffray et al. (2014) did not identify specific information on parents' perceptions, Raffray et al. did highlight perceptions of parental needs. The study participants indicated barriers for successful discharge such as socioeconomic status and cultural implications, location, competing demands, visiting hours, NICU medicalized environment, communication barriers, lack of parent engagement, difficulty breastfeeding, lack of available resources, limited health insurance, limited specialized community care, and no follow up care from the view of healthcare providers (Raffray et al., 2014).

Summary

Multiple factors affect a parent or caregiver being prepared to take care of their infant post discharge. Discharge preparedness and readiness is a complex decision and includes physiological, emotional, educational, and social factors, available support systems, and accessible healthcare (Bernstein et al., 2007). Coping and stress management, available resources, communication and education skill of healthcare staff providing discharge teaching, presentation methods of education material, previous experience with caring for a premature or medically fragile infant, and access to health care resources all make up the complex nature of preparedness and readiness. As parents make the transition from hospital to home, their confidence, coping, and role identification are impacted by the preparedness and support received.

The birth of a newborn leads to challenges and family adjustment, particularly for those with a premature or sick infant. While the infant may be in the NICU for an extended period of time, discharge can be a joyous but also stressful and challenging time for parents. The literature highlights specific areas of parental needs and perceptions for discharge in the United States and across the world; however, few studies focus on the needs for families who live in rural areas and

their perception of being ready for discharge. Many premature infants are discharged with unresolved medical issues, and families must rely on extensive types of resources and additional support once discharged from the hospital. Increasingly more NICU babies are going home on ventilator and other life supporting medical equipment; however, there is paucity in the literature that focuses on patient training and care for the very high risk infant, availability of trained nursing home care, and experienced primary care providers in rural communities. Parents end up becoming their own caseworkers if they have the means and understanding to navigate the health care system, particularly in underserved and rural areas such as Appalachia.

Infants needed regular follow up appointments depending on their level of medical complexity, home monitoring equipment, medications, and often regular hospital readmissions related to complications. Those living in rural areas experienced additional challenges and barriers to obtaining needed resources and support. Research shed light on needs for families living in southeastern Appalachia and what types of barriers they experienced. In addition, issues and challenges that occurred at home also give insight into how well prepared families were for their new parental caretaking role. This study contributed new knowledge about discharge readiness and needs for families with a premature infant who live in rural areas of Appalachia. It also contributed to current knowledge in the process to aid and facilitate the transition to home for families being discharged from the NICU and areas where follow up education and support are needed. Improvements in quality of care include possible changes in discharge teaching to meet the specific needs of NICU parents. Discharge readiness is critical to success in bonding, parental coping, and growth and development of the infant and has implication for family processes and level of function.

CHAPTER 3

METHOD

This chapter provides description of the method, underlying philosophy, and guiding theory, of the study. Explanation for study design, participant selection, collection of data and data management, data analysis, reliability and validity, and ethical considerations are included. Use of interpretive phenomenology guided this study that sought to explore parents' perceptions of discharge readiness and experiences of barriers to caring for their premature infant at home.

Research questions in qualitative research focus on the why and how of a phenomenon and seek further understanding of an experience (Creswell, 2007). The researcher using phenomenology methods of data collection must translate constructed truths into a structure, which makes aspects of the phenomenon meaningful to the practice (Thorne, Kirkham, S., & Flynn-Magee, 2004). Thorne et al. (2004) contended that qualitative analysis demands engagement, imagination, and conceptual creativity.

Phenomenological research involves inductive methods used to collect in-depth and rich rhetoric to gain insight and understanding from individual perceptions of their experience (Patton, 2002). The method is especially beneficial in nursing to explore human phenomena and develop application to clinical practice. This study used interpretive phenomenology to help understand the experience of discharge readiness and transition to home for families with a premature infant living in Appalachia. The use of semi-structured interviews and guiding questions were used to explore the lived experiences of parents following discharge from the NICU and their perception of discharge readiness. After compiling facts and extracts, coded areas were formed. From these codes, several themes and subthemes were developed.

Theory

Qualitative inquiry is not based on theory; however, use of Kenner's Model of Transition (Boykova et al., 2014) [Appendix C] guides the focus of discharge readiness in this study. The model was developed and studied over the years within this specific population of parents with a premature infant by Kenner and colleagues (Flandermeyer et al., 1992; Kenner, 1988, 1990; Kenner & Lott, 1990). Kenner's Model of Transition (Boykova et al., 2014) includes five different categories of transition: informational needs, stress and coping, grief, role development between parent and child, and social interaction (Kenner, 1988; Kenner & Lott, 1990).

Each category was developed from research studies to identify specific needs of parents after discharge from the NICU (Boykova et al., 2014). As previously discussed, attachment, bonding, and role development can be altered for families with a preterm infant, and parents experience a transition in previous expectations. Parents must develop new patterns of functioning but often have difficulty making the transition to home. This alteration in parental role produces increased levels of stress and coping.

Parents also experience grief from loss of expected normal infant. There is also a cyclical nature of this grief, especially with increased levels of developmental delays and medical complications. Finally, parents need support from a variety of sources. Social interactions are critical to successful parenting and impacted by feelings of isolation, perceptions of others, and availability of resources. One of the guiding concepts of the model includes support and information. Parents need individualized information to care for their premature infant such as feeding, bathing, providing comfort, development, medication administration, and equipment management. The theme of discharge readiness is embedded within the informational concept of the model.

Philosophical Underpinnings

The focus of qualitative research allows a creative approach to understanding subject matter (Laverty, 2003). Phenomenology is the study of individuals' perceptions and insights and involves discovering features of a phenomenon or experience (Patton, 2002). Phenomenology does not contextualize its knowledge within a social or historical moment but seeks to look beyond everyday language. Phenomenology includes the primacy of language, traditions of cultural norms and embedded history, and praxis of knowledge. Phenomenological epistemology is based on the idea that there is no reality separate from the reality of the world, and no reality exists separate from individual's experience or independent of all meanings (Drew, 1999; Omery & Mack, 1995).

Phenomenology has been defined both as a philosophical movement and an approach to human science research (Earle, 2010). In addition, Earle (2010) stated that phenomenology, developed by Husserl, is a non-traditional style of philosophizing, emphasizing an effort to get to the truth, to describe phenomena. Husserl's work progressed and changed over time from his initial focus on mathematics, turning to subjective understanding of human experiences and study of phenomena, which led him to phenomenology as equally objective and subjective, and finally to finding subjectivity and pure phenomenology (Drew, 1999; Laverty, 2003). Jones and Koch (as cited in Laverty, 2003) stated that this "was a movement away from Cartesian dualism of reality being," separate from an individual to a "way of reaching true meaning through penetrating deeper and deeper into reality" (Laverty, 2003, p.5).

While there are two types of phenomenology, Husserl and Heidegerian, both are distinctly different in philosophical approach. Husserl, the founder of phenomenology, believed individuals exist in their reality and experience realities and perceiving the world as it is,

described by Lavery (2003) as thinking about the world to find deeper meaning. On the other hand, Heidegger believed individuals seek meaning and illumination about an experience as part of that experience, defining who we are, and how we exist in the world. Heidegger developed interpretive phenomenology, with a focus on hermeneutics, the lived experience (van Manen, 1990). Analysis of hermeneutic phenomenology reveals that every interpretation of everyday life is related to a frame of relevance that embraces it (Omery & Mack, 1995).

Husserl and Heidegger differed in their belief and use of bracketing (Lavery, 2003). Husserl, with a background in mathematics, described the ability of the researcher to separate their preconceptions and biases through bracketing (Lavery, 2003). This comes from the epistemological philosophical underpinnings that included belief in a Cartesian duality of mind and body. Heidegger did not share this belief, and philosophically described life experiences as Dasein or being in the world. The person and their world are not separate (Lavery, 2003). Heideggerian, also called Hermeneutic, view of the nature of being in the world and humans as self-interpreting is defined within an interpretive paradigm (Flood, 2010; Weaver & Olson, 2005). Further analysis of Heidegger's work reveals that his focus was on studying truthful knowledge as openness to being itself thus being and truth are intimately united (Omery & Mack, 1995). A person's past experiences affect his or her understanding of the world, and thus the individual is not separate from this. While Husserl and Heidegger defined phenomenology as philosophical in nature, Van Manan presented hermeneutic phenomenology with primary guidelines to study human science (Earle, 2010), inductive and interpretive in nature (Flood, 2010).

Hermeneutics involves understanding from a specific perspective, a matter of interpretation, and keeps within context of inquiry into historical and cultural perspective

(Laverty, 2003). Hermeneutic phenomenology as a philosophical approach to research aims at producing a rich textual description of a phenomenon and extracting contextual meaning and understanding through language. Narrative interpretive inquiry is conducted through interviews to seek deeper meaning and contextual meaning of the lived experience (Patton, 2002).

According to an interpretive paradigm, meanings are formed by human beings, depending on the context of their understanding of the world around them. Using interpretive type of research, discoveries emerge within the interaction between researcher and participant (Ajjawi & Higgs, 2007). Subjectivity is valued with the implicit understanding that humans are incapable of complete objectivity (Ajjawi & Higgs, 2007). This study follows the interpretive phenomenology approach as a methodology, through collection of participants' narrative interviews and data analysis of transcripts, field notes, and reflective journal.

Nursing practice focuses on the nature of individuals and their unique interaction with their environment. To guide and influence thoughtful reflective practice, hermeneutic phenomenology provides meaning of the human experience for developing nursing theory and knowledge. Hermeneutic phenomenology as a philosophical approach to research, aims at producing a rich textual description of a phenomenon and extracts contextual meaning and understanding through language.

Research Design

Nurse researchers began to examine and study philosophical foundations of nursing in the late 1970s and early 1980s (Van der Zalm & Bergum, 2000). Quantitative methods, in addition to positivist epistemological, ontological, and methodological underpinnings of traditional research up to that point, began to be questioned as adequate for the study of nursing practice (Van der Zalm & Bergum, 2000). A method for understanding a person's reality and experience,

descriptive narrative, offers the application of qualitative design that is linked to current literature and applicable to practice (Thorne, Kirkham, & MacDonald-Emes, 1997).

Participant Selection and Recruitment

Creswell (2007) stated that planning is critical to an effective and successful research project. One of the key elements in qualitative research is use of “selecting information rich cases for study” (Patton, 2007, p. 230). Answers to questions are discovered and clarified by those experiencing the phenomena of study. Use of purposeful sample provided in-depth learning and insights from the lived experience of individuals.

A convenience sample of families was recruited through the NICU follow up clinic that serves as the regional NICU follow up clinic for families living in eastern Tennessee, western Virginia, northern North Carolina, and southeastern Kentucky. Infants who are discharged from the local level III NICU are seen in the follow up clinic around 4 to 8 weeks post discharge. Approximately 20 patients per month are seen at the clinic after discharge from the NICU starting at 4 weeks and continuing every two to six months until 30 months adjusted age. Parents were recruited over a 6-month period of time, when saturation of data was reached. Evidence of saturation ensures adequate data were collected to represent the population of interest (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

Inclusion criteria for participation was as follows:

1. Participants were parents with a premature infant
2. Infant were born less than 32 week gestation
3. Infants spent three or more weeks in the NICU
4. Infants were discharged with one or more medical complexity
5. Infants were been on one or more medication or medical equipment

6. Parents lived in Appalachia

7. Infants were discharged within the past four months.

Permission was obtained from the clinic manager by the researcher and included in the IRB application. The IRB application was submitted to the East Tennessee State University graduate studies review board. Once approval was obtained, clinic staff was notified of the upcoming research, travel schedule, and their role in the process. Approved research flyer and consent form were placed in a large manila envelope to give to parents upon check-in at the clinic. Additionally, the scheduling clerk included the research flyer and consent form along with the clinic introductory appointment mailer.

Parents were invited to participate in the study via the flyer that was included in the clinic's patient introductory packet. This packet is mailed out to new patients by clinic staff. Since recruitment included families within two to four months of discharge, this also was the first appointment made post discharge. The flyer was also placed around the clinic for families to see when they arrived for their appointment. Parents who notified the researcher of their interest in the study received explanation of what the study entailed. Additionally, parents were provided ample time to ask questions about the study, told participation is voluntary and that they may withdraw at any time, and were informed their care at the clinic would not be affected in anyway, whether participating or not. Parents were also told that the interviews would take approximately one hour and would be digitally recorded. Likewise, it was explained to parents that the recording would be transcribed as a written transcript and be used for data analysis. Similarly, parents were notified that all data would be kept confidential and secured in a locked cabinet for up to five years after the research is completed. Discussion included the potential benefits of sharing their experience and that there were no expected risks involved in

participating. Parents who agreed to participate were asked to sign a consent form that listed any potential or actual risks for participation in the study. I further explained to parents even though they were signing the consent form, they still might withdraw at any time from the study.

Human Subjects Protection

Research began after approval from the IRB committee at East Tennessee State University was received. A Data Code form was created whereby a specific code identifier was assigned for each patient and will continue to be maintained in a locked cabinet located in the office for up to five years. To protect patient confidentiality, the consent form and demographic information have been linked to the Data Code Form and placed in a separate locked file located in the locked office.

Parents were approached at the clinic while they were waiting for clinic staff to complete their assessment and asked if they would be interested in being interviewed at a later date. Once a parent expressed interest in participating, a convenient time was scheduled, for interviews to be completed in their home or another convenient and private location. Prior to starting interviews, parents signed the consent form and completed the demographic form. Interviews lasted from 45 minutes to an hour and 45 minutes and were digitally recorded. Reflective notes were also recorded after interviews were completed. All digital recordings were transcribed as soon as possible after interviews were completed. All documents will be destroyed after five years upon completion of the study.

Role of the Researcher

An important consideration for interpretive phenomenology research is the relationship between researcher and participant (Patton, 2002). Establishing trust with participants is significant and an important aspect of data trustworthiness. The relationship is central to the

interpretation of the research (Lavery, 2003). The researcher worked over 13 years in a large tertiary hospital with a level 4 NICU and has extensive experience taking care of fragile and sick neonates from a variety of socioeconomic circumstances and families with diverse racial and ethnic backgrounds. The primary interest and skills of the researcher has included taking care of infants born to families from diverse ethnic and racial backgrounds. The researcher's upbringing included living in many countries around Asia and is especially drawn to individuals from other countries. From work and life experiences, the researcher is interested in learning more about parents' experience who are caring for a premature infant. The focus has been on parents who are caring for an infant at home with chronic health problems and managing medical equipment and medications, which require extra training and skills.

Information Collection

Qualitative approach allows for flexibility in conducting interviews by maintaining structure while allowing the individual time to express their feelings and reflect on the process by establishing rapport. This is much more effective when the nurse is engaged and present, similarly in a qualitative interview. The researcher used an open format to facilitate discussion, beginning with a guiding question and follow up questions that were formulated to help gain further insight into parents' experience. Patton (2002) described the importance in qualitative designs to be emergent throughout data collection.

Gibbs (2007) discussed the importance of interpretation during an interview. The researcher continually assessed and interpreted meaning from dialogue from parents and used reflective response to ensure their intended meaning. In-depth interviews focus on gaining more information and getting behind the meanings, whereas in a structured questionnaire, a quick response is preferred. It takes much more time to delve into deeper meanings, despite having

little knowledge into the specific situation. This is comparable to maintaining a therapeutic communication interaction where the goal is to explore an individual's feeling, thoughts, perspective, and interpretation of an experience. An interviewer is very knowledgeable, provides structure, and maintains an open environment while steering the overall interview in a specific direction (Gibbs, 2007). In addition, Gibbs (2007) described that an interview needs to flow in a manner where questions and responses are interrelated. The researcher in this study used therapeutic communication techniques during the interview, maintained eye contact, and a trusting posture. The researcher also adjusted questions at future interviews to gain more insight and meaning from concepts brought up in the previous participant interviews.

Data Analysis

Lyons and Coyle (2007) highlighted the importance in analyzing qualitative data from initial reading, developing themes, linking these themes, summarizing, and presenting the analysis. Davidson (2009) indicated the different approaches to transcription, referring to Bucholtz's description of naturalized and denaturalized transcription. A denaturalized transcription preserves the basic elements of oral language using 'ums' and 'ers', whereas naturalized transcription occurs when the transcription focuses on written elements versus oral (Davidson, 2009). Inclusion of naturalized wording in the transcripts was used to analyze and code data.

Through analysis, the researcher becomes more immersed in the participants' expressions, capturing initial thoughts and impressions, while reducing and clustering themes throughout the process. The researcher analyzed the transcripts by use of inductive process of coding and developing themes. Using specific categorization and organization of data allows clearer focus to emerge. Patton (2002) further stressed the need for data organization by the

researcher into codes, categories, and themes. Coding qualitative data is a process of breaking data down into pieces and then building it back up again, thereby linking differences and similarities while connecting common patterns and identifying overarching themes (Meethan, 2011). Gibbs (2007) signified the development and construction of codes as defining a framework that reflects the knowledge and theoretical sophistication of the researcher. Effective data management is essential for qualitative researchers and includes being consistent with interpretation, developing codes, and continually reflecting on category refinement (Morse & Richards, 2002). Creswell (2014) described a detailed six-step process (Figure 3) for analyzing phenomenological data. The researcher used the steps in Figure 3, recommended by Creswell (2014), to analyze all collected data.

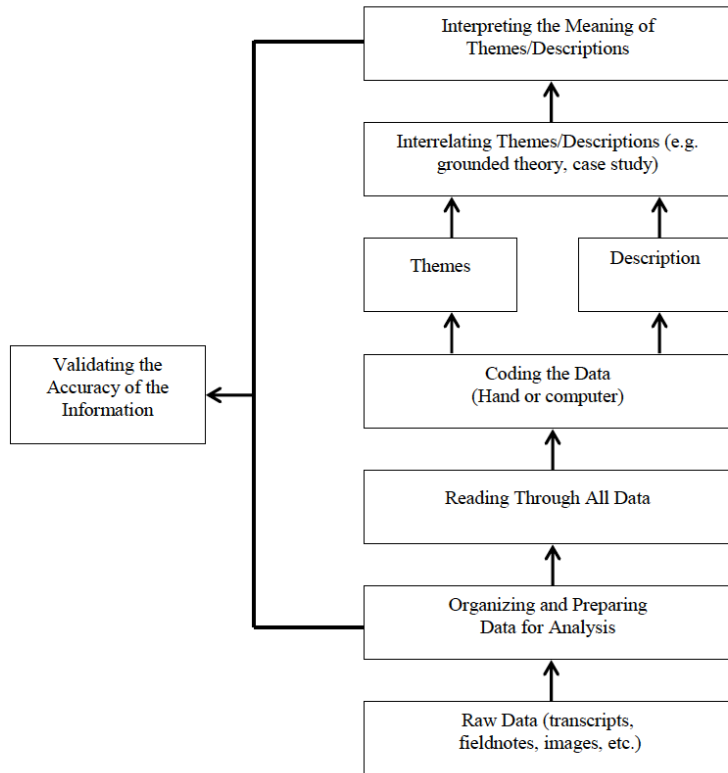


Figure 3. Data Analysis in Qualitative Research (Creswell, 2014, p. 119). Reprinted from Research Design (4th ed., p. 119), by J. W. Creswell, 2014, Thousand Oaks, CA: Sage Publications. Copyright 2012 by Sage Publications. Reprinted with permission.

Use of these six steps began first by collecting data and transcribing transcripts. Interviews were recorded with use of a digital device, and digital recordings were transcribed into word text. Second, all data was reviewed and field notes added. The identity of the researcher is fundamental to the thinking behind the research process (Smythe, Ironside, Sims, Swenson, & Spence, 2007). Smythe et al. (2007) explained that thinking does not exist outside the world; rather, the thinker is living and breathing life. The researcher engages in self-reflection through a reflective journal, which assists them in a process of reflection and interpretation, for instance outlining assumptions and influences (Laverly, 2003). Immediately

after each interview, the researcher used a reflective journal to record thoughts and perceptions of the participants' responses and reaction to the environment.

Third, the data was coded with development of themes from the transcripts. Walliman (2006) described coding as typologies or labels that give meaning to data. This is the beginning of conceptualizing significant phrases and participant rhetoric. Walliman (2006) cautioned to ensure coding is summarized and interpreted without distorting it and recommended use of reflective notes as previously mentioned. Fourth, themes were generated and categorized, whereby conceptual definitions were applied. Fifth, the conceptual meanings were verified and validated as discussed below. Finally, the themes and concepts were interpreted for deeper meaning, and results will be reported in Chapter Four.

Use of systematic data collection techniques, extensive training, triangulation, and diverse data sources help to maintain rigor in qualitative research. Establishing truth, value, applicability, consistency, and neutrality can be achieved through employing different techniques (Patton, 2002). Triangulation allows the researcher to cross validate data from observations and interview recordings. Patton (2002) described four kinds of triangulation: methods, sources or data collection, analysis or investigator, and theory to verify and validate qualitative research. The researcher ensured triangulation through conducting a thorough literature review, developing core analysis of coded data and theme development, and receiving feedback from professional content peers. The key focus is to look for similarities and inconsistencies with each type of inquiry, detailing deeper focus and insight on a phenomenon.

Trustworthiness

Researchers have set out to determine effective methods to describe and recognize valid qualitative studies (Saldelowski & Barroso, 2002). Morse (2004) recommended evaluating

qualitative research on different criteria than those proposed for quantitative studies. To ensure confidence and confirm reliability and validity in qualitative research, terms such as confidence and trustworthiness are used (Morse & Richards, 2002; Thomas & Magilvy, 2011). Lincoln and Guba (1985) proposed four criteria to establish rigor in qualitative studies using trustworthiness. Under the umbrella of reliability and validity, credibility, dependability, confirmability, and transferability make up the gold standard to establish trustworthiness (Polit & Beck, 2014).

Credibility

Credibility relates to methods of conducting research and believability of results. Confidence in truth of data and researchers' interpretation is given to the research study and strength of findings (Lincoln & Guba 1985; Polit & Beck 2014). Polit and Beck (2014) also highlighted triangulation for establishing credibility by confirming accuracy and verifying data is complete. Triangulation involves use of various methods to establish trustworthiness (Denzin, 2009). Prolonged engagement in the field, continual observation, and member checking also establish credibility (Lincoln & Guba, 1985). Interview transcripts, field notes, reflective journal, and peer feedback were used as triangulation methods to confirm trustworthiness.

Dependability

Careful record keeping and tracking all decisions, an established audit trail made during data analysis also helped to ensure dependability. It is a method to guarantee transparency in the whole process of data analysis. The audit trail ensures accuracy of data and relevance to the focus of a study. The researcher's audit trail consists of peer feedback, reflective journal, transcribed interviews, codes of transcripts, participant demographic data, and member checking.

In interpretative phenomenology, the researcher is part of the research experience and participates in the process. Lyons and Coyle (2007) described this as double hermeneutics, where

the researcher is personally involved in an empathetic manner but also objectively analyzing data. The researcher kept track of notes made during the interview in addition to reflective notes made after each interview and during coding. Furthermore, the researcher recorded all transcripts, coding charts, and theme analysis in a table method so progression toward final analysis was followed. This method also ensured confirmability throughout the process of interpretive data analysis.

Confirmability

Confirmability occurs through accurate representation of data while ensuring objective neutrality. Lincoln and Guba (1985) recommended maintaining an audit trail, a record of all activities others can follow, to establish confirmability. Reflexivity is one method to establish confirmability (Darawsheh, 2014; van Manen, 1990). The reflective journal should reveal insights of the researcher and how his or her personal experience aids in gaining new perspectives on the phenomenon of study. The researcher maintained regular self-awareness journals throughout data collection and analysis as mentioned above. Lyons and Coyle (2007) differentiated between analyzing quantitative data and the ability to generalize versus the opportunity to focus on specific individual experiences with the use of interpretive phenomenology. In addition, how the researcher approaches a study impacts his or her ability to analyze it. The justification and supposition for inquiry guides the interpretation in the findings (McPherson & Thorne, 2006).

Transferability

Transferability ensures that findings, contextual meanings, and implications are transferred or apply to similar settings. Specific details and context of the setting, and descriptions of participants, are described in chapter four. Failure to consider discrepancies in

qualitative research may lead to limited and over simplified analysis of the data. McPherson and Thorne (2006) stated that qualitative researchers focus on theoretical saturations as a gold standard for asserting claims of credibility; however, this might lead to premature conclusions. To avoid premature conclusions, a researcher must focus on all data objectively, support discovery, and include diverse findings.

Considerations

Use of interpretive phenomenology aided in collecting rich rhetoric while gaining insight into the lived experience around discharge readiness from the NICU for parents with a premature infant who live in Appalachia. Considerations when conducting a qualitative study include extended length of time for data collection and analysis (Patton, 2002). One challenge the researcher experienced with this study was the limited availability and scheduling for parents, due to time constraints they have, while caring for a chronically ill and medically fragile infant. Another consideration taken into account was the researcher's influence and impact on the focus of qualitative research (Patton, 2007). Even though the researcher has extensive experience as a NICU nurse, there was limited opportunity for the researcher to meet participants in person prior to consenting. In order to help overcome this, the researcher provided multiple methods for parents to make contact via mail, email, or phone.

CHAPTER 4

FINDINGS

This chapter provides a brief description of participants, followed by a detailed description of data collection and analysis of the findings. The purpose of this study was to explore the level of preparedness and transition to home for parents with a premature infant. The researcher set out to discover and uncover parents' perceptions and perspectives as they adjusted to the unexpected birth of their infant, interaction in the NICU, transition to home, and adaptation to parenting a child with medical needs. Major themes that emerged included: 1) Riding out the Storm, 2) Righting the Ship, and 3) Safe Port, Finding Solid Ground. These were further broken down into subthemes and are supported by coded items. Coded items were developed from participant transcripts, field notes, reflective journal, peer feedback, and member checking. The following will be a discussion of specifically coded items, subthemes, and themes, which emerged from the overall correlated data.

This study focused on discharge readiness and challenges parents might experience after discharge and transitioning home. While teaching and preparation are essential for parents' ability to care for their infant's medical needs once home, access to resources is also an important element in their success. Living in rural areas or limited access areas adds an additional challenge for parents. The specific emphasis was on those families who live in areas of Appalachia and their perceptions of transitioning to the home environment and integration of their family. This qualitative study is supported by the implementation of interpretive phenomenology through in-depth interviews with participants and triangulation of data. The topic was explored using a qualitative design and implementing an interpretive phenomenology.

Profile of Participants

The following paragraphs include a depiction of each participant and environment where the interview was conducted. This characterization will assist in understanding the individual and unique situation of each participant's experience. Care was taken to maintain confidentiality and anonymity of each participant.

Participant 1 is a married mother and quit her job to stay at home with her infant. She had previously lost a child due to extreme prematurity and expressed how the couple had felt the birth of this child was nothing short of a miracle. Prior to the decision to quit work, Participant 1 shared that her and her husband found it difficult to line up sitters, or a child care center willing to watch their infant because of their infant's health issues. While quitting her job created some financial hardships for the family, she was able to be at the hospital daily, which afforded her the opportunity to learn her baby's routine, and helped her adjust once home.

Participant 2 is a single mother with twins who lives in a rural area. This was the only interview that did not occur in the participant's home. She wanted to meet in a more public area, so we agreed on a restaurant near her home. The researcher arranged a time when there would be few customers and sat in an area that was quiet and private. There were some concerns ahead of time that the interview would be interrupted or have to end prematurely, but this did not occur. While she is a NICU nurse, she described the challenges of having a difference of perspective in being a parent instead of being a nurse. During the interview, she described feelings of being "pushed out" of the NICU before she was ready to care for her twins. She was hesitant to take the babies home earlier than she would have recommended for her patients and felt at conflict with the medical staff. In addition, she indicated that her knowledge as a nurse caused her to experience extra anxiety and thinking of all the things that could go wrong. She also described

how the discharge teaching included basic baby care, but little information was provided on how to manage two babies at once. She went into detail about the challenges of traveling with twins to follow up doctor appointments after discharge and manage daily. She also had to quit her job and take a much lower paying position that afforded her the opportunity to work from home. She was able to learn about basics of feeding, bathing, and getting in and out of her car with twins by seeking help from other parents with twins. As a single mother with twins, Participant 2 received daily help and support from her mother once discharged from the NICU.

Participant 3 is married to Participant 4, and they were interviewed together. They live in a rural area, over an hour drive from the NICU and Follow Up clinic, with few local options for primary care, especially those trained to care for the unique needs of a medically fragile infant. The interview was conducted in their living room, and the baby was sleeping in a room adjacent to the living room. Their baby was born at 23 week gestation, which is the youngest age for viability, and was not expected to survive after delivery. They also had previously lost a premature infant, who was 24 week gestation and was given a 25 percent chance of survival; however, he lived less than a week. Both parents described that despite being given less than 30 percent chance of survival for this infant, they were going to do everything in their power to fight for the survivability of this child. Both parents also described that this began their journey to always advocate and speak up for their baby. Infants born at such a young gestational age often have a lot of health problems. Their baby was discharged on multiple medications, had a tracheostomy, and was on a ventilator with oxygen supplementation, home monitoring equipment, and suction. Additionally, they qualified for at home 24/7 home health nursing care.

Participant 4 described how he felt they received sufficient training, support, and information for discharge. Both parents also discussed how their preparation for discharge

included doing practice drills in the hospital. This practice was essential once they got home. Despite receiving support and training, the whole experience left them emotionally drained and stated that they experienced symptoms of depression and anxiety. They described being prepared for discharge and becoming the primary caregiver required wearing many hats such as becoming experts to manage the health care needs of their infant and training others.

Participant 5 is married to Participant 6 and did the majority of the talking about their experience interacting with staff in the hospital. They live in a rural area, close to a major interstate, however still approximately 45 minutes from the Hospital and NICU Follow Up clinic. While they primarily stayed at the charity residence for families, Ronald McDonald House, their extended family was able to take over day-to-day activities at their home. This helped the couple have more availability and spend as much time as possible in the NICU. Their infant was born at 31 week gestation, hospitalized in the NICU for 10 weeks, and went home on medications. Both parents expressed that this extended time gave them the ability to bond with their infant and feel more confident once discharged to home. Additionally, they were very appreciative for the attention and care they received from the NICU staff.

Participant 6 was very comfortable having someone in their home and easy to talk to. The March of Dimes had interviewed them previously because their infant was one of the first in their county to be discharged at such a young age. Their overall perception was one of thorough discharge teaching and preparation by the staff. They received training for medical care, and only needed one night of rooming in prior to discharge. One thing that stood out during the interview was that, while their experience was very different from Participants 3 and 4, they also had a desire to spread the word about caring for the needs of infants with special needs and help other parents.

Participant 7 is married to Participant 8. They lived the farthest distance from any medical facility or pharmacy, deep in the Appalachian Mountains, though they did not express that this was a major concern for them. The time spent driving back and forth from the hospital and then to follow up visits after discharge was not an exceptional burden for them, although they were concerned if something might happen to their vehicle, they would be stranded. While they did not mind the lengthy two hour drive, they described many situations of feeling left out of basic infant care and bonding when they were able to visit the hospital, particularly for the father. There were a lot of discrepancies in the ability to gain access to their infant and inconsistencies in communication.

Participant 8 is married to Participant 7. As mentioned above, this couple lived deep in the Appalachian Mountains in an isolated location. Both parents described how much they needed to work, which prevented them from visiting more often, and were grateful their family could help with childcare. Their infant was born at 32 week gestation and in the NICU for two months. Participant 8 was the primary provider, worked two jobs, and could only visit once a week. He expressed difficulties he encountered during his weekly visits, sometimes not being able to do care or hold his infant, and had to wait another week to visit again. His frustrations and anger came through during the interviews, describing how some of the nurses should not be in charge of taking care of infants, and should be let go.

Participant 9 was 18 years old and the youngest of the participants. She lives in an urban area, located in Appalachia, not far from the NICU Follow Up clinic. She is single, living with her parents and siblings, and dependent on her family to meet her financial and transportation needs. She expressed concern for being able to raise her son without sufficient financial support. This created an additional burden on the family because her infant has multiple health

complications and health care provider appointments. Her demeanor initially appeared to be shy, timid, and unassuming; however, after the initial introduction and getting to know each other, she opened up more. Her infant was born at 32 week gestation and stayed in the NICU for two months. She described the need to have family support, primarily because she is a young mother. She also felt that because of her age, she did not receive adequate or timely communication from the health care staff in the NICU. Often she felt like an outcast because she felt the nurses were judgmental, patronizing, and even condescending towards her for being young.

Participant 10 is a married mother living in an urban area. She and her husband have an older child. She also had to quit her job because of the difficulty in getting child care workers. She also felt the need to be her infant's advocate and took extraordinary care to keep her baby from getting sicker due to the added complication of the rare medical condition of Cytomegalovirus (CMV). Due to her infant's risk for contracting an infection, the family is unable to have visitors in the home, or travel to public locations with their son. Although she is isolated at home, she described the attention from health care staff in the NICU as being vital to their preparedness once home. Despite the fact that they have an older child, having a preemie with unique medical issues was a challenge. Both mother and father are in the medical field, and they felt this helped them to communicate with the healthcare staff more effectively. The mother even alluded to the fact that since her husband is a physician she felt that they received more updates than other parents might have received.

Demographics

There were a total of seven interviews conducted with 10 participants. Three husband and wife couples interviewed together. Two were single mothers, and two were married mothers but were interviewed without their husbands. See Appendix B for a complete breakdown of

participant demographics. Five of the interviews were conducted face-to-face in the participant's home while sitting across from each other in their living room. One interview was conducted via FaceTime, which consisted of the participant sitting in their living room logged into FaceTime with the researcher, who was located in their home office. One interview was conducted with the participant at a restaurant. This interview was in a private area of the restaurant at a time when there were few customers present, though none were nearby. The participant was reassured we could reschedule if lack of privacy became an issue. The interviews lasted anywhere from 45 minutes to 110 minutes, were audio recorded, and transcribed verbatim.

Participants' ages ranged from 18 to 40 years old with 70 percent between the ages of 26 and 30. More than half (60 percent) lived in rural areas of Tennessee or Virginia, with the other 40 percent living in small urban areas. Five of the parents, lived less than 50 miles from the NICU Follow Up clinic, whereas four lived between 50 and 100 miles, and one lived more than 100 miles away. Nine participants lived in their own home, and one lived with her parents in a Townhome. All study participants were Caucasian. Although attempts were made to recruit a more diverse sample, there were no participants that met the study inclusion criteria at the clinic. A breakdown of participants' education level, ranged from High School Equivalency Program (HSEP) through completion of an undergraduate degree. Income ranged between \$10,000 to above \$50,000. Thirty percent of parents had lost a child the previous year: one at birth and one married couple lost their first baby, seven days post-delivery. Twenty percent of parents also had an older child.

There were a total of eight infants, six singles, and two who were twins. Infants' ages ranged between 23 to 32 week gestational age at birth, and they weighed from one pound to four pounds two ounce birth weight, and four to ten pounds by discharge. All infants had some form

of medical need after discharge, such as daily medications ($n=6$) and extensive medical equipment ($n=3$). Medical equipment included apnea monitor, oxygen, ventilator, suction, and feeding pump. Thirty percent of parents took their infant to the Emergency Room (ER) after discharge: One infant had one visit; two infants needed to go to the ER twice, and two infants visited the ER a total of five times. Seventy percent of parents had to take their infant to multiple medical appointments immediately after discharge, however over 50 percent lived greater than 50 miles from the ER, hospital, pharmacy, and medical provider.

Detailed Analysis

The overarching theme, *Adapting to New Family Roles, Transforming Normalcy*, highlights the adjustment from an initial shock of an unexpected early birth, learning how to navigate the NICU, and obtaining information and support. Parents further adapted and rose to the challenge of parenting an infant with medical needs. They were able to transition to home, find safe harbor, and redefine their new normal family.

Three major themes were developed (Table 1): 1) *Riding out the Storm*, 2) *Righting the Ship*, and 3) *Safe Port, Finding Solid Ground*. Ten subthemes emerged from the data analysis to support each major theme (1a.) *Having the carpet pulled out from under me*, (1b.) *Things I lost*, (1c.) *Feel like an outsider*, (1d.) *Sink or swim*, 3), (2a.) *Quest for knowledge*, (2b.) *Caring for me, caring for my baby*, (2c.) *Customized learning*, (3a.) *Getting to know baby*, (3b.) *Becoming the expert*, 3c.) *Ongoing emotions*, and (3d.) *Adjusted parental role, finding normalcy*.

Table 1

Major Themes and Subthemes

Major Themes	Subthemes
<p>1. <i>Riding out the Storm</i> Shattered dreams & preconceived ideas. Initial shock of birth and into the NICU</p>	<p>a. Having the carpet pulled out from under me b. Things I lost c. Feel like an outsider d. Sink or swim</p>
<p>2. <i>Righting the Ship</i> Learning to parent a preemie while preparing for discharge. Coming out of shock, intensity surviving the NICU and preparing for discharge</p>	<p>a. Quest for knowledge, begging for more b. Caring for me, caring for my baby c. Customized learning</p>
<p>3. <i>Safe Port, Finding Solid Ground</i> Leaving the NICU and surviving at home and finally stabilized.</p>	<p>a. Getting to know baby b. Becoming the expert c. Ongoing emotions d. Adjusted parental role, finding normalcy</p>

Riding Out the Storm

With the unexpected delivery of their infant, extended stay in the NICU, and the need to learn how to parent a premature infant with medical issues, participants described their experiences adjusting and adapting to their new role as parents. This was an uphill climb and became apparent as parents shared how they learned to care for their infants’ medical needs and discovered how resilient they were. The first major theme, Riding out the Storm, highlights parents’ responses and experiences transforming normalcy and settling into a family routine. Subthemes such as having the carpet pulled out from under me, things I lost, feel like an outsider, and sink or swim are described in detail below and further explain specific components of this major theme. Additionally, each separate subtheme is supported by specific codes (Table

2). Several coded items are subtly and closely interwoven within several subtheme areas such as inconsistencies, lack of good communication and information flow, and emotions.

Table 2

Major Theme 1: Riding Out the Storm

Subtheme	Code
1a. Having the carpet pulled out from under me	i. Emotions running wild ii. Roller coaster ride iii. Curse and blessing
1b. Things I lost	i. Broken bonding ii. Finances iii. Time iv. Privacy
1c. Feel like an outsider	i. Access to unit and baby ii. Broken promises, inconsistencies iii. Singled out, being judged iv. Stayed away when felt intimidated
1d. Sink or swim	i. Learn the lingo ii. Just surviving the day iii. Sleep deprivation iv. Jumping through hoops

Having the Carpet Pulled out from under Me

Having the carpet pulled out from under me is a subtheme that was revealed after parents expressed their first response to the unexpected delivery of their baby. Parents were forced to adjust to being a parent of a premature infant, were unprepared for the level of commitment needed to care for a child with medical needs, and were faced with having to make life and death decisions. For most participants, these decisions were made without any previous medical knowledge. Any premature birth is unexpected and leaves the parents to handle difficult decisions for their newest family member. The absence of a natural feeling experienced around a term birth was replaced with anxiety and fear of an unknown outcome and uncertainty of

parental role. Categories that arose from transcript analysis included multiple emotional responses, feelings of loss and lack of control, and the gift of a new baby. Codes were developed into Emotions running wild, Roller coaster ride, and Curse and blessing.

Emotions running wild. Parents with a premature infant went through an emotionally charged process balancing preconceived ideas of having a normal family to the new normal family based on the needs of their infant. Parents expressed ongoing and fluctuating emotions, feelings of shock, and looking for answers to why it happened. They described feelings of being overwhelmed and multiple emotions such as anxiety, fear, stress, grief, and guilt. Participant 2 indicated she was shocked her twins were born at 33 week gestation but also grateful they were not born earlier. She stated, “I knew I had a 50 percent chance that they would come early...so on one hand I was glad they were at least 33 week.”

Participant 9 described a combination of emotions, added with a sense of confusion, looking for answers after the birth of her son.

It was a mix of heart breaking and wanting to just break down and cry, wanting to yell and scream and throw stuff, because I didn't understand, why? Why did this happen to my baby? Why, was it my baby? Why was it me that has this stuff happening...why aren't you explaining to me what's going on with him? And why is he not breathing right now? And why aren't you explaining why he's not breathing? And um, it was very heart breaking and maddening. At the same time, so I didn't know how to react, and at one point I had to just walk out, because I didn't know what to feel or what to think. So I just had to leave, because I just couldn't be calm at that point.

Most of the interviews occurred several months after discharge; however, the premature babies were hospitalized for anywhere from two to six months. Even with this extended length of

time, parents shared overwhelming emotions with the unexpected and sudden nature of their premature delivery. As mentioned above, none of the participants except two expected an early delivery; Although Participant 10 was sick throughout her pregnancy, she also did not anticipate an early delivery.

Roller coaster ride. Participants shared they felt a lot of uncertainty, chaos, and helplessness that was also complicated by frustration. Participant 10 reported how she experienced day to day changes: “There’s good days and bad days, It’s like you have a few good days and you are on a high. And then the next day is just not good. And you know, nobody really prepares you for that, roller coaster ride.” She also added once home “you have these really good little milestones and then you have set backs and then good milestones and then setbacks...nobody really prepares you for that.”

Moreover, Participant 5 also described the changes related to having different nurses providing care: “The most common problem that we would have would be we understand you are going to have differences from nurse to nurse. But the day to day changed a lot.” Participants 1, 3, and 4 defined the changes in a more dramatic fashion as riding an emotional rollercoaster, where things changed daily with uncertainty, and that it was very scary. The continual level of uncertainty and the unknown was difficult for parents to deal with. Participant 1 explained how things begin to change daily and stated, “yeah, it was definitely a roller coaster...I call it an emotional roller coaster.” Participant 3 also further added how the emotional roller coaster continued after discharge:

I know every parent and every parent group in the NICU. They call it the NICU roller coaster. And that is exactly what it is for the entire time and for a while after you come

home and you have the baby and it is a roller coaster. And it's a roller coaster that you are blind folded for. Because you can't see the turns

Participant 4 went on to define not being able to see what was coming, referring to the experience as “a blinded rollercoaster and can't see what's around the bend.”

Curse and blessing. It is especially difficult for a new family to have to make continuous life and death decisions, all while experiencing the joy of a new birth. Some parents described the experience as a blessing and curse, highlighting the dichotomy of a joyous occasion overshadowed by critical medical issues. While premature birth comes with expected risks, one family described how they were excited after being given only 30 percent odds of survival for their baby because their first infant did not survive.

Participant 2 reported how she felt overwhelmed with twins, calling them her curse and blessing, and stated, “they are my biggest curse and my biggest blessing at the same time.” She also described the dichotomy of guilt and anger, disclosing, “you might have feelings like, I really wish they weren't twin,” in contrast to “But I wouldn't take anything for them! I love them more than anything but there are moments that any parent even any married parent with multiples would have feelings of like why did this happen.” Furthermore she stated, “why did this happen to me...How am I going to make this work and this kind of sucks?”

Participant 9 also described the blessing of her son, “even though he was a surprise, he is a blessing in disguise...where would I be without him? I don't know! I can't see my life without him.” Participant 10 went on to explain despite her baby being born premature, “it was a blessing because they found out he had CMV.”

Things I Lost

This subtheme came about after analyzing categories where participants recounted things they lost or sacrificed. With the unexpected delivery and the ensuing challenges and sacrifices, parents described multiple losses. The primary sentiment expressed from parents was the shift from having a normal delivery experience, a loss of normalcy, toward a new reality. This normalcy loss was compounded by other losses, such as time, job, insurance, privacy, sentimental items, and bonding. The codes that were used to develop this subtheme include broken bonding, finances, time, and privacy

Broken bonding. Parents felt separated from their baby and shared that they did not really know their infant or infants very well but were faced with making life and death decisions and had many unanswered questions. The separation from their baby created a barrier to bonding and getting to know their baby. As Participant 1 talked about her experience, the researcher jotted down notes about a tone of fear and anxiety as she described separation from her baby after the birth. She shared those feelings,

So I had to go that length without seeing her and I think maybe I got to see her maybe not even a minute after she was born. And I could barely see her because they had already put her in the Isolette and was getting ready to ship her up to.... So that was pretty hard, pretty draining

Participant 9 also referred to the separation of not having a natural feeling with your baby after birth as a loss.

to not have that natural feeling of having your baby right there....that kind of took some of it away....and now I just have to wait to see him the next day and that killed me! That killed me a lot because, I only got to kiss him....and then they took him away

Participants described the separation as a loss of time for bonding and getting to know their infant. Participant 9 also had waited to hold her baby, finally speaking up, explaining, “I waited until after three weeks after he was born to hold him for the first time.”

Participant 7 stated, “it would have been nice to spend more time getting to know what he likes and how to take care after being in the hospital.”

Participant 2 also stated, “I feel I did lose some baby phase when I first brought them home.”

Finances. Several parents were faced with loss of employment and income, increasing financial challenges from reduced income, limited insurance coverage, and loss of providers. Participant 1 stated, “of course when you lose income that’s always challenging.”

Participant 3 also shared their loss, “loss of job as a result of stress, and I had quit my job because I couldn’t work with the small children any more...So, our insurance had changed, and we couldn’t see our previous providers anymore.” Participant 3 went on to clarify that it was a significant loss of employment for her husband. This resulted in loss of income and insurance, thus they had to change providers and almost lost their house. She described this loss:

he wound up losing his job....you know once the FMLA leave is up to the good graces of your boss, whether you can have any more time off. And he used up all his FMLA and...had one more surgery to go through before we got him home...he went back to work and he requested off for the day...and his supervisor approved it...her supervisor went over her head and he lost his job and it didn’t even count as his being fired so he couldn’t claim unemployment. They called it job abandonment...he lost his job and he came home and he had had no income for six months...Almost lost the house.

Participant 5 revealed he was unable to visit because of not having time off: “it was rough because I didn’t have that personal time.” Additionally, Participant 10 commented on the stress and difficulty in continuing to work while trying to visit and care for their baby, especially since he was so sick: “you know I quit work and because he was so sick and I knew that I wasn’t going to be able to go back. I don’t know how people can do it. I mean having jobs? That would be a huge stressor.”

Time. Particular aspects of this study focused on families who lived in rural areas, who were required to organize and prioritize time to visit the NICU. The majority of participants, 70 percent, had to travel 50 miles or more to get to medical facilities, taking anywhere from one to two hours total. Parents experienced a loss of time visiting with their infant due to traveling back and forth from their residence to the hospital. This usually involved the working spouse.

Participant 1 stated how she finally got settled in and felt more at ease, referring to the stress of traveling back and forth in order to spend as much time with her baby as she could, and sharing,

I was constantly having to go back and forth to see her? It was stressful. Because I would go during the day and her daddy worked second shift, so we would be like out there at two in the afternoon and we’d stay until three or four o’clock in the morning. So some of that will wear you out, the drive having to go back and forth but we wanted to be with her as much as possible.

While loss of time for travel to visit baby was a concern for parents, this distance also created challenges for the working spouse. Parents had to take time off from work, and their ability to visit with baby was limited. Participant 7 experienced exceptional difficulty taking time off work to visit his baby, only able to get off every other week. He became exceedingly

frustrated when he finally did visit but was told he could not hold his baby. He shared some suggestions for nursing staff to help working parents:

give em a chance to have contact with them if you can't get them out, they can at least open the door...if their body temperature is good and there is no harm...I don't see any harm in opening that door just for few minutes? And if everything's really good, I don't see the harm in getting her out for a few minutes"

Participant 5 also described the sacrifice of having to take time off work and the need to plan accordingly due to the extended distance from the hospital. This was exacerbated by status changes in their baby and being at the whim of whomever was making decisions about their baby. He stated, "depending on all the choices that they made, it was us driving and leaving our jobs." This occurred when the parents were told their baby would have surgery the next day, but when they arrived at the hospital, they were told he was not going after all. He further described the time lost as added stress, worry, and anxiety.

Privacy. Loss of privacy was one of the most prominent losses described by participants, especially for those infants who were the most fragile. As a result of needing medical interventions and support after discharge, parents described the adjustment to having medical equipment and caregivers in their home. Participant 3 indicated the loss of privacy as

a very big adjustment, we are pretty private people. But not anymore...that's changed a lot...it was weird going from just the two of us and our cats in our little house to constant noise and constant machines and constant people...there's no privacy...we have 24/7 nursing so there's no privacy.

Participant 3 also revealed how they were able to adjust to the loss of privacy, stating,

But I think that it helps that we are best friends and above anything else, we are best friends. Because we have no privacy in a high stress situation that you have to have something aside from you know Romeo and Juliet love, there has to be better than that or you're not going to make it

Her husband, Participant 4, further described the loss of their privacy as “they brought the hospital home with them.” This interpretation portrayed a mental picture of the impact it had on both parents and the level of care needed for their infant.

Parents welcoming a new baby into their family often want to keep items that are associated with their newborn and a sentimental reminder, such as the umbilical cord. Loss of the umbilical cord can occur from lack of communication from parents, between caregivers, and by accident. Participant 7 and 8 were hoping to keep their baby's umbilical cord; however, it was misplaced. They both expressed displeasure with not having their baby's umbilical cord for one of their family members. Participant 7 commented to his wife, “it was something Nana wanted you to save for the scrapbook,” further adding, “you wanted to save that but she threw it away...yeah, well she had a dirty diaper and I didn't pay no attention to it.”

Feel Like an Outsider

As difficult as it was for parents to be separated from family and loved ones, they also had to deal with challenges and barriers that prevented them from being able to visit and be with their infant. Many parents described multiple inconsistencies and discrepancies, such as access to the unit and their infant and communication updates. Participants emphasized their frustrations and indicated not being able to visit or hold their baby created barriers to bonding with their baby. Several participants also expressed having feelings of being judged or singled out and felt intimidated about speaking up. Additionally, several participants described how the healthcare

staff have degrees, so they act entitled and make all the decisions. Codes that were used to develop this subtheme include Access to unit and baby, Broken promises, inconsistencies, Singled out and being judged, Stayed away when felt intimidated.

Access to unit and baby. Parents found that being in the NICU did not necessarily mean that they could visit their infant whenever they wanted. The rules for entering the unit and being able to hold their baby depended on who was working. Participants described access as conditional, limited, and inconsistent. Participant 7 was particularly upset that communication changed from shift to shift and became increasingly frustrated, as he shared his experience,

It's the last time I put up with any more petty nurses. You got one that tells you one thing and then you got one that tells you another, I'd just go ahead and tell them, say you don't want that nurse anymore. You want someone that will or has communications with other shifts, and not just say what they think you want to hear and they say what they want to say. Go by the facts. I am more of a facts person.

Daily changes in staffing and between shifts compounded the problem with inconsistency in communication and access. One of the methods to ensure consistency was unit staffing with primary nursing; however, several participants did not have the same nurses on a regular basis. Additionally, the role of nursing staff would change, limiting the ability for parents and primary nursing to become familiar with each other. Participant 4 indicated that the nurses who “fell in love” with their baby were also in charge, “so his primary nurses he didn't have the solid set up that a lot of babies do.” Furthermore, Participant 4 clarified access depended on who was working: “whether we get to hold him or whether we are charge of suctioning...All of that was very dependent on the nurse, and in the end I think that was the only part that I really struggled with.”

Participant 5 also discussed how frustrated he was with the manner in which his wife was treated. He perceived some nurses who did not seem interested in helping parents, adding “that it had turned into just a job...a long time ago.” He also felt the nurses made their work more convenient for them rather than taking time to get to know a parent’s experience level. He was aware of an overall underlying tension from nursing staff and observed a “quiet violence.” His frustration also extended to the level of inconsistencies that occurred and how access depended on which nurses were working, stating

There were times that it seemed like some nurses were okay with us getting him out and handling him, and some nurses weren’t. And I think that a lot of times they stay incredibly busy. I think that a lot of times they get in a mood at work or if we don’t get instruction?

This resulted in delaying their ability to hold and bond with their baby and “ended up with us not holding him for about the first week and a half of his life.” Participant 5 also indicated there were a lack of updates and changes in status, possibly from nurses also not being aware: “nurses that were saying, like oh, my gosh, you haven’t held him yet...and a lot of times we weren’t told why it was changing or what was changing...and a lot of the times the nurse simply didn’t know.”

To further describe receiving limited information, Participant 8 stated her level of frustration and anger, pointing out feeling like an outsider, “kind of put outside the circle.” The nursing staff created a barrier to parental ability to perform hands on care while denoting “every time she planned on doing it with her, someone would or somebody else would be in there.” She explained “that nursing staff conducted themselves, as having all the control, however should be required to give more information and decision making to parents.”

Broken promises, inconsistencies. Over half the participants shared they were confounded when others contradicted specific information given by one person. This is similar to having inconsistencies in communication and going against what was previously communicated. For instance, Participants 7 and 8 shared together how the father, Participant 7, had held their baby right after she was born, but the next day was told only the mother could hold the baby first. Participant 8 went onto explain “after that, they told him he couldn’t till I come up there,” and when he did go visit the next shift, they told him no.” Participant 7 further shared his level of anger and frustration:

they said nobody can hold her now until the mommy, they said mommy has to be the first one to hold her...Hell if that’s the case, why are you all handling her? How you going to change her diaper! How are you all going to feed her?

Participant 5 also described the conflicting information being given and further clarified “they weren’t sure who to go to, who had the final say, or who they could trust.” He further clarified, “the doctors would make a decision, and then a nurse would counter act that decision. And then they would counter act it again.”

Additionally, parents were not sure what the expectations were until after the fact. Participant 5 and 6 described how the nurses were surprised when they found out they had not held their baby yet, Participant 6 stating “there actually were nurses that were saying, like oh, my gosh, you haven’t held him yet? Well, yeah, we didn’t know we could.” Furthermore, Participant 5 indicated, “We were in the constant game of catch up....trying to get information about our son and what are they planning on doing next.”

This was compounded by the medical condition of their infant, Participant 5 adding, “The worse their baby was, the harder it was to get information.”

Participant 9 also shared how she had to speak up and find information about holding her baby and specified

they were like, oh, you haven't held him yet...no one told me that I could! And oh she's like oh you could have held him a long time ago, and this would have been nice to know! Instead of waiting for three weeks

Participants 7 and 8 shared their frustrations about being told they needed to do daily routine care for their baby before going home but could not because other people were always in the room and Participant 7 added

every time we started to do it...there would be either the physical therapist there or the speech therapist there or something going on so we couldn't do it. No planning! They wouldn't even come in and tell us if they were coming or going

Furthermore, participants also described being told one thing and, when they came in prepared to complete a task, were told something different or opposite. Participant 4 shared how they were finalizing discharge paperwork after being in the hospital for 4 months and a nurse not familiar with the parents attempted to stop them from going into the baby's room.

Participant 8 shared her anger about the nurses not listening. She described how when she did communicate that she and the baby's aunt were going to do a feeding and diaper change, the nurse had already done everything 30 minutes prior. In addition, Participant 8 shared her confusion about being told conflicting information, repeating what she told the nurses,

you all are confusing both of us because, one nurse on one shift says you can't come in until right at either, three, 12, six or nine. And then one nurse says come in at 11:30, or 2:30...I was so confused

Singled out, being judged. Parents indicated feelings of being judged, singled out, or ostracized. Participants offered descriptions of feeling belittled and talked down to, stressing that some nurses did not bother to take the time to know parents' abilities or bother to explain information because they thought parents would not understand. Participant 9 expressed frustration and was visibly upset when describing how she felt ostracized because she is young, then criticized for not being able to perform tasks. She also described feeling like an outsider, receiving information from nurses depending on who was working, was intimidated, and ended up staying away depending on which nurses were working. She also added that she was at a disadvantage because of being a new mother and not knowing how to give basic baby care. She shared, "I am not a nurse!...I don't know what babies are supposed to do. This is my first one, I have never been around other babies...I have never taken care of one." In fact, Participant 9 further specified that some of the nurses were not very kind, adding, "I am fine..if I don't see them again."

Participant 5 contended his primary issues were how the nurses treated his wife, asserting his regret for not being there to help because he had to be at work. He described how they treated his wife and felt the nurses didn't take the time to get to know his wife and anything about her prior experience level, stating "they treated her, well like a dummy, essentially, and that hurt her and it hurt me because I wasn't there."

To highlight a different perspective on being singled out, Participant 2 felt she was not treated the same as other parents in the NICU. She was the only participant with direct knowledge of how normal care and teaching occurs since she is a NICU nurse and stated that she felt singled out, adding, "I really felt like they kind of pushed me out faster than what we normally do." She shared that on the second day her baby dropped his heart rate, so it was a good

thing they waited. Furthermore she described how she felt the rules did not apply to her; the staff expressed overconfidence in her ability because she was a NICU nurse, and she felt they were not as thorough, which increased her anxiety once they got home, adding

you know the discharge paper, and we'll go through it, but do you have any specific questions and I didn't so they probably didn't even go through as much as they would have if I had not been a NICU nurse and worked there....they were like you're fine...you're a NICU nurse. You know what to look for. So I was like the first week or two that I was home, it was like almost always like a major anxiety attack. Every single time I would feed him.

Stayed away when felt intimidated. Parents who experienced being singled out, judged, or ostracized by medical staff were also reluctant to visit when those individuals were working. For some it became necessary to schedule their visits only during specific days and times or leave the unit when certain staff was assigned to their baby. Participants became disempowered, were afraid to be too outspoken, and felt separated from their baby. Participant 7 and 8 talked about how they were afraid to speak up after experiencing issues with visitation and inconsistent communication.

Participant 8 shared that she had been holding her baby, and the nurses got mad, adding they “start fussing and hollering at me, who told you could do that” and further added “no one had explained the rules.”

Participant 7 stated they were afraid to speak up and take charge because they were afraid they would not be allowed in and described “I know I would have liked to, but I know I'd never been allowed back in there.”

Participant 9 also encountered several nurses who intimidated her, and she would leave if they were working, adding, “there was a point in time where if I saw...a couple nurses...I would high tail my behind and leave, because I didn’t want to interact, it kept me from spending time with my baby.” Furthermore she explained,

I felt like I was this little ant, standing and looking at a dog. And wondering when I was going to get squashed. Basically, cause, I didn’t feel like I had any right to come in and ask any questions. I felt like I didn’t have a right to anything at all with him, because that was how they acted towards me. A kind of you don’t belong here, kind of feeling and that’s when I would just turn around and just leave because, if I don’t feel welcome, I am not going to stay

Shift change created challenges for accessing the unit, especially with limited time for visiting. Participant 9 discussed how she would not visit sometimes because the only time she could visit was during shift change: “you weren’t allowed to go in, you weren’t allowed to see your baby. And so if that was the time you had come, you couldn’t see your baby at all that day.” Furthermore, she often only had 15 minutes to visit but knew staff would not let her take the baby out for that short amount of time, adding

sometimes you have only 15 minutes to come in the day and see him, and you need as much interaction with him as you can...they wouldn’t allow you to do anything with just those 15 minutes...they would tell you, it’s shift change and you can’t come in. so you wouldn’t go see your baby at all.

Sink or Swim

The overwhelming situation of early delivery leaves parents making critical decisions and the need to overcome fear, anxiety, and feelings of inadequacy. They become resilient and

motivated to learn what it takes to care for their infant. In other words, the challenges they experience encourages them to overcome feelings of vulnerability, learn to become strong, and speak up for their infant's needs. While they felt loss seeing their baby suffer, this motivated the parents to take initiative. Codes that identified and formed this subtheme are Learn the lingo, Surviving the day, Sleep deprivation, and Jumping through hoops.

Learn the lingo. Communication in a hospital setting typically includes descriptions specific to the environment, and the NICU is no exception. Part of survival for parents includes being able to understand the unit rules and communication, especially as they learn to care for the unique needs of their infant. Discharge readiness includes being able to communicate and understand information effectively. This means learning a new language and vocabulary, related to care for premature infants. Surviving in the NICU means learning the abbreviations, terms, and lingo. During the interviews, parents used common terms they had learned while in the NICU, which otherwise they did not know prior to this experience.

A portion of the researcher's field notes included a description of terms used by parents, which are unique to the NICU, in case questions came up during analysis. The researcher mentioned to Participant 4 about his use of specific NICU terms such as Epiglottic Stenosis, little 'roid' baby, and use of paralytics. He jokingly responded, "you have to learn the language, know the lingo, to survive."

Participant 5 also mentioned "ringers," when referring to a type of medication their baby was receiving. While this was not the focus of the study, parents both stated directly and implied the need to learn the lingo to survive.

For example, Participant 9 described the need to have things explained, stating, "when he starts doing weird stuff, you need that explained...Because you get worried."

Participant 4 also included how he had to learn the terms, and revealed, “you have to learn the language,” and Participant 3 added, “we get some looks.... all this different terms and terminology...It helps that we have a lot friends and family that are in the medical field.” Finally, Participant 4 described the relation between communication and health status, stating “as things became much more simplified, as he got better, communication did seem to be more straightforward.”

Surviving the day. Parents felt they needed to be present as much as possible, revealing that their infant’s survival depended on them being there. Survival meant self-reliance, support from family, friends, and medical staff. Participant 1 stated, “I think it would have been a lot different if I hadn’t been able to be there with her every day,” and added “Just take it a day at a time. It’s all you can do.”

Surviving the day to day began at the day of birth, as illustrated by Participant 3 and 4, from inducement of labor and being given a zero chance of their baby surviving. The medical team who were creating an environment to support the parents, had calm music piped in and reassured the mother that she would have a moment with the baby lying on her stomach, in the event their baby did pass away right after birth. Due to their previous newborn loss, Participants 3 and 4 were faced with another possible death and prepared for the worst. The baby survived, and Participant 4 described “the second he came out and started screaming my knees buckled and I hit the chair.”

Surviving also applied to changes in an infant’s condition requiring medical intervention. Parents were faced with making life saving decisions. For instance, Participant 1 revealed how scary it was to know the pros and cons about the surgery her child needed.

Additionally, Participants 3 and 4 realized their infant was the only one in the NICU with a Do Not Resuscitate (DNR) sign on his crib; however, they questioned whether they had made the right decision. Participant 4 added, “it would have just been putting him through more than he should have to go through.” Participant 3 also shared, “Because you really second guess, your choice as a parent you know. None of the other parents have made that decision. Are we making the right one?”

Participants 3 and 4 also talked about survival in terms of defiance. Their baby needed surgery for a serious infection of the bowel; however, they were faced with the decision to have an abdominal drain placed instead of surgery because he was too small to survive surgery. In the end, their baby pulled the drain out after four days, and Participant 4 described it as “his first act of defiance.” He also included how the NICU called their baby “Houdini” because he kept pulling out his tubes. Finally, Participants 3 and 4 insisted on informed consent for every issue going on with their baby. This let them take an active part and being in control assisted them in surviving mentally and emotionally while in the NICU and once home.

Parents needed to have a high level of stamina to survive the experience. Participant 5 described overwhelming frustration and fatigue. An aspect of stamina included motivation, being attentive and assertive, in caring for their baby.

Participant 9 revealed that she became motivated once discharged from the hospital, adding,

So it’s still a very big motivation to keep pushing him and pushing myself, to keep going, and once he got out of NICU, that’s when my motivation came. While he was in NICU, I didn’t really have that motivation. I was really depressed and I was really upset about it

all. And I felt like I wasn't able to raise my baby and when he came home I was like, okay, this is what we gotta do and we gotta push, we gotta get you on track here

Sleep deprivation. Parents described how they sacrificed sleep in order to be able to visit the hospital, sometimes after a day of work, and to take care of their baby in the hospital and once they were discharged to home. In the hospital parents became accustomed to the equipment and relied on staff and monitors to let them know how their baby was doing; however, once they were on their own at home, they did not have this instant feedback. Participant 1 described how they were unable to sleep and kept watching to make sure their baby was breathing, “not having the monitors to know her heart rate and oxygen level, it was a little nerve wracking.”

Despite being tired and exhausted, participants noted it was worthwhile and meaningful.

Participant 1 explained

at the beginning they just demand so much of your time and you're exhausted all the time, but I can't imagine the other side of the spectrum, you know, that when they leave, and they grow and they don't need you anymore.

Participant 5 also denoted, “We were tired, and frustrated all of those things that you would expect if you had a child that was sick or in the NICU or going in for an operation, and you know, we love our son.”

Not wanting to miss anything, parents were involved in every aspect of care they could, and Participant 7 indicated, “the first night we stayed up there, we went there for every single feeding. We didn't sleep much at all.” After not sleeping very well for several nights, staff provided support for parents, and Participant 7 added the nursing staff told them, “you need to get your sleep while she sleeps.”

Jumping through hoops. Parents were required to make adjustments and accommodations in order to gather information, gain access to the unit, and care for their baby. Participant 5 described “it was a lot of hoops to jump through.” This code dovetails with several already mentioned in subtheme Feel like an outsider. Parents took action, were beginning to speak up, and became motivated in reaching their goal. After describing frustrations when getting conflicting information from various medical staff, Participant 5 began to question who exactly was making the decisions and stated

we kind of sat back and said who is providing care for our child? Where is the head to cut off? To sort of speak. Because we don't know who to go to? Who is the final say so? And that bothered us, especially because at the time the issue that our baby was suffering

Due to the length of travel from home to the hospital, over two hours from the NICU, Participants 7 and 8 had to adjust their schedule to accommodate visiting restrictions. Participant 7 added, “it was going to be too hard, because we were going to have to get up early and go up there, and stay all day and come back or whatever.” Fortunately, they were able to get a room at the Ronald McDonald house, which was close to the hospital.

Scheduling her visits around when certain nurses were working created issue for Participant 9. This depended on who was working, the rules for shift change mentioned above, and overcoming feelings of being intimidated. She shared that some nurses told her if she could not hold her baby for an hour, she could not hold him at all. She articulated in a frustrated tone:

I mean they have schedules too? But we have schedules as well. You can't always stay for an hour and sometimes you need 15 minutes to hold your baby to make your day a whole lot better! And they wouldn't let me. And that kind of broke my heart, so I knew

that if those nurses were working, I knew that I wouldn't be able to do anything with him anyway? And I'd just leave. And it was heart breaking

On a positive note, Participant 9 figured out which nurses would give her more support and allow her to hold her baby, stating

But then there were some that I absolutely adored and I would stay for hours on end...and just holding him, and just cuddling him and they would just let me. They'd just let me stay and wouldn't tell me to leave or anything like that; and that was the good part...But it was up and down a lot

The researcher noted how Participant 9 became more animated and exhibited an excited tone when describing finally being able to hold her baby for hours. It appeared that she was trying to hold onto the more positive moments with her baby, and this seemed to be a defining moment when she began feeling like a mother.

Summary of Major Theme 1: Riding out the Storm

Adjusting to a new environment after the unexpected birth of their premature infant, parents experienced frustrations, challenges, and barriers. They had their world turned upside down and were required to change any preconceived ideas for their family and to search for new meaning in their parental role. Parents were faced with ongoing day-to-day changes, unable to see what was around the corner, and experienced multiple losses. Despite the extreme disruption in their lives, parents were determined to overcome these challenges. Their underlying goal while in the hospital was to take any necessary steps to get their baby home, whatever it took to be in charge of day-to-day care, integrate their new baby into their lives, and cultivate a new normal for their family.

Righting the Ship

Righting the Ship is the second major theme depicting the level parents reached to adjust in the NICU, beginning to speak up more, becoming familiar with the rules in the NICU, learning to care for their baby, and settling into their role as parent. Additionally, this major theme included how parents were beginning their transition to home with their babies. This major theme is made up of subthemes: Quest for knowledge, Caring for me, caring for my baby, and Customized learning (Table 3).

Table 3

Major Theme 2: Righting the Ship

Subtheme	Code
2a. Quest for knowledge	i. Begging for more, help me understand ii. Need sympathy in the chaos iii. Empowered, I need to be heard iv. Finding my voice, becoming an advocate
2b. Caring for me, caring for my baby	i. Nurses and doctors become like family ii. Battles are different for mother and father iii. Loving from afar
2c. Customized learning	i. Emotional learning (solace in shared experience) ii. Learning the basics, having a premie iii. Hearing the nurses voices in my head

During this phase, parents were further adjusting to their new family and learning to meet the needs of their baby by learning new skills and information. Traditionally, learning includes steps of going from unknown to known. Parents had to be taught direct hands on care and be able to perform tasks correctly to a certain level of competency. They were going from unknown to known as they built self-confidence and ultimately self-reliance as they prepared for discharge.

Quest for Knowledge

It took a while for parents to become adjusted to their baby being in the NICU, to learn how to navigate the hospital setting, and to understand their babies' condition. Codes that support the development of this subtheme include the following: Begging for more, help me understand; Need sympathy in the chaos; Empowered, I need to be heard; and Finding my voice, becoming an advocate. During interviews parents described specifically what helped them be prepared and what information they felt was lacking.

Begging for more, help me understand. Several participants emphasized that they did not know how to be a parent, received inadequate resources and information, and wished for more. They were not sure what to do or expect, experienced a lot of uncertainty, and ended up figuring out many things on their own. Parents described how they transitioned into learning by doing, revealed they learned from actively participating in activities versus just getting information.

Despite being a NICU nurse, Participant 2 specifically stated that she had to ask for further information, even requesting that her twins not be discharged for another day. She had communicated that the discharge nurse only went over the discharge checklist when the first twin was released; however, the nurse did not review it a second time for the second twin. Furthermore, she felt that the education she did receive did not adequately prepare her to manage day-to-day activities to care for her twins and transport them to medical follow up appointments. She took it upon herself to search for other parents of twins to get additional help and web searches to locate helpful information, adding

I would have to Google things like how to safely get twins out of car if you are by yourself? And parked? Cause, like you've got to get the stroller and if you are like this

you can't fit a stroller between two cars and it gets to really strategic, in finding the good parking spot. like if you park beside or like if that wasn't there or that was the target that is an area you want this spot because you've got that extra area. so if you are by yourself, I mean there were literally many times that I would look in the bathroom and say you look like a decent person can you please like, because you are not going to leave the door open so. there is just things that a normal person wouldn't think about that come up sometimes you don't know it until you are in that situation

Participants 7 and 9 depicted being frustrated, seeking out information to help them learn how to be new parents. Comments by Participant 7 included, "We needed to learn how to care for our baby, you know, we were first time parents."

Participant 9 shared,

Well, it's hard, you don't even know how to run your own house or have a job, and now I am a parent. I am in between, have so many responsibilities and expectations. I have to learn things, you know, how to manage my son's health problems

She also specified, "I really had to pry for information about him."

Participants who reported receiving adequate information also stated they had a positive experience. Primarily, these participants shared that they felt discharge teaching was thorough and complete. One commonality was the ability to receive hands on experience and practice.

Participant 1 shared,

They um, went over everything with us, the doctors came in and talked to us...they went over how to do her formula, they gave me a number (to call) if I had any questions...they gave us a copy of her discharge summary...a list of all her appointments... they had all the information together, they had printed everything off.

Need sympathy in the chaos. Support, caring, and encouragement from medical staff play a large role in helping parents deal with the uncertainty and fear while in the NICU. Parents reported a dichotomy of feelings around support from the nurses, with some stating they stayed away and did not feel like a parent to others indicating they could not make it without the support they received. Overall, participants noted that their level of stress decreased, and they experienced increased comfort from sympathy and support. Participant 1 shared, “if it hadn’t been for some of the nurses, yeah, I, um I think I would have been more stressed and more emotional than I was.”

Parents also noted the need for support and encouragement, no matter how dire their situation seemed. Participant 3 and 4 shared their experience receiving such support, despite being told how deadly the condition was, and they were offered support from one of the nurses, who recommended that they pray. Participant 3 included,

the charge nurse, um she kind of came over and she gave us big hugs and she said you know if you are praying people, and you want to know what to pray for. Very rarely, very, very rarely this will heal on its own. Now I don’t want you to get your hopes up that this is what is going to happen, but if you want to know what you are specifically praying for, that’s it

Due to Participant 9 being young and being a first-time mother, she needed a lot of support from the medical staff. Additionally, she had never lived on her own and relied on her family for additional help and support. When asked what would have helped her, she included statements on how nursing staff should include parents in everything. As extrapolated from the subtheme, Feel like an outsider, Participant 9 experienced feelings of being singled out, judged, ostracized, and disempowered. She wanted to include information on how to help other parents

who might be in her situation by sharing the need to provide not only support but also sympathy for parents: “Even though my child’s in there and I want to fight for my child, I physically can’t do that and mentally stay strong enough to handle all of this, when I am being belittled.” She also highlighted that instead of making parents feel like outcasts, they could be more supportive and sympathetic and revealed

that’s very hard to watch your baby in there. Not knowing if they are going to make it out...Especially if they stop breathing, and you are watching them bag your baby! And they are telling you to step back...and they are all surrounding him and you don’t know what is going to happen. They could choose right then, to not wake up. So I feel like that the sympathy needs to be a little bit more...the nurses know that he’ll probably be fine, but the parents don’t.

Support and sympathy from staff included the need to speak up and encourage parents to take care of themselves. Having a baby in the NICU becomes a daily challenge, and parents stand vigil, trying to identify their parental role, while also managing their other children.

Participant 2 detailed how the medical staff encouraged her to leave the NICU and take care of her older child and expressed, “I wasn’t going to leave but one of the fellows said, you’ve got to go! They are fine, you gotta’ go.” She further stated, “so I went, it was kind of against my will...but they were fine.”

Likewise, Participant 9 added, “I think just in the NICU having more communication and sympathy and not belittling anybody. No matter their age, their looks....Because they are still a parent.” She further elucidated, “like having the nurses over there taking care of the baby and have someone sitting right there with the parent,” and finally highlighted, “that would have helped me a ton! With all those feelings, I just needed someone to talk to.”

For some parents, their frustrations led them to take initiative and seek out support. When referring to seeking out help, Participant 5 added, “we begin to search out people who can, and it seems like they can’t tell us the same thing. Which just makes us even more frustrated.”

Moreover, Participant 10 described the importance in support and presence from friends and family, stating “without the friends and family, they actually kept me sane. Very grounded because they were always there.” Additionally, she added “just knowing that someone was there was good enough, they didn’t have to do anything for me...just thinking about you today...it was just nice to have that support.”

Empowered, I need to be heard. This code was a result of hearing parents’ stories about being frustrated and feeling disempowered. Participants 7, 8, and 9 described how they had to speak up after waiting an extended period of time to hold their babies or do any type of daily care. Participant 9 shared how she had to wait to hold her baby and disclosed, “I couldn’t wait anymore. I had to ask the nurses if I could hold him.” Furthermore, she added after the nurse told her she could have held him several weeks ago “this would have been nice to know...instead of waiting three weeks.” This was also depicted under subtheme Things I lost, to elucidate the losses parents experienced not being given the chance to bond with their baby.

Participant 7 indicated how parents should have the say so, not the medical staff, referring to both him and his wife: “Both of us have the say so, I mean both of us are the parents.”

Participants 3 and 4 had decided they would give their infant all the chances he needed, with Participant 3 adding, “we were committed to that as long he himself was fighting, then what ever support we had to give him, and that meant for the rest of our lives.” She had kept a log of all activities, calling it her “old fashioned version of charting,” and eventually needed the

information to verify her infant's status with the attending. When she mentioned to the attending that something did not seem right, he asked her to explain and show her what she meant, and she relayed, "he looked fine, until you said that...show me what you see." She further explained,

we went over step by step, well his colors, yesterday his average stats were this and today they are like this. And he was like whoa! A point difference and I said I know it doesn't look like anything, but something is wrong. And he said I believe you

Participant 9 also spoke about the need to be heard by the nursing staff, stating

It's hard to raise a baby that you don't know how...you don't know what needs they have, and if they have different needs than babies who are born on their due date, you need to understand them a little bit more

She specifically described what she would like to tell her nurses: "You need that time and that person to help, and you don't get that...in order to learn the unique needs of her baby while in the hospital, so she would know how to care for him once home."

Participant 2 felt she was being pushed out of the NICU that is also discussed under the code Singled out, being judged. To further depict how she became empowered and needed to be heard, Participant 2 shared, "if they born today you would automatically keep them for 48 hours anyway so I just don't understand. Why you are pushing me out and so they did keep us one more day and pacify me." She further added, "if I had been the nurse and I was taking care of this baby, you'd make this baby safer." This statement depicts how parents progressed from empowerment, to finding their voice, and becoming an advocate for their baby.

Finding my voice, becoming an advocate. As described in subtheme, Felt like an outsider, parents were uncertain of rules, felt intimidated, and were afraid to speak up. Parents began to unconsciously and then consciously overcome their fears of the unknown by

progressing to a take-charge mode. Once parents realized the barriers and challenges, they began to overcome feelings of intimidation and became more motivated to turn their frustrations into action and voice their concerns. This developed into the role to protect their baby, not only speaking up about their personal concerns, but also advocating for their baby.

It became apparent that during interviews all participants found their voices and learned to speak up. Participant 2 articulated concerns for her twins' safety, felt pushed out of the NICU earlier than she would have done for her patients, and illustrated the point for the need to provide safer care by keeping babies longer, "seven more days probably."

Participant 9 also had to speak up and voice her desire to hold and care for her baby. She was reluctant at first, very shy and intimidated, and shared, "I am a very quiet person. I don't like talking if I don't have to. So that for me, was a very hard thing to do." She further clarified how she realized the need to speak up and advocate for her baby:

It's my time now, I need to be able to hold my baby and interact with him...Because I thought they would just go ahead and let me whenever...and they didn't, and I was like, well, I guess I gotta' start talking here, you know, to get something done

The researcher's perception of parents speaking up and being firm was described in the field notes during the interview with Participants 3 and 4. Participant 3 stated, "she had to find her strong voice." It was at this point the researcher realized that parents had to speak up and become an advocate for their infant. Consequently, this further motivated them to learn how to care for their baby. Finding their voice also included being informed on all actions being taken to care for their baby. Participant 3 expressed, "We are very big on we try to make sure we are very educated on everything that happens with our son."

During interviews that involved both parents, one participant was dominant and did most of the talking, whereas the other participant was more passive. This was especially evident in the interview with Participants 7 and 8. Although Participant 8 added valuable input, she appeared to be rather shy and gentle in nature. She relied on her husband, aunt, and grandmother to speak up and be her voice. Participant 8 described how her aunt got mad at the nurse after waiting 30 minutes, and she told the nurse, “well when are we going to be able to get her out.”

Participant 8 mentioned that her aunt told the next nurse in regards to the previous nurse, “I would really rather not have her as a nurse, and the nurse told them, that kind of request has to come from the mother.” Participant 8 also added what her Aunt told the nurse, “I said that, well if she’s not going to let me feed her, like all the other ones, I’d rather have somebody else.” Her husband, Participant 8 chimed in, “It seemed like one or two of them, didn’t really care,” appearing to question their level of professionalism and concern for parents’ welfare.

As many of the parents experienced contradictory instructions, leaving them the with question of whom has authority and final say, Participants 5 and 6 shared that they finally spoke up and voiced their concerns to the physical therapist and physician trying to get answers. Participant 6 stated, “Hey this happened what do we need to do? And they made it very adamant, to write it down and say hey, this is what you need to do, this is what you need to let her do.”

Participant 10 was one of only two parents who had older children. She possessed a definite maturity level being a mother already and had no problem using her voice and being her child’s advocate. She also discovered the need to step in and speak up. She expressed eloquently, “you have to be the advocate for them because if not, nobody else is going to be.”

While parents became an advocate for their baby, speaking up also came at a price. Participants 3 and 4 identified how they became fearful to be too outspoken. Their infant required medical technology to remain stable once home, and the parents received extensive training to manage his equipment. They encountered situations where speaking up and questioning interventions when readmitted to the hospital resulted in threatening to refer them to Child Protective Services (CPS). Participant 3 stated, “when you have a medically fragile child and you go against the advice of a physician, then CPS will be contacted.” According to Participants 3 and 4, the medical staff emphatically informed them, “it doesn’t matter if you don’t want to be here, we say you should be here and you can walk out that door but if you try to we are going to call in someone.”

Finally, Participant 9 stressed that she experienced people judging her but articulated how she felt medical staff should not talk to her as if she did not know anything. She expressed the need to speak up and find her voice, adding, “I have to really just stand up for myself, and be like I am a mom...I know what I am supposed to do here...going through that NICU experience.”

The subtheme, Quest for Knowledge, highlighted the interactions between parents and other individuals, though primarily NICU staff, in order to gather information on their babies’ status and develop knowledge to care for their baby. It takes personal courage and initiative to speak up and request information, take charge of their family, and gain some sort of control over a situation that threw them into chaos.

Caring for Me, Caring for my Baby

Even though some parents talked about having a lot of family members, they expressed that it was still overwhelming at times taking care of their baby. Additionally, several of them talked about wanting everything to be perfect, especially after everything their baby had gone

through in the hospital. This subtheme, Caring for Me, Caring for my Baby highlights the level of support that is needed to help make that transition for parents to bond and develop their role. This helps build trust and self-confidence. Support is provided on multiple levels for baby and family and in a cooperative manner. The following codes help clarify this subtheme: Nurses and doctors become like family; Battles are different for mother and father; and Loving from afar.

Nurses and doctors become like family. Support for parents while in the NICU from the nurses and doctors was essential. Participants described how support and caring from the medical staff helped them experience less stress, feel grounded, and able to learn more. Emotional stability in the face of uncertainty was a big concern, and parents revealed how the medical staff also helped them keep it together.

Parents felt they had more access when they knew the nurses. This relationship went even deeper and some felt some of the nurses were like family. Participants described how much they needed and valued help from staff in the NICU, especially mentioning those who felt like part of their family. Participant 1 revealed how NICU staff “became like family to us and really cared,” helping her remain sane, stating,

I would probably have more break downs than I did so, um, I think it’s good that yes I know, they are there to take of your child but they also extend their hand to you, reach out to you and make sure that you are okay. And take care of you so that’s why I said they became like family

She also shared how she was comforted by the care her baby received, particularly from one nurse, and was “able to come home at night and be at peace knowing that she’s up there and because you know that they are taking care of her.” This sentiment was also expressed by Participant 10, stressing the importance in knowing who is taking care of your baby, that they are

providing the best care possible, and not “just some Joe Schmoe who didn’t care about your child.” Moreover, she stated that support kept her “sane” and “grounded” and was reassured when she had to leave to care for her older child. She went on to explain becoming close with the NICU nurses:

I bonded a lot with a lot of them...even when we were in the PICU, they would come down and say hi to him...bring him little gifts...and tell us that they were praying for us and that was really sweet

Finally, she added “it’s more than a job, but more personal, you know they just care for them like they are their own little babies” and also shared her gratitude for receiving this level of personal attention: “I can’t thank the NICU enough for everything that they did for our family and this little guy.”

Participant 3 shared how her baby’s physician was “her hero,” further explaining, “he especially encourages participation in rounds and he had us listening in rounds... at the end of rounds, he asked me is there anything that we need to talk about.” This attention empowered Participant 3 to continue her commitment to take care of the extreme medical needs for her baby.

Participant 9 highlighted how she came to rely on several nurses she trusted, indicating these nurses took the time to explain everything, and she could count on them. She also shared, “They didn’t know the kangaroo pumps as much, and stuff like that, so they did the best they could and I respect them for that. They did more than some of the other nurses even bothered to do.” It became apparent that Participant 9 was more comfortable with the nurses who made the effort to teach her, thus giving her more confidence.

When the researcher asked for clarification in regards to whether it was the nurses’ knowledge or their effort in explaining information that helped her feel more comfortable,

Participant 9 replied, “it was definitely effort. They need to put that effort into trying their best to make it easier for the parent.” She also continued describing, “it’s not just about the baby; it’s the whole family...and they need that effort put into them...sometimes you don’t get that. And those two nurses, they were the only ones who did that.”

Battles are different for mother and father. Mothers and fathers approached communication with medical staff and interpreted their babies’ needs in a unique and different manner. This is related to previous codes Quest for knowledge where parents found their voice and felt the need to be heard and became an advocate for their baby. In becoming the advocate, each participant found their inner strength that they did not have before.

Participant 9 spoke about what it takes to become a mother, sharing “once you become a mother and you want to do everything for your child, to make them happy, you want to and you give up everything of yourself and you give it all to them.”

Two of the fathers took a protective stance, reacted differently, and were more outspoken. In fact, Participant 8 talked about getting physically upset with some of the nurses when talking about the way they treated his wife, indicating, “if it had been a guy there would have been a nurse down.”

Additionally, Participant 7 shared that the nurses went ahead and fed their baby, instead of letting her and her aunt. Then, Participant 8 chimed in and stated, “right then and there I would have called the head nurse.” Moreover, he also made the point that the nurses were making a bigger deal than needed when referring to nurses not letting him hold his baby until after his wife had held the baby, adding “they said nobody can hold her now until the mommy.”

Participant 5 was also protective, stating “I definitely did not care for the way my wife was treated and it seems very lackadaisical or nonchalant with her.” Furthermore, he added, “that frustrated me because you want every health care professional to be very concerned about you.”

Participant 7 could only visit once every other week. He had to juggle two jobs, and when asked about getting off before the baby was born, he was told he could work at both on the same day; however, after the baby was born, all that changed. When discussing difficulty visiting because of work, the researcher noted in field notes and later in the reflective journal that both Participant 7 and 8 did not appear upset or overly frustrated that Participant 7 had to work so much. In fact, they were both lighthearted and jovial about the topic. They were more concerned that accommodations were not made by Participant 7’s workplaces nor by the NICU in helping facilitate visitation. Additionally, when the researcher made a comment that despite difficulty visiting, Participant 7 seemed to have bonded very well with his baby, he responded “as much as her mommy would let me have her.”

While Participant 7 had challenges getting off work in order to visit his baby and the nursing staff prevented him from holding his baby, Participant 10 shared a different experience for her husband. Participant 10’s husband also worked a lot, but when he was able to visit the NICU, nursing staff made sure to allow him to hold his baby. She gave an example:

he worked and so sometimes he couldn’t get to go during the feeding times...he just wanted to go and look at him and they would let him hold him...so it was really sweet...they knew that he wasn’t able to come a lot and so they were like we’ll let you hold him for a little bit. Which was really, really nice, and he appreciated that too because, he was like I just want to go look at him!

The code, Battles are different for mother and father came about while interviewing Participant 10, where she actually stated, “when it is your child you will go to battle. A mom’s battle is different than a dad’s battle.” She admitted that since this was her second child, she became a lot more demanding than previously, and when asked about protecting her baby, she replied, “I think that kind of comes with it...I definitely wasn’t like that before.”

Accordingly, she added that she became more protective and said things she would not otherwise, claiming “I became more of a mama bear with him.” She also described communicating in a more direct fashion than her husband, specifically repeating what she said to him:

sorry if I ruined your reputation but I just got into it with one of the pediatric attending...Because he won’t do what I want him to do. But I am also not just one of those people who do that all the time...it’s just the care for him...I was a lot more demanding

Loving from afar. Parents had to juggle activities and, for some, other children at home, while also trying to manage being with their newborn in the NICU. They relied on family and friends to pitch in and handle things at home, while also trusting NICU staff to care for their baby. Participant 10 felt that NICU staff went above and beyond to care for the small patients in their charge, stating “just like you know that the love and care that they put into that you know for somebody else’s’ baby is incredible.” Specifically, she stated, “I bonded with a lot of them and it was really nice and we still keep in contact and they like to follow him just to see how he is doing.”

Parents who could stay at the hospital as much as possible. One service provided by the local community charity house, Ronald McDonald House, gave parents who lived a long

distance from the hospital an opportunity to remain close by and visit more. For some parents, family members took care of their residence so they could stay with their baby. Participant 5 shared, “we actually spent those two and half months in the Ronald McDonald House.” Subsequently their extended family took care of things at the house. He added, “but as far as taking care of things...whether it be financially or something to do with the house...my and her extended family.”

Participants 7 and 8 also discussed using the Ronald McDonald House and shared how it helped ease their having to travel back and forth because they lived two hours from the hospital. Additionally, Participants 3 and 4 lived over an hour from the hospital, so they were also able to stay at the Ronald McDonald House.

Participant 1 was separated from her baby because she was in one hospital and her baby had been transferred to the regional NICU. She described how difficult it was to not see her baby, and she stated,

I could barely see her because they had already put her in the Isolette and was getting ready to ship her. That was pretty hard. Pretty draining. Knowing that I couldn't be up there. But her daddy was there. And he sent me pictures and videos

Participant 2's situation was very different from the other participants because she had twins, with one of the twins being discharged before the other. She was also one of two participants who had an older child, so family members had to step in and help out. While Participant 2 had family helping out at home, she was also conflicted because of being separated from the twin who remained in the hospital. Fortunately, this was for only one day, and she was able to have her whole family together after several weeks of being in the hospital.

Customized Learning

Parents talked about needing unique and specialized education, training, and support. Each family experienced varied and distinctive situations and was faced with making the adjustments in caring for a medically fragile baby and transition to the role of parent.

Customized learning includes the following codes: emotional learning (solace in shared experience); learning the basics, having a preemie, and hearing the nurses' voices in my head. Parents also experienced a wide range of support and educational materials, from being frustrated and having to beg for more to feeling fully supported and trained. Learning and training occurred within a shared experience between parents and medical staff, and becoming more confident and self-reliant occurred through practice.

Emotional learning (solace in shared experience). Emotional learning was associated with the level of trust and developing familiarity between medical staff and parents. Parents reported the need to feel comfortable and supported while adjusting to the birth of their premature infant and learning to care for their unique needs. Those parents who stated they felt prepared also reported discharge teaching was thorough, and they felt well supported. In contrast, Participant 2's perception was that she did not receive any. The NICU nurses she currently works with made assumptions that she already knew what to do. It became a point of contention, as discussed in previous subtheme, Feeling like an outsider. Participant 2 felt pushed out of the NICU before she was ready.

Participant 9 made this connection between trust and whom she could rely on. She described how she was able to learn alongside the nurses and stated, "they are also learning and not looking down on me the mother." Additionally, she expressed that the medical staff she trusted were more down to earth, adding "their noses aren't so far up in the sky, like I am a

doctor and you're a little citizen, you don't understand, all this stuff, you aren't entitled to this information."

This made her more comfortable, less stressed, and more at ease. It reduced her feelings of intimidation by witnessing others learning and motivated her to learn. The researcher asked Participant 9 if these nurses' motivation had an impact and motivated her. Participant 9 responded, "uh hm, yeah! Because they didn't know what the kangaroo pump was supposed to do and that stuff, because they didn't have it that often." She further shared,

when we left...I was like, those are the two that I want to go back and see in time, when he's actually in a good mood. Go back and see them because they are the two who absolutely helped me the most. Out of all the nurses in there, those were the two I could count on! I got to know and trust them

Participant 9 also specified how NICU staff really need to consider not only the mother and baby, but care is for the whole family, adding "it's not just about the baby; it's the whole family is in that together."

Participant 1 echoed similar information. She described being able to stay in the NICU, which allowed her to watch the nurses provide care, which helped her learn. She stated, "you get to see what all the nurses are doing." Furthermore, she added how helpful it was that the nurses stayed with her to make sure she was feeding her baby correctly, adding "when I got to the first starting feeding her and they sat down with me talked me through it and stayed there in the room with me."

Trust goes both ways between parents and medical staff. For example, Participant 3 contended that in order to be trusted by nursing staff, they became more involved in their baby's care: "the more we participated...the more we showed that we were determined to be strong

enough to do this, the more we were trusted, and the more we were respected.” Moreover, she added, “once they figured out that we didn’t panic they let us stay in the room.” Furthermore, she articulated that the key to survival was to remain calm so they could be involved and not be asked to leave,

Ease of discharge occurred when parents were not rushed. Participant 5 specifically mentioned that discharge was, “in-depth, it was informative...our experience with discharge wasn’t really rushed at all.” Both Participants 5 and 6 felt very prepared; they were doing physical therapy exercises on their baby and noticed improvements right away, before their first appointment. Participant 5 shared,

by the time he came home, maybe a week later, before his first physical therapy, he was already showing improvement to us...doing things that he hadn’t done before in the NICU so we decided that it would be easier for us just to take him it wasn’t too terribly difficult to learn.

Several Participants described how medical staff took special consideration in not overwhelming them. However, Participant 9 articulated how the NICU should have staff designated to support and give information to parents when things become chaotic,

I feel like they should have someone specifically in there to talk to the parents to help them with those feelings and make sure that they understand everything that’s going on like having the nurses over there taking care of the baby and have someone sitting right there with the parent.

Participant 5 noted that medical staff shared information in a compassionate manner so as not to overwhelm parents and revealed, “I really do think a lot of it had to do with the fact that

the doctors and nurses really didn't want to give terrible news, but they also didn't want to give overwhelming good news.”

Sometimes the solace or comfort is from a spouse. Participant 3 opened up about her and her husband's relationship, adding the difficulty in having a premature infant with so many medical issues was a real challenge. She stated when asked about supporting each other: “it helps. I know we saw a lot of couples that didn't make it. I take it that we are not the norm.”

For some parents, they received solace in the learned experience from family members. Participant 7 received solace and comfort from her aunt and husband as they tagged team because each had to work: “see my Aunt would come and stay so he could come back home.” This allowed parents to not be alone at the hospital, have family members learn to care for the special needs of their baby, and increase time spent at the hospital with their baby. In summary, participants pointed out the benefit of being able to be at the hospital, learn from the nurses, and have more hands on practice. Participant 1 added

you get to see what all the nurses are doing and like you know, when I got to the first starting feeding her and they sat down with me talked me through it and stayed there in the room with me... picking up on how to adjust all the wires that she had and as far as holding her and taking care of her.

Learning the basics, having a preemie. This code directly related to parents feeling prepared for discharge. Parents discussed they felt more confident when they had opportunities for hands on care and felt more like a parent. When asked about what their definition of being prepared meant, several replied being prepared meant having the skills and knowledge to care for their baby once at home. A major point parents articulated was knowing when and who to ask for help, describing whom they could count on for help.

Participant 10 replied, “just make sure you have all the bottles...you know, just make sure you have all the bottles. All the necessities that you need. To take care of him.” She also described how nurses got down on parents level, “they are extremely thorough on the things that they do.” She also indicated her experience was excellent and stated,

they helped in every single way. You know I was always there for rounds. They never failed to communicate if something was wrong or if something was happening. And so upon discharge, I mean they went over everything. With me plenty of times, I felt very prepared to come home with him.

The researcher asked participants what type of information and training they received. Participants replied they received a combination of information from basic baby care, CPR, feeding, bathing, diaper changing, and specific training depending on their babies’ unique needs.

Participant 1 mentioned that she received more hands on experience, as it got closer to discharge and shared, “I think if I wasn’t able to be with her as much it would be a little more challenging.”

Participant 5 included “the worse baby was, the harder it was to get information... at the end...he was ready to go home and we just got an influx of information and we were instructed on certain things.”

Several parents had family who were going to help them care for their baby, and they described including family members in care and training. Participant 2 highlighted that even though she was a nurse, she watched the video with her mother and stated “I did watch the CPR video but yeah I was already certified but I watched it with my mom since my mom was going to be there.”

Participant 5 talked about how they would include family members and disclosed, “when the physical therapist would come by and the family members were here, we made sure we were all in cue with him.”

In addition, Participants 7 and 8 depicted how their aunt was included in care and instructions at the hospital. Previously mentioned in subthemes, Feel like an outsider and Quest for knowledge, it became evident that their relationship with the aunt was close. Participant 8 exclaimed, “She’s more of a mom to her, then an Aunt...She ran interference and helped obtain and clarify information for the parents, and performed basic baby care.”

Medical staff insisted that Participants 3 and 4 had respite or relief care and made sure family members were also trained. Their baby had qualified for home nursing care, due to the extreme medical complications, Participant 3 shared communications from medical staff, stating

This is what you need to be able to do...they trained us, they trained each of our parents, and his sisters and an RN. They made sure that we would have...baby sitters who could do it...So we could go out occasionally and get away and know that he was okay, because his grandmothers were there and they knew how to change a trach in an emergency

Participants 2, 3, and 4 had to learn additional skills and resources due to unique circumstances. Participant 2 had twins, so she needed to learn how to feed and transport them. This required learning how to transport twins in car seats, navigating parking with two babies, and getting them in and out of their car seat. Participants 3 and 4 had ongoing extensive training to manage their very fragile infant, who had a lot of medical monitoring equipment, and they needed to be able to perform two man life-saving procedures. In essence, their baby was in the

hospital over seven months, so there were multiple opportunities to learn. Furthermore,

Participant 4 specified about the nurses letting them provide care, stating

I know for a lot of things, they were really good from the beginning. Letting us be a part of his care whenever we could, and as we went on, more and more of it. Changed diaper, did like his care, and gave him baths.

In addition, both parents shared how they were required to stay for a week and perform care independently. Participant 4 specified “they actually did speed drills with us. They made us go out of his room and then go in do a trach change.” Additionally, he stated “we had it down where we could do it in under a minute.”

Participant 3 chimed in:

That was our threshold, the nurses set for us, we needed to be able to go from his room or his doorway, to a new trach in place in under a minute. Before we are comfortable with you going home with your son. It was a chance for them to observe us and for us to try it in a controlled environment. I think it’s a hard transition. Between the nurses do everything and you do everything.

Participant 9 highlighted that when she was able to stay with her baby was when she really started learning. Direct contact with him helped her to start feeling like a parent and began to get to know her baby, adding

I stayed with him and that’s when I really had to start learning...this is my baby, what do I do? If I hadn’t had that time with him, it would have been harder...just like setting up the feeding, how long it supposed to run, how to connect it, and how he is supposed to react to it.

Participant 1 explained the steps staff went through ensuring she was prepared to go home. She described “they took us through this little CPR refresher.” In addition, when talking about direct hands on care, she shared

They moved her into one of the rooms where we could actually stay with her, months before she even came home, I had already started hands on changing her diaper she still had her ostomy bag, so I would clean it out. Before she even came home I already had a lot of hands on with her and I was comfortable

The researcher asked if Participant 1 had received any written information or demonstration. She described

They came in and they showed me, they trained me and went over everything with us. How to do her formula, a number to call, a list of all her appointments that had been scheduled. The doctors came in and talked to us and they gave us a copy of her discharge summary

Participant 10 added information on how medical staff helped her and revealed “when they found out he had CMV, they went above and beyond, got me the pamphlets for CMV and support groups, different web sites they printed all that out and gave them to me so that was incredible.” The researcher asked Participant 10 if she felt they prepared her to transition to home, and she replied, “oh, absolutely.”

While most parents described being prepared, nevertheless, several parents talked about things they wished they had learned. As previously mentioned in the major theme, Riding out the Storm, many parents described inconsistencies and barriers to access. This definitely interfered with and impacted the parents in their abilities to learn and obtain information. Participant 2 shared that she did not receive information on how to manage twins, and Participant 9 described

what would have been helpful to learn more, stating “What they didn’t tell me, was what to do if the button popped out, and they didn’t tell me the things that could happen.”

Hearing the nurses’ voices in my head. One mother, Participant 9, described hearing the nurses’ voices in her head: “you have to have somebody’s voice in the back of your head that is saying, okay, you can do this. I don’t know where I’d be! I’d be off in the bathroom crying. I wouldn’t know what to do.” She had to think and act quickly to replace a feeding tube that was placed in her baby’s abdomen but came out during a feeding. She felt the nurses’ instructions were ingrained in her, and she was able to calmly react to the situation. Moreover, she stated, “I could hear their voices, you can do this. You know what to do, you just do what you know.”

Afterwards she was reassured at the physicians’ office that she had correctly replaced the tubing without her baby suffering any health issues or complications. This further motivated her to take care of her child, increased her self-confidence, and indicated that the nurses had helped prepare her for discharge.

In the subtheme, Customized Learning, parents talked about how hands on care and practice helped them to feel confident and prepared to care for their infant at home. Trust and emotional learning went hand in hand with the developing familiarity between medical staff and the parents. This directly related to time spent in the hospital and is described as covering all bases. Specifically, parents were taught the basics of baby care, learned tasks step-by-step, and worked with nurses. Having customized information and resources helped make sure parents’ needs were being met. The amount of time parents spent in the NICU helped them become better equipped to handle situations. It was a huge step to go from the hospital to caring for their baby alone.

Contrary to the majority of parents being taught basic baby care and specialized training for their baby, not all identified the importance in going to their follow up appointments.

Participants 7 and 8 described how nursing staff did not explain what the NICU follow up clinic was for, only that their baby had an appointment after discharge. Participant 7 mentioned she noticed her discharge papers had the comment “high risk” and added, “I looked it up.”

Participant 8 chimed in, stating “only thing they told me was when we got down here to call our family doctor where she was high risk. They really didn’t go into the follow-up.” Since their baby was recently discharged from the hospital, the researcher took approximately 15 minutes to explain what high risk meant. Additionally, the researcher took time out of the interview to explain the importance, significance, and reasons for the follow-up appointments.

Summary of Major Theme 2: Righting the Ship

Parents maintained an optimistic outlook and were willing to do whatever it took to get through and struggle for their baby. Most had a warrior type spirit, ready to tackle even the most difficult decisions. The biggest frustration that parents expressed was the inability to get updates on their infant’s status and the inconsistencies with individual staff personnel, communication, and access to unit. Parents adjusted to the unexpected birth, became self-reliant and motivated as they took control, and stepped up to perform necessary measures to care for their infant. Through support and adjustment, parents developed a new family unit. Despite inconsistencies, some nurses and doctors became like family. As mentioned previously, approaches to care and the emotions evoked were different for mothers and fathers. Parents became empowered by gaining control, making choices, and becoming more involved in decision making.

Safe Port, Finding Solid Ground

Parents focused on their ultimate goal of taking their baby home and having everyone safe and sound under one roof. It was apparent that parents had settled into a routine once home, despite ongoing and unresolved medical conditions of their infant and uncertainty for their future. They learned the tasks to care for their baby and jumped through the necessary hoops to prepare for discharge. Parents described feeling normal once home with their family back together. Subthemes that were used to develop and describe this major theme were Getting to know baby; Becoming the expert; Ongoing emotions; and Adjusted parental role, finding normalcy (Table 4).

Table 4

Major Theme 3: Safe Port, Finding Solid Ground

Subtheme	Code
3a. Getting to know baby	<ul style="list-style-type: none"> i. Adapting to new normal, changed expectations <ul style="list-style-type: none"> a) Ride home b) Lost in the day to day care, robotic parenting ii. Taking charge, caring for complex needs of baby iii. I have more confidence now, self-reliance
3b. Becoming the expert	<ul style="list-style-type: none"> i. Wearing many hats ii. Physical resources iii. It takes a village <ul style="list-style-type: none"> a) Trusting caregivers b) Paying it forward
3c. Ongoing emotions	<ul style="list-style-type: none"> i. Prior loss, experience, guilt ii. Additional negative feelings <ul style="list-style-type: none"> a) Anxiety b) Stress c) Fatigue, depression iii. Standing guard, hypervigilant iv. Having joy with my baby
3d. Adjusted parental role, finding normalcy	<ul style="list-style-type: none"> i. Home safe ii. This is my baby, ownership, I can do it myself, follow up iii. Worthy sacrifice, the price I paid

Getting to Know Baby

For some parents, the transition to home was easier than others. Several parents described how they did not really know their baby until once home, whereas others were so focused on the day-to-day care, did not have time to bond at first. This subtheme is made up of the following codes; Adapting to new normal (a. ride home, b. lost in the day to day care, robotic parenting):

Taking Charge, caring for the complex needs of baby; and I have more confidence now, self-reliance.

Transitioning to home and discharge readiness is a complex process that requires coordination and collaboration from many disciplines. The ultimate goal for parents should be focused on bonding and becoming a family. Parents expressed feelings of not really knowing their baby until they got home. That is when they began to feel they were a real family. Parents also described they felt more like a parent when they were able to visit in the hospital, participate in infant care, and were able to engage in everyday activities with their baby. While in the hospital, some parents felt powerless and unable to define their role as a parent; however, as they learned needed tasks and were discharged to home, they became more confident.

Adapting to new normal, changed expectations. This subtheme was developed from the codes ride home and lost in the day-to-day care, robotic parenting. Coming home was momentous to families; it was the beginning of being together and the start of becoming a normal family. The nurses taught parents different techniques needed to deal with a micro preemie. Being prepared meant that when something happened at home, parents would be able to help their baby in a logical and step-wise manner.

Nurses also gave family members information so they could help the parents care for their baby. Their baby's life depended on the hands on training and resources they received while in the NICU. There were discharge instructions to give to the pediatrician, and special instructions for how to manage medications and oxygen. Other forms were for the home medical equipment company and insurance companies, car seat instructions, and a pamphlet about having babies sleep on their back. Parents who were able to visit and spend extended time in the NICU were able to bond and get to know their infant.

The momentous occasion of discharge meant parents were finally taking their baby home and adapting to parenting alone, and this began with the initial ride home. Parents reported that car seat safety was included in discharge teaching, and several participants described the need to have a car seat in order to be discharged. For example, when asked about the discharge process, Participant 1 indicated, “I mean they made sure that her car seat was okay. That I had put her in the car seat, and they asked me if I had any questions.”

Participant 7 exclaimed that even though nursing staff kept telling her that her baby would not be discharged until her due date, when they asked her to bring in the car seat, she stated “we knew she was going to come home.”

Participants 5, 6, and 10 also added comments about car seat teaching when the researcher asked them about being prepared for discharge. Participant 10 stated “dealing with the car seat, making sure everything’s in the car.”

Some parents shared that their stress level went down once they were at home, were no longer separated from loved ones, had all their family together, and were finally able to get into a regular or normal routine. Participants described their best day as discharge and taking their baby home. Participant 1 stated, “the discharge was as far as getting to bring her home... was the best day.” Furthermore, she added, “her dad and I brought her home as a family. We went and picked up her sister so we, we actually had to come home as a family that day which was very special.”

Ride home. While most parents were so excited to take their baby home, Participant 2 was very stressed and already felt she had been discharged too early. She felt that her babies were not ready and vividly recalled,

I remember on the way home I would stop at every exit on the way home and make sure he was breathing, and then every now and then I’d like chuckle to myself that in the event

he quit breathing there were plenty of exits. And his brain is still mushed between those two exits so I am still good. I stopped at every single exit on the way home to make sure he was okay.

Admittedly, she added her concern was related to being a NICU nurse, adding “I am pretty sure that some of that was, I was NICU nurse and knew a little too much information, so I was a little more worried than most probably people would be, but we were okay.”

Participants 3 and 4 had to perform emergency CPR right after discharge, while they were still in the hospital-parking garage. During the process of getting the baby in the car, his tracheostomy was pulled out, and the parents had to perform CPR. Participants 3 and 4 both described the event

So it popped out and we didn’t know until we were in the car and suddenly all of the alarms were going off, he was blue, and (the nurse) ran back in for help. I got in the back and was doing chest compressions over the back seat while he bagged

They described how they went home with a lot of equipment, adding “we came home with a vent, oxygen, G-tube, feeding pump, and of course the monitor. There was a lot to manage and navigate just getting baby and all his equipment in the car seat.”

Lost in the day-to-day care. This is a category used to support the code Adapting to new normal. When parents were talking about their first experiences being at home, some of them described just trying to get through and make it on their own. Several participants also revealed that even though they felt prepared prior to discharge, once they got home they did not feel so confident. Participant 1 stated, “When you first bring her home I think you feel like you are not prepared. You know, like I know when I first brought her home I was of course nervous, scared.” She also revealed, “It was an adjustment, bringing her home, I don’t let her out of my sight.”

Participants 5 and 6 had a similar experience, and even though they felt prepared, they were a bit apprehensive and noted, “I think that we left with the feeling that we are on our own now.”

Participant 9 shared that she did not know how to react as a parent, expressing “it took me a week to really learn, What is a baby, What do I do. I didn’t even really know who he was. I didn’t register that he was my baby until he came home.”

She also confided that when the nurses would not let her hold her baby in the NICU she shared that she “didn’t feel like a parent,” and she went on to explain “If I had felt more like a parent, then it wouldn’t have been such a shock when I brought him home.”

Some parents were so caught up in taking care of their baby or babies, they were not able to enjoy being a parent and were just going through the motions. One category used for this code was robotic parenting. Participant 2 described how she felt the lack of support from the NICU and felt she was being pushed out early. This caused her to feel overwhelmed and stressed, and she felt unprepared to take her twins home. She claimed, “I was like the first week or two that I was home, it was like almost always a major anxiety attack. Every single time I would feed him.” Furthermore, she explained

I didn’t get to, really get to soak in, you know like when you do when you have one child, but with twins, you’re really not maybe take as much time to like enjoy that baby part. So in some ways I kind of feel like I lost out.

She did reveal that even though her babies were discharged early, her feelings of being unprepared were not solely related to lack of anything from the hospital, although she also stated that the hospital did not give any information on managing twins. All this was further compounded by the fact that she was also taking care of her older child.

Participants 3 and 4's baby experienced the longest hospital stay, and their baby went home on life saving medical equipment. The parents were required to have extensive education and training in how to manage the equipment and perform skills such as CPR and tracheostomy suction. They described being in survival mode. Participant 3 stated "they had trained us, we had practice drills so that it was rote" and added "that was really good" because "immediately we had emergencies."

Taking charge, caring for complex needs of baby. Coming home meant their family was together, and this had a profound impact on their morale and served as the beginning phase of adapting to their new family roles, finding normalcy, and settling into a family routine at home. Additionally, parents described the time spent in the NICU helped them feel prepared for discharge. Likewise, parents reported being able to participate in their babies' care made a difference in life and death decisions. Some parents needed to become the expert on their babies' special needs, making critical decisions as primary caregiver, trainer, and advocate. Complex needs do not just comprise on-going medical care at home but includes many follow up appointments.

Information received by parents from medical staff facilitated feelings of being prepared. Also, parents became experts and trained family members. Participant 5 shared, "occasionally when the physical therapist would come by and the family members were here, we made sure we were all in cue with him."

Participant 6 chimed in and gave specifics "measuring syringe, without a needle, you know. They drew pictures so we would know which number to fill with medicine. Participant 5 added "we were showed how to do certain things for his therapy."

Parents reported once discharged, they were happy not to travel back and forth between home and the hospital. However once home parents were faced with taking their baby to multiple outpatient follow up appointments. Depending on the severity of their unresolved medical conditions at discharge, babies had appointments with physical therapist, speech therapy, eye exams, pediatrician, specialists such as pulmonologist and surgeon, and the NICU follow up clinic to name a few. Participant 9 stated that “she had appointments every day” after her baby was discharged.

Participant 1 shared she was glad to have quit work, stating, “we kind’ av knew it was going to be a challenge as far as doctor’s appointments. We seen the pediatrician at least three times since she’s been home and she’s had two eye exams since she’s been home.” Another challenge Participant 1 shared was the difficulty finding baby sitters, and she described,

It would be challenging, trying to find a baby sitter around here. A lot of the daycares don’t want to take to her because of that is too many children that she’ll be around. So trying to find a one on one. We thought we had one, but we think she got a little nervous with of all of C’s little conditions that she has and she kind of backed out on us. So it would be challenging because we wouldn’t have a babysitter

As mentioned previously, Participant 2 commented that she did not receive training on how to manage more than one baby at the same time. Given that there are often multiple appointments after discharge, Participant 2 specified how difficult it was to feed and travel with twins, navigate parking, and even go to the bathroom. She stated, “things you just don’t think about, until you are in that situation.” She indicated when parking her car, she had to calculate whether a stroller would fit between cars stating, “it gets really strategic, in finding a good

parking spot.” She also highlighted safety concerns: “physically get them in safely and get them out without hurting one in the process.” She further added,

So you are literally holding two babies, trying to unlock your car, trying to one that has absolutely no tone or head control into a car seat while your holding your, I mean there are things that you just have to lay one down on the floor board, because they aren’t rolling over yet

Although that was challenging enough, she also had to trust others while going to the bathroom because the stroller would not fit and revealed,

There were many times that I got stuck in a bathroom. You won’t fit through a stall, you’ve got to leave them outside...so if you are by yourself. I would look in the bathroom and say you look like a decent person.

Participants 3 and 4 also had to learn to navigate for travel and day-to-day life because their infant had a lot of medical equipment. As mentioned previously in the code, ride home, their baby came home with oxygen, feeding pump, a ventilator, and monitor. She commented, “taking him anywhere is impossible, we had so many appointments.” Furthermore, she described how the hospital did a great job training them, stating “he codes in under a minute if the trach comes out. So keeping the trach in was really important.” She further shared that their first night home, they relied on the training to help save their baby. Even though they received home nursing care, their nurse was not attentive to the critical needs for their baby. They actually found her asleep on the floor, and the baby’s monitors were going off. Participant 3 revealed “we have had to kind of take charge...so it was really good that they not only did that we had a week rooming in.”

With continual monitoring of their infants, parents put their training to use. Participants 5 and 6 also had to navigate medical interventions, giving medications, performing physical therapy, and keeping an eye on the swelling in their baby's head.

Participants 7 and 8 described how their baby had a rash and were considering which action to take, whether to call or take her to the pediatrician. The researcher noted in field notes and reflective journal how the parents appeared to be very nervous and concerned about the rash. The parents did not specifically state this, but the researcher was left with the impression that since they had difficulty in the NICU with nursing staff, now that they finally were at home, they could deal with the rash on their own and just keep an eye on it.

Participant 9 discussed different situations where she had to perform specialized care for her baby at home and shared,

I have to work with him constantly to build that tongue muscle up so that he can drink a bottle. And hold onto his pacifier and stuff and his latch is still there. And have to remind him to curl his tongue

She was also faced with an emergency when her baby's feeding tube came out, and she had to replace it.

While participants talked about taking care of the complex needs of their baby, they were also very protective. Participants 3 and 4 had commented on how their quick actions were essential to save their baby's life. Parents were unable to take their baby to childcare or have babysitters.

Participant 10 described how she would not allow many people around her baby since not only was he potentially contagious but also his immune system was compromised and others could also pick up something from him. The researcher noted in her field notes how the mother

appeared isolated because she could not take her baby out in public. She explained keeping everything very clean and clarified, “I wash everything in hot water, we sanitize, like wash our hands like a million times. I clean a lot. My whole day is laundry and cleaning.” Furthermore, she insisted on having the interview via FaceTime. While the researcher did not realize this was the reason and Participant 10 did not explicitly explain that was the reason, it became apparent her primary concern was having people come into her house and possibly make her baby at risk.

I have more confidence now, self-reliance. Parents gained more confidence after learning and practicing skills in the hospital and on their own. It was a fine line for most parents between learning to speak up, finding their voice, and taking on an advocacy role for their baby, whereby parents also began to develop more confidence. Depending on how extensive their baby’s medical needs were, medical staff spent time training parents for their independent role as caregivers once home. Parents adjusted once home and began to find their own rhythm, and as their experience increased, so did their confidence. Each of the parents had to learn some form of tasks and specific criteria in performing basic baby care. For some parents their infants required more medical intervention, and they had to learn complex medical interventions and equipment. As previously discussed, this was especially true for Participants 3 and 4. Their infant was born at 23 week gestation, was discharged to home still medically fragile with extreme health needs, and required medical equipment to survive. Participant 4 described how they had to do “practice runs” while in the hospital just to make sure they were able and confident in their ability to care for their infant.

Participant 3 also described how she and her husband developed the philosophy that they will give their baby every opportunity available, stating “there will never be an excuse for not trying, he will always try, even if he can’t do something, but we are going to know what his limit

is.” This required a higher level of confidence and self-reliance in order to successfully carry out. Moreover Participant 3 added, “we were committed, as long he himself was fighting, then what ever support we had to give him, that meant for the rest of our lives.” Participants 3 and 4 transformed this self-reliance into being in charge of their baby’s primary care. Participant 3 shared that “it was too critical for us to be on top of our game all the time, so they worked to train their home health nurses, “knowing that we were responsible and it was just us and the nurses 24/7 if something happens, you were the ones who were going to have to fix it.”

Participant 1 shared that she also became more comfortable as time went on and noted, “I got more comfortable, we started sleeping and not waking up as much.” She also confided that she had worked in the medical field, the perception being that she held a certain level of confidence and assuredness in her ability to care for her baby.

Participant 2 was also in the medical field, having worked as a NICU nurse, but described how too much experience leads to overconfidence and reaching for perfection and confided that she “had to let some of that go. I had to quit being so anal, let some of my, structure go.” Realizing that she needed help with how to manage twins, she became more self-reliant and reached out to other mothers with twins.

While medical experience helped several parents feel confident, having previous experience with children also helped participants feel more confident. Participant 8 talked about having “a lot of nieces and nephews” when the researcher asked if he has a lot of experience with kids and if this previous experience helped make him feel more comfortable. Participant 8 answered “well a little bit.”

Participant 2 and 10 had older children. While they described being comfortable taking care of children, they both expressed their premature infants had very different and unexpected needs.

Participant 6 was very quiet, so when she added to the discussion, it was especially noted. When the researcher asked about feeling prepared and being at home, Participant 6 shared “finally being home. Not being confined to one area. Far away from our family.” This revealed how important it was to her to be around family, she felt more confident being closer to her support system. She grew into her role as a mother, her husband chiming in, “in those two weeks...it was the first time we were at home just you two.”

Participant 9 also talked about how she was the only one who could provide care to her baby as she knew how to manage his feedings and special needs. When asked about her level of responsibility, she described, with a sense of self-awareness, how she was the only one who knew her baby. She shared that the support she received helped her to feel more confident. This was especially true when she had to replace the Gastrostomy-tube for her baby on her own. She was unsure if she had done the procedure correctly; however, when the doctor told her she did great, she repeated, “he said it’s perfectly fine now”, she was relieved and stated, “I was like, thank goodness.” This instance helped to build confidence and validate that she knew how to care for her baby.

Getting to know baby meant spending time in the hospital, being able to bond, and learning to care for their unique needs, receive support from medical staff and family, and develop confidence and self-reliance. Parents continued in their personal growth in their home environments, overcame challenges, and become resilient to take care of their baby alone

without the medical expertise. Getting to know baby also included the impact of transitioning home, the significant milestone of that first ride home as a family.

Becoming the Expert

As parents learned to care for their infants' unique needs, they also became the expert and, out of necessity, ended up training others and organizing. Preparing parents for discharge meant they needed support and resources, tailored to their needs. While parents described instruction on basic baby care, planning for the unexpected was essential. Participants 3 and 4 described being trained for all eventualities. Several parents discussed how they felt much more calm and at ease when situations arose once at home or when they were faced with unexpected events and had to provide life saving measures and even in some instances of challenging the medical experts. Becoming the expert is supported by the codes of Wearing many hats, Physical resources, and It takes a village.

Wearing many hats. Becoming the expert also meant that parents played multiple roles, depending on the specific need and situation for their baby. It was a product of managing, becoming motivated, increasing confidence, and setting out with self-reliance. Not only were parents the primary caregiver, they also ended up having to be the educator and trainer for medical staff, friends, and family. Furthermore, some of the parents had to be a case manager and negotiate between insurance agencies, providers, and medical supply companies. Taking on so many roles added to parents' resiliency and confidence.

Parents are required to become experts in caring for their fragile infant, making critical decisions to the point that it becomes a life or death issue. They also found themselves needing to train other healthcare workers and family members to meet the special needs for their infant. This was taken to the extreme with Participants 3 and 4 because their infant was very fragile and

required life-saving interventions. As stated in previous subthemes, Participants 3 and 4 indicated they were committed to caring for their infant's needs, became advocates, learned to speak up, and took on the role of expert. They both talked about the struggle and extra work required in educating and teaching others in how to care for the special needs of their baby, even medically trained professionals.

Participant 3 shared how she and her husband were in charge and responsible for everything. The interview was well underway, and they had begun talking about the multiple roles they had to perform when Participant 3 explained, "you have to wear a lot of hats. You have to be prepared to learn a lot of new things." Additionally, Participant 3 explained

so if we had come home and not been prepared, our nurses wouldn't have been either.

We would have lost him on several occasions, because we did have times when the trach came out...we had to put into practice you know that you are the expert here it is your job to resuscitate. You have to be in charge, because we are in a rural area

She further clarified

you have to coordinate dealing with the nursing company...the nurses they send, the times they don't send nurses, and then the insurance company...coordinating the supply company whether they are sending the right supplies...the requests for supplies to the correct doctors.

Both parents were forced to be the case manager, interpret the physician orders, and communicate the correct amount of supplies from the supply company because, as she stated, "it's not just insurance not approving it. Was medical issues between the Ear, Nose, and Throat (ENT) and the supplier...And insurance and how you deal...I had to learn to be a receptionist...All this was required to keep him alive."

They proceeded to take on the additional role of being the expert in regard to caring for their infant. They both talked about the struggle and extra work required in educating and teaching others how to care for the special needs of their baby, even medically trained professionals. They both also described how they had to vet and evaluate their home health care nurses because of the unfortunate event, previously described, when the nurse fell asleep the first night they were home. It was at that moment they realized how critical their role was. Not only did they have to ensure competency levels for their home health nurses, frequently they questioned medical staff when their infant was re-hospitalized.

Shortly after discharge, their baby was readmitted and required his trach to be replaced. After the physician replaced the trach, both parents mentioned to the doctor that it was too small. Participant 3 stated that she asked the doctor and his response: “so I did tell the doctors, that his trach is too short”, and the doctor replied, “No, that’s an appropriate length.” Participant 3 asked the doctor to check and make sure by performing a scope; however, the physician refused.

After the doctor agreed to perform the scope, medical staff realized that the parents were correct: Their baby’s trach was too short, and he required hospitalization. Participant 3 also shared the conversation that she had with the physician:

I had to explain to him, aside from code medications that can be administered when the ambulance arrives, there is nothing in this room that is not in my house. We have trachs all the way down to Two oh, the smallest they make so I can do anything except re-intubate, and give code medications. I can do any of that.

Despite Participant 9 being young, she also realized her role and responsibility in caring for a baby with medical issues. She described her process of becoming more confident and increased self-reliance and being the expert for her child. She also shared that the speech

therapist told her, “you are going to be a speech therapist, a surgeon and all this, after all this.” When the researcher asked her about becoming an expert, she replied, “several people have told me that and, I don’t want to be the expert.” Even though it was apparent she did not choose this role, she further explained, “I have to be. I mean I am the only one that has his feedings down to a science. I am the only one that can work with his tongue...I gotta do this...for him.”

Several parents were healthcare providers and used their knowledge to help them care for their baby. While this was beneficial, it also hindered bonding and being in the role of a parent. Participant 2 stated “I felt like I was working...I felt like a NICU nurse” instead of a mother. Since she was a single mother with twins, her mother stepped in to help her with day-to-day tasks. Participant 2 also had to train her mother in how to hold and feed the babies.

Physical resources. Parents relied on help and resources from multiple sources even including social media. Despite infants being able to qualify for state and federal programs, often parents still had to negotiate for those resources. Parents shared that they had received instructions and written information while in the hospital; however, once home, they relied on their training and own efforts to gain more information. Parents were faced with challenges such as inconsistencies between insurance coverage and state regulations, discrepancies between provider and insurance communication, lack of provider knowledge for required supplies, and parent’s ability to collaborate with vested parties. Participant 3 shared “coordinating the supply company whether they are sending the right supplies which often they don’t and whether they are sending the requests for supplies to the correct doctors.”

Participants 3 and 4 described in detail some of the issues they had to deal with. Their available insurance provided home health care for Licensed Practice Nurses (LPN), however tracheostomy care is outside the States’ scope of practice for LPNs. This practice restriction

meant that only older LPNs, grandfathered because of a change in licensure, had experience with tracheostomy care versus younger or newer ones.

Participant 4 shared, “so we had to teach the LPNs how to do a trach...because they weren’t taught in school...it was outside their scope of practice;” however, he also revealed “it was easier to train the younger ones.”

They had settled into a routine and were grateful for full time nursing care, especially since their baby was very fragile and required two-person resuscitation. Participant 4 revealed We need 24/7 nursing just in case the trach comes out. It’s a two-person job to resuscitate, so you have to have two pairs of hands...he can never be with less than two trained adults at all times every day...I have over quailed, highly trained, baby sitters.

Two participants described the benefits of an outpatient chronic disease management services for premature infants. Participants 5 and 6 had a positive experience with support from nurse phone calls. Participant 5 explained how the company acted “as a medical middle man between us and the doctor and insurance.” He further clarified “they get the information from the doctor and talk with the insurance and say yes, he needs this care” and added, “They also provide several benefits for home life. Like they have been in contact several times checking in on us.”

Furthermore, she added, “each of them would come into the room, we didn’t have to move rooms, you had one room, they would come in and see us and at the end of day they would talk together about his care.”

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The researcher asked both parents several questions about the service, “do they call you at home...maybe more personable, than an insurance company.” Participant 5 replied, “yes, very much so...their first and foremost concern is I [baby] and his health. Moreover Participant 5 (5) and his wife (6) shared, “they send us a lot of good information and literature”, (6) “and they are very helpful...helping you to get certain things started like with social security, and that stuff”, and (5), “they were the ones really pushing for physical therapy and in our area.” This service really highlights the extent that community services can offer support for parents and families.

Parents described how much support they received in the NICU from the medical staff; however, once discharged, if their baby had to be readmitted, they were in a different unit. Parents talked about how they did not receive as much personal care and were required to stay with their baby in the unit. Participants 3 and 4 had spent seven months in the NICU, so they knew the medical staff and vice versa. There was a high level of trust between parents and medical staff, whereas when their baby was readmitted to the Pediatric Intensive Care Unit (PICU), they experienced difficulties communicating and assuring staff they knew how to care for their baby. Participant 4 described how they had to defend the level of care and expertise they provided at home, explaining, “we had 24/7 care watching specifically him, where as in the PICU they had one nurse to two people.”

In addition, Participant 10’s baby was also readmitted to the PICU after discharge from the NICU and could no longer leave to go home and care for her older daughter. These situations created a disruption in their transition and adaptation to having their new normal family rhythm; however, once again parents demonstrated how resilient they were.

Ongoing support also came from social media sites. Participant 3 opened up about how she did not really go to the parent support meetings at the hospital: She was uncomfortable talking with so many people, and she did not really like to talk on the phone. What did help her was a support group on Facebook for parents with preemies and micro preemies. She also shared there are groups for specific issues like having a baby with a trach or vent. Participant 3 made a point of saying that these are closed groups, and she was relieved, calling it her “safe place.” She revealed,

And I know that I have a safe place that I can go to that is a closed group...and not be judged on it because they understand. That just helps a lot. To have a place where you can vent and where you can get information from people who aren't. I mean I stressed here all the time about whether his doctors would think I was smart enough or competent enough to handle him. And so if I had a question that I felt like was a stupid question? I had a place to go first, well this doctor never talked about this, what's a smart way I can word this.

It takes a village. Parents were able to manage and cope with the help and support from friends, family, and health care resources. Additionally, parents described the need to trust their caregivers to take care of the critical needs for their baby. Moreover, parents also talked about how they would like to help others to cope and manage after going through this experience of learning to care for a medical fragile infant. The categories that also support this code include trusting caregivers and paying it forward.

While it was a challenge for some parents to get sitters, many had family members who helped out. Participant 1 described how she had quit work because it would be too difficult to get sitters: The one they had lined up backed out on them, and the daycare centers would not take

their baby because of her smaller size. She shared, “we talked to one who’s really good, she’s had years of experience. She was a little nervous about taking care of her because of, we thought she was going to have come home on oxygen.” In addition to staying home with her baby, Participant 1 talked about how she was able to get help from her sister, her best friend, and her stepdaughter. Participant 1 summarized how important the support was, adding, “so as far as the support; I have an amazing support team. And if it wasn’t for them it would be challenging.”

Participant 2 was a single mother with twins in addition to having a slightly older child, so in order to manage; her mother was involved from birth. She described her mother’s help as “She is my only support system here, she’s kind of like my husband.” She also confided that she would have preferred to get help from the twins’ father as it was not her mother’s responsibility, and while she was grateful for all the help, she felt some guilt. Because Participant 2 felt the NICU discharge teaching did not help her learn how to manage twins, she sought help on her own, contacting another nurse who had twins. She was able to give her suggestions and a book on how to manage with twins.

While most participants talked about their family support, not all were on board initially. Participant 9 had to deal with family pressure since she was young and single. She opened up about how hard it was when she first found out she was pregnant, trying to make decisions about what to do, because her family wanted her to adopt or abort the baby. She revealed the difficulties stating,

it was very hard, because my mom didn’t fall in love with him until after he came out.

My whole pregnancy it was trying to convince me. First it was the abortion, trying to convince me to do, everyone was trying to convince me to do and I didn’t want to do

it...then it was adoption, and I faked it...I went into the adoption agencies and looked at the books and everything

She further added,

then once I had him, my mom fell in love with him, and she helps me to this day. She'll take him and she'll disappear outside and I'll be like, where's my kid? Where did you take my kid, and she loves him, and that makes me so glad that I didn't do anything.

One parent didn't have many extended family members who were able to help out, those that were nearby work full time, however some family and friends stepped in. Participant 10 described how even though many couldn't help out physically; the emotional support is very valuable. She stated when asked by the researcher would it be difficult without support, she replied,

without the friends and family, because they actually kept me sane, very grounded. They were always there, like you know, what do you need...just knowing that someone was there was good enough, they didn't have to do anything for me. They would be like hey, just thinking about you today or something like that. It was just nice to have that support. It's good to have a support system because, I feel like if you don't, you could fall pretty quickly

Parents not only had emotional support from friends and family, but some were required to receive medical training. Some had more training than others, from basic infant care to more complex training such as managing a G-tube and feeding pump, performing CPR, managing oxygen and ventilator settings, and performing trach care and changes. Participants 3 and 4 received the most training and had to perform practice runs before they were discharged. They also had extended family members who were trained, even some who had previous medical

training, so parents could have help and be able to leave their baby with family if they wanted to go out. Participant 3 shared, “So we could go out occasionally and get away and know that he was okay, because his grandmothers were there and they knew how to change a trach in an emergency. It saved his life.”

Trusting caregivers. Parents described how they had to learn to trust caregivers, especially when their baby’s life depended on being able to perform lifesaving interventions. Participants 3 and 4 talked about how they had to train home health nursing and make sure they knew what to do before trusting them to care for their baby alone. Participant 3 added,

it was a very hard adjustment, there are people in your house and you have to trust your child’s life to them, you don’t know them, you have never met them before. The only thing they have to vouch for them is that they have to have a nursing license, but you don’t know anything about the nursing license or the company where they are coming from

Participant 10 also discussed how she had only a few babysitters that she trusted, adding “he’s not really allowed in the public so yes, I have to ask someone to watch him when I want to go grocery shopping.” Moreover, she confided, “well, I only have a couple that I really trust with him. I am very picky. I have two really good ones, my mom on the weekends if she can, and my sister-in-law is really awesome with him.”

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Participants 5 and 6 had extended family members that were trained in basic baby care and also how to do physical therapy exercises on the baby. Because both Participants 7 and 8

work a lot, they talked about how their extended family have helped them out at home and how much they trusted and relied on them. Participant 8 chimed in, “basically I am out of the house by five at the latest and then I am usually home by five or six in the evening and she’s already at work.” The help and support began right away; because Participant 7 was very sick and could not visit her daughter, her aunt had a big presence from day one. It also continued through discharge and at home. In fact, during the initial recruiting efforts at the NICU Follow Up clinic, the researcher met one or both parents but also several extended family members.

Paying it forward. Parents described that despite their challenges of dealing with their babies’ health issues, feeling belittled or outcast, and inconsistencies, they became resilient which motivated them in helping others by paying it forward. One parent described that they wanted to make it better for other parents and make it just a little bit easier on all of them. Participant 9 expressed the value in learning to care for her baby, and this motivated her to become a NICU nurse: “it’s worth it to watch him grow and watch him learn all that stuff. I have actually thought about going into it after all this.”

After meeting Participants 5 and 6 in the NICU follow up clinic, they both shared that the March of Dimes had interviewed them previously because their infant was one of the first in their county to be discharged at such a young age. They wanted to help with this study and expressed how they also wanted to help other parents going through a similar experience.

Participant 10 described how she was trying to get the word out to help other parents avoid the problems she has encountered. Moreover, she specified how being in the NICU is a unique experience and most people do not understand, adding

I think for other parents it would just be support honestly and anybody else who’s been in the NICU, like if you know of anybody who has been in that, regardless of whether their

child was in there for three days or for however long because I feel like that experience is different than just having a baby and taking it home. So if you know of somebody who's been in there to talk to them to talk about your experience and kind of where they are coming from.

Participant 10 felt passionate about sharing with other parents and healthcare providers about how to help prevent the rare condition her infant had. She explained how she was in the medical field but had never heard about CMV. She stated, "I feel like everyone and their brother knows about this Zika virus, but nobody knows about CMV, and this is way worse than Zika." Furthermore, she added, "Zika's not rampant in the United States yet, but this is." When asked about getting the word out, she also exclaimed, "oh, trust me, I am doing all I can to get that out there, to all my friends who want to have babies."

Ongoing Emotions

A mixture of emotions was felt upon the birth, several parents described how these also continued after discharge. While the excitement of being home as a family and getting to know their baby was the pinnacle of their experience, described as a gift, they were seemingly impacted by the experiences of having an infant who required lifesaving medical equipment. The serious health issues and constantly changing health statuses that these prematurely born infants experienced while in the NICU seemed to be reflected in the ever changing challenges that the parents faced, and continued to face, while they were coping at home. The subtheme, Ongoing emotions, is supported by the codes; Prior loss, Additional negative feelings, Standing guard, hypervigilant, and Having joy with my baby.

Prior loss. Parents who had experienced a previous loss were affected by the possibility of another loss, much less a premature baby. The code, Prior loss, is supported by categories, experience and guilt.

Experience. Participant 1 discussed how it was emotionally draining to see her baby in the NICU, knowing her previous child had died when she was 38 weeks pregnant. She opened up and specified,

I actually got pregnant pretty quick...when I actually had her at 26 weeks, of course I was scared, we both were scared, her dad and I uh, we had just lost our son so seeing her, it's emotional, when you walk in and see your baby

Participants 3 and 4 also had a previous loss; their first baby was born very premature and only lived for eight days. When Participant 3 went into preterm labor, they were given very low odds of survival this baby, and she shared,

going into it we already had one NICU experience and where we didn't get to bring our baby home and then we had our big long one with K. so that's kind of where we were at going into the process

While both parents shared level of loss was overwhelming, they were focused on giving this baby all the chances they could. Despite being given very low odds of survival, they remained optimistic and highlighted the differences between both babies, "there was always a really big difference between K and T in, their level of fight. Well um Ts APGARs were one and then three and then five. And K's were eight and eight."

Guilt. Even without a previous loss, parents also can be impacted by just the scare of an early delivery. Participant 2 was honest about the difficulty she had caring for twins. The responsibility was overwhelming, and as discussed previously, she was just going through the

motions but had some guilt and revealed reluctantly, “there was a lot of time, like guilt, there were a lot of times, not really angry at them, but on a bad day...I really wish they weren’t twins.” She also expressed guilt for having to get help from her mom and further added, “a lot of guilt of what I had put on her that wasn’t her responsibility.”

The researcher noticed the emotional response and sad affect Participant 1 displayed while talking about her previous loss. She shared, “there was guilt...as far as losing my son and then there was guilt as far as her being born early.” In the reflective notes, the researcher noted that Participant 1 seemed to be so focused on her baby, see her as a gift, and help to heal the grief from losing her son. She went onto state, “I blamed myself for everything that she was having to go through, so you have to let that go.”

Participant 10 also described how she felt guilt about her baby being sick. She had to go on bed rest because of the fear she would go into early labor around 33 week gestation with her first child, though she ended up holding off and not delivering until 37 weeks. With her next pregnancy, she experienced multiple illnesses, fearing a possible miscarriage or preterm birth. She looked at her baby and added, “you’re a little fighter.” Again, she came across as being grateful, though reticent to open up any further on this personally painful topic.

Additional negative feelings. Parents’ symptoms of anxiety, stress, fatigue, and depression were results of being in the NICU for so long and having to care for a medically fragile infant once home. The serious and constant changes of their baby’s health statuses combined with uncertainty, fear, and lack of knowledge. These symptoms continued once they were home, though with some participants these feelings tapered off.

As previously mentioned, parents were just trying to keep up with the day to day and managing critical needs for their baby after discharge. This left little time to assimilate how

stressful it was. Even though the interviews took place several months after discharge, parents shared that they were still experiencing high levels of stress, anxiety, fatigue, and depression. The subtheme Additional negative feelings, is made up of categories of anxiety, stress, fatigue, depression.

Anxiety. The experience of being in the NICU left residual symptoms of excess anxiety. Participants 3 and 4 were especially prone to continued anxiety and stress. Participant 3 described the anxiety, “when I hear the vent alarm going off, It causes a lot of anxiety.” She shared this delayed reaction was a result of not having time to deal with it previously, adding “when we first came home we didn’t have the opportunity to for that anxiety to hit...because it was too critical for us to be on top of our game all the time.”

Furthermore, Participant 4 added, “it was like weird like, I was able to get through it at the time...now there’s times where there will be like a sound or a smell and it’s kind of like the whole thing slams back into you.” The interview with Participants 3 and 4 was primarily focused on their baby, with less discussion about what they went through. The interview itself was primarily about the extraordinary medical difficulties that their infant had experienced and continued to experience. Their prematurely born infant was one step above the “worst case scenario”, as far as all the medical challenges in regards to physiological aspects. The parents’ focus and narrowed world perspective reflected that it was all about the baby.

Participant 2 also had a similar delayed experience, confiding, “so I was like the first week or two that I was home, it was like almost always like a major anxiety attack.”

Stress. Day to day activities caring for their premature baby causes excess stress for parents, and all participants communicated experiencing stress at one level or another. Participant 10 shared that she stayed busy and stressed over trying to protect her baby from an

infection, cleaning the house, and making sure those who came into contact with her baby washed their hands. After Participant 9 had to replace her son's feeding tube, she confided that the whole experience terrified her, and she was worried until her baby's doctor appointment. "I was terrified! That was like a week later too. That whole week, I stressed myself out."

Participant 2 who had an older child and already experienced motherhood, shared the following:

it like the luxury of, I do remember being very stressed and feeling like I you know I was just trying to do everything somewhat like I did with my first born and like everything sterilized everything I just had to let some of that go

Depression and fatigue. Participant 9 also described how she became depressed, especially when she realized her baby was medically fragile. She shared,

it is kind of depressing? Because people do consider us a special needs, and there's one thing that breaks my heart, is special needs...I thought that I would never have a kid like that...it really shocked me and it broke my heart. And it still does to this day

For some mothers, going home coincided with being in the post-partum period. When the researcher asked Participant 10 about having enough support to cope, she replied, "it would have been a lot tougher. Because you know you are also in post-partum during that time." Participant 10 implied minimizing post-partum depression from effective support in this statement.

When asked about how they were coping, Participant 3 opened up and revealed some of the challenges they were having. She poignantly stated,

there has never been any other option this is the hand we we've dealt so you just make the best of it that you can. We are both on medication; both take Zoloft, Prozac, for anxiety and depression and try to stay in good health

Moreover, Participant 4 clarified,

the weight of the entire experience, was like it could be just the slightest little thing and it could just like trigger it and like everything at once just kind slams into you. It's almost like it's hard to breathe through it

Several parents talked about being exhausted and came across as being tired. Participant 5 sounded weary when sharing about their experience taking care of their baby and revealed, "we were stressed, we were tired." Moreover, he clarified, "overwhelming frustration; and fatigue, it would be fatigue it was a long hard run race, and at the end I am glad that the end came when it did. Because we were very, very tired."

Standing guard, hypervigilant. Some babies spend weeks to months in the hospital prior to discharge. While parents learn to care for their baby in the hospital and prepare to go home, they become reliant on monitors and equipment in the NICU. Once they are discharged to home, some infants no longer require monitoring, so they are at home without any; however, parents are nervous and describe standing watch over their baby.

When parents are first at home, they experienced more difficulties adjusting without nursing staff around to help, not having the baby on cardiac monitors, and were in a state of continuous attentiveness or standing watch. Parents reported not sleeping and watching their baby breathe.

Parents described how they were attentive and cautious about being prepared, just in case something was to happen. Another parent stated, "how do you prepare people for the problems that happens?...walk through the problems when lives are at risk?" Additionally, when asked about the type of resources given for discharge, parents stated that they also were given a number to call if something does occur. Several parents also described being "panicked stricken" about

going home and not knowing what to do. One parent kept that number with her telephone, so she would have quick access.

As previously described, Participant 2 was nervous on the ride home after discharge, stating, “I would stop at every exit on the way home and make sure he was breathing.” Once home, parents were hypervigilant.

Participant 1 shared, “I don’t let her out of my sight.”

Even a simple task such as feeding had potential to cause extra concern for some parents. Participant 2 talked about how she had to be very careful while feeding her twins because they had reflux and could aspirate. She stated,

my biggest thing was I have to have my eyes on them because...if have use something to prop that bottle up it was a little scary and sometimes you can’t see them. I wouldn’t do it and then walk away...I was physically sitting there.”

The extensive training paid off for Participants 3 and 4. The very first night home Participant 3 was not confident that the home health nurse knew how to care for her baby and had a sense that something was wrong. She confided, “something felt wrong, something felt off...about the whole situation...So I stayed up.” It ended up being a good thing because her home health nurse was asleep and not attending to their baby who was having a medical crisis.

Moreover, she shared,

that was one of our first signs that oh, my gosh if we had not been taught what we were doing...which makes you feel kind bad...because here is screaming and crying and no telling how many hours he had been screaming

Being hypervigilant also extended to taking preventive measures to keep their baby from getting sicker. Participant 10 had to go to extreme lengths to keep her baby from getting an

infection because his immune system was so weak, this combined with the infant having CMV and highly contagious with the suppressed immune system. While Participant 10 was sharing about protecting her baby, Participant 10 inferred that she had to be vigilant about hygiene and protecting her infant. She continued to share that she is constantly cleaning and making sure family members do not bring germs into the house, especially when her daughter comes home from day care and contended,

you know when she comes home from day care, I give her a bath before we do anything, and you know put clean clothes on her...it's just an extra step of everything, to make sure he's protected but it's worth it, it's tough but it's worth it

Having joy with my baby. Despite experiencing challenges and the above-mentioned negative emotional responses, parents demonstrated positive aspects, too. They showed their love and affection for their baby during the interviews. Parents either held their baby during the interview or they were in another room sleeping. Only the mother was present for the interview held at the restaurant, and she had left her twins at home with a sitter. During one of the interviews, their baby was sleeping in the next room, and when he woke up, his mother brought him into the living room where the interview was taking place.

The researcher noticed the loving glances, sharing of recent photos, and tender caring of babies during the interviews. In addition, parents would answer the researcher's questions by glancing at and speaking to their baby. During the interview, Participant 1 truly demonstrated her joy in her baby, adding, "yeah, yeah, that was the hardest thing. Yes, you are pretty baby." This was especially true when the discussion consisted of how far their baby had improved, receiving a positive report from the doctor, and listing accomplishments. Upon sharing that she had

received a good diagnostic report, Participant 1 looked at her baby and said, “we are happy about that aren’t we baby.”

Throughout the interview, Participants 3 and 4 kept showing pictures of their baby from his hospital stay, similar to what any new parent would do while showing off their pride and joy. However, these pictures were not of a cute baby, but of an infant surrounded by all the medical equipment and were a visual image of their story. It was evident that parents held so much pride for their baby, acknowledging the struggle they had all gone through and showing how far they had come. Participant 3 showed pride, bragged how her baby was a real fighter, and kept doing things other babies in the NICU had never done before, exclaiming, “he somehow managed somehow to move and get a finger under the stich and pop it up...So Dr. W. told him, you are my first baby to ever do that.” The researcher commented, “it sounds like he’s quite strong,” and Participant 4 chimed in, “he is a feisty red head, a fighter.” Participant 3 added with pride,

he is doing so much better. Then any of us ever expected him to we’re not pessimistic people, but we try to be realists. To hope for the best, but prepare for the worst? And he’s exceeded everything we could have ever hoped for

Participants shared those tender moments that new parents experience and further acknowledged the struggle their baby had gone through. Furthermore, describing overcoming difficulties, Participant 10 mentioned with pride as she glanced at her baby and talked to him, “cause you’re a little fighter.” Then glancing back to the researcher, chuckling and adding, “He is an excellent baby, I didn’t realize how tough my daughter was until I had him.”

Participant 9 exclaimed in a lighthearted and loving manner, “My mom fell in love with him. And she helps me to this day. She’ll take him and she’ll disappear outside and I’ll be like, where’s my kid?.”

Participant 1 also talked about sharing love and affection toward her baby, stating, “she’s our little miracle, yes you are (talking to the baby).” She continued talking to her baby, making eye contact, and expressing her love, adding, “which I love, yeah. Are you smiling again.” Glancing back at the researcher, she shared, “So she wakes up in the middle of the night and wants to play.”

Furthermore, Participant 8 talked with pride about being the first one to hold his daughter, and when the researcher asked about bonding because he worked so much, he added in a joking manner, “as much as her mommy would let me have her.” The researcher commented, “It’s sweet. So despite all that, difficulty and challenge, it sounds like you all came through it... and found a way to have fun with your baby”, and Participant 7 chimed in with an affirming and resounding, “yeah!”

Despite being a proud new parent, Participant 2 was busy and overwhelmed with twins, stating, “everything times two” and added, “instead of one so like if there’s two you don’t have time to sit and do all that ew and goo and ah and stuff.”

Participant 1 also shared how she was overcome with fear but also excited when she brought her baby home, “I first brought her home I was of course nervous, scared. Um, excited all of that at the same time... um, I think I am going to cry.”

Moreover, Participant 5 described the conflicting emotions of loving their new baby, but sometimes having no control, adding, “we have this only child, that we instantly love, and we can do absolutely nothing.”

Parents described and displayed a variety of ongoing emotions once they were at home with their baby. While most experienced less stress once home, described pride and joy, parents

were still adjusting to being new parents. They finally had an opportunity for the whole family to be together and able to reflect on the experience of being in the NICU.

Adjusted parental role, finding normalcy. Once home, parents adjusted to their new normal and family flow. While some found it stressful, other parents described they had anticipated the day when all their family could be together and get into their own routine. Parents had already had to adjust to a new normal; their expectations for a normal experience were changed with the early delivery of their baby. For some they found it difficult to feel like a parent, did not really bond with their baby, experienced challenges and emotional upheavals, and required multiple resources and support to manage. The process of coming home meant that many of the issues and concerns were resolved, and parents experienced relief and less stress; however, for some parents their adjustment has just begun. They had made it home safe and sound. The codes that make up this subtheme include Home safe, This is my baby, and Worthy sacrifice.

Home safe. Settling in at home really was the ultimate goal for parents, a day parents were looking forward to. While some had difficulties being on their own, they demonstrated positive emotions about not having their family separated any longer and no longer having to travel back and forth to the hospital. For most parents it seems as if being home was a subtle signal that everything is going to be fine and now we are a normal family. Participant 1 described being home as less stressful, adding

when you get her home or him home, it's you just get settled in, you feel at ease at home...the drive, I was constantly having to go back and forth to see her? It was stressful...some of that will wear you out, the drive having to go back and forth but we wanted to be with her as much as possible.

Furthermore, she shared

actually getting her home it was like it was easy, more comfort, you know more comfortable being here and not having to get up and rush up there. See it just feels more complete with you being home, huh, doesn't it baby

For some parents, going home meant more stress and they were just getting by.

Participant 2 had confided that she was going “all day long, it's really like you got to survive the day, it was a job. I mean I did love them, but it didn't feel real.” She described how in order to take care of them and keep them safe, she had help from her mother and quit her nursing job. This helped her adjustment to a new normal.

Setting up the home environment and being home safe also meant an adjustment to changes. Participant 4 indicated “it was great being home that was the best part of it, But it was also kind of nerve wracking.” He stated that “there was still all the equipment and all the noise and there was you know, we had 24/7 nursing so now there is always someone in our house! And so that took some getting used to.” Furthermore, Participant 3 shared, “I guess once the reality of everything that happened finally settled in...once we got home and finally got to settle into something like normal.”

Participant 6 was quiet throughout the interview, but she did share about the first two weeks at home her time alone with her baby, adding “it was very, very hard, just having those two weeks to have just me and him...it was just a relief.” Additionally, when the researcher asked her “a relief how”, her husband chimed in, “to finally be home.” While it was a relief for most, Participant 9 described her experience as difficult in contrast to her friends with new babies, sharing,

it's not easy. And especially watching my friends and stuff... They had their babies around the same time and they went home, and everything was going fine and I am sitting here watching my little two pounder, fighting for every breath

Participant 9 also stated, " it was, it was just a relief... to finally be home... yeah, just finally being home. Not being confined to one area. Far away from our family...and his family. It was nice"

This is my baby. As parents became adjusted at home, they also increasingly bonded with their baby. For some parents, they had been in the hospital for weeks to months, whereas others spent only a short period of time in the hospital. In addition, for some parents, providing hands on care was limited by challenges previously mentioned in gaining access to their baby.

Participant 1 described directly about taking ownership of her baby, stating, "now that we are home, she's mine, I get to take care of her." She also added, "I don't always have somebody standing over me." She also confided, "you have your mother's instincts...you know if your baby's okay...you know if something's different...you know your baby better than anybody else."

Having their baby at home became more convenient to do simple tasks, such as holding their baby. Participant 5 also shared, "I mean because, like here at home he is sitting right here straight across from me. Where I can pick him up and I can take him with me." He also showed his tender feelings and love for his baby in a lighthearted fashion,

you can sit there and think about all the things that might happen or might go wrong...But it's not that hard, I mean I am not taking away from child rearing or anything like that, it's not that hard. Uh, just care for them, just love them and don't do anything foolish you know.

Participant 8 also expressed pride, in a bragging tone, that he was the first to hold his baby, stating, “see I was actually the first one that ever held her.”

For some parents, the pregnancy was unexpected, as was the early delivery. Participants 3 and 4 they took immediate ownership and knew they wanted children when they were first married. Even though they lost their first child shortly after birth, they continued trying for another baby. That spirit of determination show how committed they were to raising a child. Participant 3 shared how difficult it was to pursue care for their baby as they had already been through a loss and knew some of the struggles their baby would experience and the lifetime commitment. She revealed,

we communicated was that we understood what we were signing up for and was for the potential of 24/7 full life care for the rest of his life. And that we might be signing up for the rest of our lives, to be his caretakers

Feeling ownership of their baby, parents identified that despite the commitment and work involved, their baby was worth it. Participant 9 revealed, “I have to step it up and realize okay”, as she took a deep breath and exhaled, “I gotta do this! For him...I have to do it...And it’s worth it to watch him grow and watch him learn all that stuff.” She also indicated that as a mother, she knows what is best for her baby, adding,

just having someone, to support you in what you feel is best as a mother. Not pushing you to do everything, else that you don’t feel is right...Because, sometimes, it’s not what’s best, I know that doctors think that it is, but, I know as a mom sometimes that it isn’t.

Taking ownership also involved motivation to do their best as a parent. Participant 9 stated, “Because he motivates me to keep it going. Because every time I see him smile, this is

why I am doing this. This is exactly what wakes me up in the morning and makes me continue to be positive.”

Part of taking ownership also meant managing medical appointments. Parents made sure their baby continued to receive the best care and take their baby for follow up care. This included the initial follow-up high-risk appointment along with Physical Therapy (PT), Occupational Therapy (OT), Gastrointestinal (GI), Pediatrician or Neonatologist, Ophthalmologist, and even in some instances, Neurosurgeons.

Since the researcher recruited from the NICU Follow Up clinic, participants were asked about taking their baby to appointments and whether they understood the importance in keeping appointments, describing “the follow-up clinic can really help to find problems early.”

Participants 7 and 8 did not understand and stated that the NICU staff did not explain it to them, but Participant 8 added, “doesn’t matter what she’s scheduled for, she’s going.”

Worthy sacrifice, the price I paid. Despite the challenges, emotional stress and anxiety, and struggles parents experienced having a medically fragile infant, all expressed gratitude and a worthy sacrifice. After everything Participants 3 and 4 went through, Participant 3 expressed, “Sometimes I feel like it’s a reward for everything we went through. Just to have them here.”

Participant 3 also talked about how feisty her son is, in a bragging tone, and personally felt her struggle was a payback for how she treated her parents as a child, revealing,

He is a really cool little kid. Feisty, but I feel like I deserve that because I was terrible to my parents as a kid, I was awful! They say your kid’s give you back everything you were? So I deserve every bit of this feistiness

Sacrifices came in the form of giving up employment in order for parents to be able to care for their babies. This also gave parents more power to be able to set their own family rhythm.

Participant 2 shared, “one reason why I did walk away from my nursing position...I can and I have time and we can sit and do things one on one.” Participant 1 also quit her job to spend more time with her baby, sharing,

Worthy sacrifice, so I just took off from work so I could just kind of be here with her.

That way I can take her back and forth and not worry about taking her to a baby sitter and picking her up and then taking her to the doctor

Participant 10 also talked about doing whatever it takes to care for her baby, which meant quitting her job and expressing gratitude, “thankfully we are in a position, well I love working and I would go back today...It is worth the sacrifice, we are determined to do what it takes, you know to make it work.”

Worthy sacrifice is made up of parents’, commitment, ownership, and pride for their baby. Participant 9 eloquently described how she had gone through was worth it for her baby:

it’s worth it to watch him grow and watch him learn all that stuff...this is what we fought for, this is exactly why we went through all of this. To see this baby grow and be happy.

The first time he laughed? I was like, that’s it! I am going to cry! That’s it! That’s why I fought so hard.

Furthermore, she added, “Once you become a mother and you want to do everything for your child, to make them happy, you want to and you give up everything of yourself and you give it all to them.” Participant 2 also expressed parental pride for her children, acknowledging that her efforts are worth it, and shared,

I wouldn't take anything for them! I love them more than anything but there are moments that any parent even any married parent with multiples would have feelings of like why did this happen... Why did this happen to me? How am I going to make this work and this kind of sucks. (Chuckles.) You know there's times when it's not fun.

Moreover, she added, "but then there's always some time that comes along and it kind of makes up for it and you're kind of okay, it's a new day. I'm good."

Summary of Major Theme 3: Safe Port, Finding Solid Ground

For most parents finally coming home was a long awaited milestone. It appeared as if being home was a subtle signal that everything was going to be fine and parents felt their family was normal. While this was their new normal, once home, things were not necessarily that simple. Some parents experienced ongoing emotional responses, and many parents had to take charge in caring for the complex needs of their infant. The parents gained confidence and became self-reliant. They learned to play multiple roles, utilized resources, and realized the importance of family and support. Parents were committed to consciously take control and ownership of their baby, while acknowledging their sacrifice as worthy for the joy their babies brought them.

The journey for parents to settle into a family routine with their new baby involved a lot of uncertainty, emotional upheavals, learning to speak up and becoming an advocate, identifying their personal needs and those for their baby, becoming the expert, and recognizing their role as a parent. The process of discharge readiness required going through a state of transition that included training, support, information, and guidance from medical professionals and specialists. Parents rode out the stormy beginning, adjusted to their surroundings and situation, and finally found solid ground where they were safe at home with their baby. Ultimately all parents went

through a similar adjustment and transition to having a new family normal, though for each one, their story was unique and in some instances very personality driven. Despite the different time length for hospitalization, in addition to acuity of baby, each parent welcomed their challenges and overcame obstacles throughout the process.

While parents learned to care and advocate for their infant in the hospital, they became more self-reliant once home, however were faced with the challenge of playing various roles. Training from medical staff, repeated practice, and encouraging support helped parents feel prepared for discharge. As a result, many became experts in performing tasks and ended up training others who were in the role of helping to care for their baby. Parents described how they had to adjust and play different roles once home such as expert provider, case manager, and train others to care for their baby. Preparing for discharge and planning for the unexpected, parents described how they felt much more calm and at ease when situations arose once at home, and had to provide life saving measures. Highlighted in the transcripts, parents communicated that if the nurses had not prepared parents for these situations, they felt their infant's life was at risk. Additionally, parents described the different types of support, coming from multiple sources, they received in order to manage at home. Not only resources like insurance government programs to even ER, but to an equally important resource; people, friends and family or their village.

CHAPTER 5

CONCLUSIONS

Interpretation of the Results

The purpose of this study was to understand the experience of parents with a premature infant related to discharge readiness from the NICU. The study was conducted in the Eastern and mid-Southern areas of Appalachia and included recruitment of families who are caring for a medically fragile infant at home, and experience exceptional difficulties and challenges as a result of compounding factors and an underserved area as described in Appalachia.

Participant sample consisted of a wide range of ages, socioeconomic status, education levels, and distance from hospital and NICU Follow Up clinic. The overall complexity of infants medical issues presented various challenges for families, regardless of education, resources, and distance from the hospital. Some of the participants were signed up for public assistance programs and described receiving nutrition subsidies through Women's Infant and Children's (WIC) program. It was clear that many of the participants were required to quit work in order to care for their infant, creating extra financial burden. Due to their infant's medical complexities, participants were not able to locate baby sitters or childcare center in their area, which created additional burdens on family life. Participants discussed the ongoing mental health issues they were dealing with, some describing symptoms of hypervigilance and possible PTSD, however none of the participants described being involved in individual or group therapy.

Medical technology has had a direct effect on decreasing mortality for premature infants; however, they are discharged to home with unresolved medical issues (Blencowe et al., 2012; Sneath, 2009). Increasingly parents are required to learn how to care for their medically fragile infant and manage the medical technology at home. Parents' primary goal is not only to meet the

needs of their baby but also specifically have their family all together at home. This study highlights the process of how parents experience discharge readiness from the NICU to home and subsequently settle into a routine with their family. Chapter four included a complete analysis of the raw data, resulting in theme development from interview transcripts.

Previously published literature depicts challenges and concerns that parents experience as they transition to home and detail parents' needs around being prepared for discharge; however, few studies describe the experience for families with a medically fragile infant that were born under 32 week gestation. Sneath (2009) conducted an integrative review of discharge preparedness, summarizing parents' perception of the discharge process, however there was no specific focus on the medically fragile infant. The primary themes listed in Sneath's review included limited information on how to measure parents perception of readiness for discharge, discrepancy in medical staff and parents' perception of discharge readiness, the need for training and information to be tailored to each parent, and the ongoing need for parental support.

The current research study highlighted the journey for parents to settle into a family routine with their new baby involved experiencing uncertainty and emotional upheavals, learning to speak up and become an advocate, identifying personal needs and those for their baby, becoming the expert, and recognizing their role as a parent. The process of discharge readiness required going through a state of transition that included training, support from family and medical staff, information, and guidance from medical professionals and specialists. Parents rode out the stormy beginning, adjusted to their surroundings and situation, and finally found solid ground when they were safe at home with their baby. Ultimately all parents went through a similar adjustment and transition to having a new family routine, though for each one, their story was unique and in some instances very personality driven. Despite the different time length for

hospitalization, in addition to acuity of baby, each parent faced their challenges and overcame obstacles throughout the process.

The overall goal for this study was to add to the existing knowledge, while shedding light on discharge readiness, and fill gaps in the literature. Discharge readiness is tied to the need for parents to adjust to their parental role and find normalcy. In order to establish a new normal, parents navigated through rocky waters and unexpected depths, then found their bearings, discovered their strength and motivation to learn what it takes to reach safe port, and putting down an anchor.

Theme Emergence

As a result of data analysis, three themes emerged which can be placed under the overarching theme of Adaptation to New Family Roles, Finding Normalcy. The three major themes are 1) Riding out the Storm, 2) Righting the Ship, and 3) Safe Port, Finding Solid Ground.

Ten subthemes resulted from the data analysis that support each major theme:

1) Riding Out the Storm

- 1a. Having the carpet pulled out from under me
- 1b. Things I lost
- 1c. Feel Like an Outsider
- 1d. Sink or Swim

2) Righting the Ship

- 2a. Quest for knowledge
- 2b. Caring for me, caring for my baby
- 2c. Customized Learning

3) Safe Port

3a. Getting to know baby

3b. Becoming the expert

3c. Ongoing Emotions

3d. Adjusted parental role, finding normalcy.

The first major theme of Riding Out the Storm was developed by the initial shock that the parents experienced. Parents experienced the entire gamut of emotions. They reported that they did not know which way was up and which way was down. They were required to change any preconceived ideas for their family and search for new meaning in their parental role. Parents were on a blind roller coaster ride. Unconsciously their underlying goal while in the hospital was to take any necessary steps to get their baby home. The participants were forced to deal with broken promises, inconsistencies, judgment, and intimidation and even learn a new language, all while suffering sleep deprivation. The parents showed perseverance reporting that whatever it took, including jumping through hoops to be in charge of day-to-day care, they worked toward integrating their new baby into their lives and cultivating a new normal for their family.

The second major theme of Righting the Ship deals with the primary setting of being in the NICU and the beginning process to the transition to home. Still climbing that mountain, parents reported finally reaching the peak and the beginning journey down. This is was a big mountain of experiences to climb. The parents were starting the first serious step in trying to understand and comprehend what had happened. This immediately led to the need for more information.

The parents needed sympathy and support and grew to develop their own voices to become advocates for their babies. For this to occur, development of a trusting relationship with

the medical staff was essential, which ultimately grew into a family-like relationship. The topic of customized learning was also addressed and interwoven into the parents' experience. It was not a case of the traditional going from known to unknown. For the majority of the Participants it was a case from starting in the unknown to going further and deeper into the unknown. Parents not only had to learn basic baby care items but also had to learn both basic and advanced care for a prematurely born infant and all the potential medical complications and issues. Once that foundation of learning and self-confidence were on equal par, the parents had only to remember the nurses' voices in their heads.

The third and final major theme of Safe Port, Finding Solid Ground, was a transition out of the NICU and, finally, life at home. The transition itself truly began with that initial drive home. Once home parents found themselves a little lost initially establishing new routines, and this included taking care of the complex needs of their prematurely born infants. In facing these multiple challenges, parents reported that they gained self-confidence and reliance and they became the experts wearing many hats or playing many diverse roles. For example, some became case managers, educators, and providers. All of this would not have happened without resources. These resources include insurance companies, as well as state and federal programs. Being home safe was an important final step and transition for the parents to fully realize their role as parents and where they took ownership of their babies without supervision. They were responsible and acknowledged unanimously that even though there had been, and are still, ongoing challenges that their experience was a worthy sacrifice for the love and joy of their baby.

Detailed analysis was applied to each research question with discussion related to the overarching theme of Adapting to New Family Roles, Finding Normalcy. Discovering whether

families felt prepared, had sufficient support and training, and what type of emotional responses occurred as a result of caring for a premature infant are also highlighted throughout the data analysis.

The researcher's interview style included use of a guiding inquiry, a Grand Tour question, with follow up questions to gather further rich description of parents' experiences. The research question guiding this phenomenology study was: How do families perceive their level of preparedness in taking care of their infant at home after discharge?

In addition to the guiding question, follow up questions focused on discharge readiness. Clarifying and expanding data, summarizing exceptions and highlighting unique issues were used to elaborate on each focus area and are discussed below. The following sections give detailed descriptions on how these focus areas were answered, how they apply to the three Major Themes, and are depicted in a visual representation (Appendix F).

Focus 1. How do families perceive their level of preparedness in taking care of their premature infant at home after discharge?

There is a plethora of information in the literature on specific criteria a premature infant must meet in order for discharge, such as hospital protocols, AAP (2017) guidelines, and early intervention outpatient services. Additionally, there are studies that focus on discharge needs for parents of premature infants; however, few studies address parent readiness and specific needs to care for a prematurely born baby with the technological needs continuing at home (Lee et al., 2011). The following subthemes, Quest for knowledge, Caring for me, Customized learning, Getting to know baby, Becoming the expert, and Adjusted parental role, are interwoven throughout the discussion below.

Parents who felt prepared stated that staff communicated very thoroughly, were there to support them, felt like family, and really cared. Being prepared is directly related to interactions between staff and parents. Moreover, parents also reported being prepared meant that staff covered details on travel, feeding, and basic baby care. Parents who received technology training and instruction on use of equipment or specialized training reported that they felt prepared by being able to complete practice drills. This training included instruction for equipment such as a feeding pump, oxygen tank, ventilator, and a cardiac monitor. Specialized training for interventions included daily tracheostomy care, ostomy care, physical therapy, and medication administration. Increasing contact and detailed communication between parents and staff was critical to feeling prepared.

Overall parents felt prepared for discharge; however, many had to jump through hoops, learn to speak up, and take initiatives to fill in the gaps in their learning. The perceptions participants expressed once home were influenced by what happened in riding out the storm and righting the ship, in addition to events that occurred prior to delivery. Their preconceived ideas, coping mechanisms, and family situation, including if they had other children or if they had previously lost an infant, all had an impact in being prepared to go home and becoming the primary caregiver of their baby.

All of the participants, but one, clearly stated that the time they spent in the hospital helped them feel more prepared. Focused demonstration from medical professionals and parental direct hands on experience were specifically related to participant's perceptions of feeling prepared. The subtheme, Getting to know baby and Becoming the expert, is represented by support from staff and being able to observe in a controlled environment, then repeated side-by-side demonstrations for parents and family members. Additionally, printed material and training,

specific to parents' needs is well documented in the literature as beneficial to discharge preparedness for parents (Broedsgaard & Wagner, 2005; Kenner & Lott, 1990). Participants' described specific training they received to feel prepared such as CPR, car seat, bathing, feeding, and specialized physical therapy. These findings are consistent with more recent studies by Zamanzadeh et al. (2013), for the need to focus discharge planning and teaching parents unique needs and preferences.

Discharge preparedness is a process between establishing family bond with premature infants, development of parenthood, and transition from NICU to home. The model Adapting to Family Roles, Finding Normalcy (see Appendix G), depicts how the bridge to readiness comes from support, resources, information and assists parents to develop new family roles and a new normal. A study by Broedsgaard and Wagner (2005) identified that families found meaningful support and resources beneficial to their discharge readiness. The researchers focused on parent-infant bonding as an element of being prepared for discharge versus just focusing on other tasks related to discharge preparedness. Satisfaction and meaningful interventions implemented to prepare for discharge included group discussions, structured discharge plans, coordinated support, written material, visit by health visitor, primary nurses, and parent groups (Broedsgaard & Wagner, 2005).

In this current research study on discharge readiness, findings revealed that after discharge, most participants expressed how happy they were, felt more at ease, and identified their role as a parent and ownership of their baby. There were several parents who did feel increased stress, felt like they were just going through the motions, and weren't able to bond when first at home. Those same parents were inundated with the medical complications of caring for their baby. Research studies have highlighted that parents of premature infants often continue

to experience feelings of being overwhelmed after discharge to home (Griffin & Pickler, 2011; Hess et al., 2004; Reyna et al., 2006). Furthermore, parents might report being confident with discharge teaching in the hospital, but once home, their reported level of confidence decreases (Raines & Brustad, 2012). This discrepancy in the literature might be a result of differences in level of parental coping and complexity of infants needs.

Participants also described their attention to detail and extra focus toward their baby, identifying the level of vulnerability, and need for protection. Parent infant interactions are impacted by premature birth. Studies have shown that mothers react different with a premature baby (Forcada-Guex et al., 2006), particularly if mothers experience postpartum depression and have symptoms of PTSD. Studies also show the connection between parental depression and ongoing poor outcomes (Huhtala et al., 2012), whose prospective cohort study added knowledge about father's responses.

Support and parental need for information is well documented in the literature, especially related to overall improved parental confidence (Holditch-Davis et al., 2003; Jones et al., 2009). Furthermore, McKim (1993) denoted inverse relations between information received and parental stress levels. Quality teaching and information directly correlates to perception of discharge readiness Burnham et al. (2013), whereas Hager (2010) demonstrated that increased readiness and satisfaction resulted in reduced excessive use of healthcare resources.

Some parents felt they did not get adequate information and sought out information on their own. This is consistent with previous studies, highlighting that parents did not receive enough information about discharge and sought out more information on their own (Conner & Nelson, 1999). Despite parents reporting they did not receive discharge information, studies highlight a discrepancy between what parents remember receiving and what actually occurred

(Flandermeyer et al., 1992; Smith et al., 2012), or the difference between parents perception and medical staff related to discharge readiness (Sneath, 2009).

The subtheme, “Begging for more” is depicted through statements parents made about feeling they had to speak up and ask for more. For instance one participant discussed how she searched websites to obtain information on how to manage twins because the NICU staff did not mention this might be a concern. De Rouck and Leys (2011) highlighted that parents will reach out to become more educated on their own by also looking up websites for information. Brazy et al. (2001) denoted the transition parents make in obtaining information and go through four phases, from prenatal, acute, convalescent, and finally to discharge. Parents reported support from the nurses helped them adjust to being a parent of a premature infant and became more involved in daily care. Parents offered advice for other parents in order to cope such as gathering as much information as possible, become involved in their babies care, and emphasized the importance of having a primary nurse. In addition, the study highlighted the need for specialized education, communication, and information from staff.

These findings are consistent with a phenomenology study by Jackson et al. (2003) on parents with a premature infant, born less than 34 week gestation. Parents went through four stages, alienation, responsibility, confidence, and familiarity. The Jackson et al. findings have similarities to the current study, where parents went through stages of feeling left out or ostracized, learned to speak up and find their voice, increased their confidence where they incorporated their parental role, and familiarity where they increased self-confidence as they took over independent role at home.

Depending on the medical complexities, parents were required to learn to manage equipment, give medications, perform life saving techniques, monitor and educate others who

are helping care for their baby, and negotiate between healthcare providers and insurance companies. One family in particular described in detail some of the roles they had to assume in order to care for their very fragile infant. The subtheme, *Becoming the expert*, was developed specifically from interpretation of their experience. Specialized training for home caregivers of medically fragile infants has become a necessity. In a study by Tearl and Hertzog (2007) a training program for parents was evaluated by respiratory therapists, parents, and a Durable Medical Equipment company. Results demonstrated improvements in performance and satisfaction scores were statistically significant upon completion of training program for parents.

While the literature highlights parents' needs for individualized teaching and information, very little specifies the multiple roles that parents must assume in order to care for their baby. This might be a direct result of technology saving more babies at a younger age, in addition to a health care culture where patients are sent home with more frequency on medical equipment and therapies. Two participants described in detail about their experience learning complex medical interventions and denoted that their knowledge and expertise was essential to save their baby's life and on multiple occasions they had to intervene quickly, and were required to be on top of their game 24/7. Tearl and Hertzog (2007) identified the significant role parents have in managing home medical care and monitoring, especially in light of the critical nationwide shortage of home healthcare nurses.

Studies also show a relationship between being able to spend time in the hospital and parental bonding. During the interviews, several participants stated that they had to make an adjustment after discharge. Several participants described how they wished they could have spent more time in the hospital, all but two felt they had sufficient time to bond, and three identified they felt confident with bonding because they had previous experience with children.

Research has revealed that extended hospitalization of premature infants and separation can have an impact on parental role and bonding (Bernstein et al., 2007; Broedsgaard & Wagner, 2005; Odom & Chandler, 1990; Rikli, 1996).

The subtheme, Getting to know baby and Adjusted parental role details the necessary steps participants went through in order to bond and feel they were a parent. Approximately half the Participants identified how they really did not know what their babies' needs were until they got home. One participant was especially poignant describing that she would like to have spent more time in the hospital getting to know her baby, but was reluctant to visit when certain individuals were working. This created a barrier to her bonding and thus feeling prepared.

Some participants' felt pushed out too fast, noting that their concerns were not being heard and were very nervous, didn't really know how to care for their babies, and was just going through the motions. The literature highlights that often parents of premature infants feel discharge is rushed and they received inconsistent information (Bernstein et al., 2002; Kenner & Lott, 1990). Despite one specific participant having previous experience as a NICU nurse, she was so nervous that she stopped at every exit on the way home. In a study by Olshtain-Mann and Auslander (2008) identified that more educated parents also experienced increased levels of stress and lower levels of confidence after discharge. This was contrary to other studies (Miles, Holditch-Davis, Burchinal, & Brunssen, 2011) and Feeley et al. (2014) where more educated parents had increased confidence and experienced increased parent role attainment. Both the current study and the contradictory findings of Olshtain-Mann and Auslander, Miles et al., and Feeley et al. may be explained by Holditch-Davis et al.'s (2011) on maternal role attainment, using measures to identify presence and competence in mothers with a medically fragile infant. Holditch-Davis et al. (2011) noted maternal competence related to responsiveness to infant;

however, increased technology dependence negatively correlated to presence. Despite the level of severity in infant's health status, maternal role attainment influenced the quality of parenting (Holditch-Davis et al. (2011).

Focus 2. What, if any, challenges do families with a premature child face in attempting to access medical resources after discharge from the hospital?

Parents had jumped through hurdles to learn to care for their baby and these tasks extended once home, with many adjustments which had to be made in family roles, quitting their job, and training other caregivers. Although going home was an anticipated event, parents were still faced with dealing with medical issues and knew it was going to be a challenge getting to all the doctor appointments. The following subthemes Quest for knowledge, Caring for me, caring for my baby, Customized learning, Getting to know baby, Becoming the expert, Ongoing emotions, and Adjusted parental role, finding normalcy are interwoven throughout the answer to focus two.

One of the expectations for discharge of a medically fragile infant is the return to repeated medical appointments. Therefore transportation and safe travel needs are specific to this population. There is a paucity of research studies identifying the need for transportation needs for premature infants and preparing parents for repeated appointments. Specialized training in how to manage child safety seats, how to secure medical equipment, and strategic parking is important for parents taking home an infant on medical equipment or multiples.

Immediately after discharge, infants have multiple follow up appointments, sometimes several a week or even daily. Premature infants need careful follow up on medical issues such as getting eye exams, neurological and developmental follow up, feeding and nutrition concerns, respiratory and cardiac issues, and well child exams. One of the most vulnerable time parents

experience is directly after discharge, but their engagement with postnatal care is critical. Ballantyne et al. (2012) identified the importance in parents participating in NICU follow up appointments; however, parents often do not keep their appointment. The most frequent point of dropout in Ballantyne et al.'s work was between discharge and the first appointment. Ballantyne et al. suggested that parents be connected with the NICU follow up clinic prior to discharge. In addition, Ballantyne et al. recommended that NICU nurses reinforce the importance of attending the follow up clinic, focusing on identifying potential ongoing needs for their infant and providing information that NICU follow up clinics can assess and follow infant's progress such as feeding and neurological, developmental, and physical issues.

It was clear that that living in a rural area created an enormous challenge and disadvantage for the families. Parents experienced difficulty getting qualified or trained babysitters or adequate daycare for a baby with medical needs, especially in a rural area; however, there is little in the literature that discusses the needs of parents. In this study, one family received full time nursing care after discharge; however, they experienced challenges with getting approved caregivers by the insurance company. Often the licensed nurses that were scheduled were not trained or licensed to care for the specific needs of their baby. Due to changes in state practice guidelines, the newer nurses were no longer trained in tracheostomy care, and it was outside their scope of practice.

Because the insurance company only approved a lower level of trained nursing care, parents described that, as this was their only option, they were forced to train the caregivers themselves. In addition, parents felt they had to be in charge of everything, just to save their baby's life. Parents revealed that their detailed training in the NICU helped them manage and perform needed skills to care for their baby and train other caregivers. Again, there is little in the

literature to discuss this issue between practice guidelines and insurance coverage. This same family also shared that the Emergency Medical Technicians, especially in rural areas, were not familiar with taking care of a pediatric patient, particularly a baby with a tracheostomy.

Parents also revealed that they had challenges with getting supplies and had to be the liaison between provider, insurance company, and the supply company. One family shared that if their pediatrician didn't place the correct order, their baby didn't receive enough of a needed item, none at all, or the wrong type. There is little in the literature that discusses the multiple roles that parents must assume after discharge from the NICU.

Parents in this study also discussed the feelings of fear and anxiety along with the difficulty in adjusting to a different level of care when their baby had to be readmitted to the hospital after discharge. The difference between being in the NICU and PICU was a stark awakening. Many parents spend months in the NICU; they got to know the expected routines, and became familiar and trusted the medical staff that took care of their baby. One participant described how detailed the NICU prepared parents to be caregivers, however in the PICU, the nursing staff did not really know how to interact with parents, especially those parents who were well trained to care for their babies special needs.

After being in the NICU for an extended period of time and learning to navigate the unit, parents must make the transition and learn to negotiate community resources. Parents often develop close relations in the hospital, only to find new challenges navigating community resources and providers. They have already been through a harrowing experience, survived through, developed confidence, and made it home. With this new self-reliance, parents often don't expect a community setting to be an additional challenge. Relationships have not been set

up yet, and each setting is different, so parents must learn to navigate something new. The settings are busy and might not offer the level of support parents received in the NICU.

Parents realized that the community pediatrician wasn't as experienced in the special needs for their baby, especially those with more medical needs, such as tracheostomy care. Parents revealed that they realized they knew more about their babies care and condition than the doctor. Some of the biggest barriers in the community setting included coordination and communication with medical staff. As previously mentioned, parents developed relationships and learned to navigate the NICU, only to have to redevelop relationships with community providers. While parents felt their baby was protected in the NICU, they quickly realized that they needed to ensure that protection after discharge.

With multiple outpatient appointments, parents had to ensure they scheduled all appointments when not many people would be at the clinic because their infant could be susceptible to infections. Several parents described the benefits of having access to a comprehensive follow up clinic, where they could see multiple specialists all in one visit. Some parents revealed that the stress they experienced upon admission to the NICU returned after discharge. The anxiety of all the unknowns and responsibility they now had to ensure their infants' needs were met.

Focus 3. What, if any, type of medical and social resources are families with a chronically ill child utilizing?

The primary focus of this study included participants who had a baby with medical conditions, but the ranges of medical complexity varied greatly. Use of medical resources is dependent on the level of medical complexity a patient has. The following subthemes Sink or

swim, Customized learning, Becoming the expert, and Adjusted parental role are interwoven throughout the answer to focus three.

Support and resources are either ones offered, where someone reaches out to them, or parents seek out help on their own. The majority of Participants utilized the Ronald McDonald House, while their babies were in the NICU. Additionally most of the mothers participated in the state WIC program. When the hospital tether was cut, parents had to function more independently. While many appointments were arranged by the hospital, once home, parents were responsible for organizing any follow up appointments and in control of any use of community resources. Resources included a combination of medical professionals, friends, and family.

Parents in this study were utilizing recommended resources, such as their follow up medical providers but also reached out to find information on their own or made decisions to change providers. Medical professionals that parents utilized for the baby included physical therapy, occupational therapy, speech therapy, nutrition, neonatology, Neurosurgery, Ear Nose Throat (ENT), pulmonology, and gastroenterology.

Being in a rural area added to the challenge of finding medical help from professionals who are knowledgeable about their unique needs. All participants in the study are taking their baby to a pediatrician; however, as previously mentioned, not all of the pediatricians are trained to care for the medical needs of premature infants. Even going to the emergency room for care, the medical professionals did not know the specific needs and requirements of a prematurely born infant. Communication between the medical staff and parents were crucial in regards to explaining in medical terms what their baby needed. Little in the research identifies how parents manage accessing outpatient clinic appointments and resources.

Parents discussed the benefits of having medical follow up appointments that are coordinated with multiple specialists. It becomes easier on the baby and parents. Family members help fill in the gaps, offer support, and change roles as needed. Parents take babies to the NICU follow up clinic, but revealed that they were not told much about the clinic, or that it was for high-risk babies. Parents also discussed how their individual church family helped give support, hold parents up, and helped keep them going.

Focus 4. What, if any, concerns do families have related to taking care of their premature infant at home after discharge?

The following subthemes Quest for knowledge, Caring for me, caring for my baby, Customized learning, Getting to know baby, Becoming the expert, Ongoing emotions and Adjusted parental role are interwoven throughout the answer to focus four. Participants were more comfortable once home, though several talked about being nervous, and having additional stress. The primary concerns were getting through the day-to-day care and basic baby care, but also attending to all the appointments. For some parents, the intensity from the NICU was still present, and they were dealing with ongoing emotional challenges. Some participants were able to rearrange their schedules and some decided to quit their jobs, giving them time to take care of their baby at home. The transition from the NICU medical staff making all the decisions, to parents having more control was the moments where they began to develop normalcy at home. Parents made adjustment and transition to primary caregiver, but also adjusted to having less finances, time, privacy, etc. The transition to home took parents time to adjust, developing their new family routine, learning to manage travel with a baby, and negotiating multiple outpatient appointments, etc.

While in the hospital parents had medical staff and monitoring equipment to rely on, whereas once home, they were in charge, so several participants described it as not letting their baby out of their sight and got little sleep. They were nervous bringing their baby home, but over time things became easier, and they were more relaxed. Participants described their hands-on care in the hospital helped them feel better once discharged. Their level of comfort increased with additional time spent with their baby. Some parents described the depth of instruction the medical staff provided to help them. For instance, with feedings, one participant shared that they went over her baby's special formula and that it was a big deal.

Once home, participants talked about being scared, but after a while things settled down, and parents became more at ease. Also, parents talked about feeling like they weren't prepared after all, but after some time, they became more comfortable. Some participants shared their emotional response that was elicited when talking about coming home, all together as a family. It was the pinnacle of their experience, no matter what they had been through, ultimately everything was going to be ok. While this was an exciting event, many described how the experience became real once home.

Jones et al. (2009) conducted a study which examined the relation between parental and appraisal of the premature birth for their infant. In addition, the study highlighted strategies for coping, social support, and parental efficacy. The results highlight areas medical staff can assess at risk families and recommend interventions for families experiencing difficulties. Findings in Davis et al. (2003) and Singer et al. (1996) are also consistent with Jones et al. (2009), denoting that parents did not exhibit high rates of psychological distress. However, Davis et al. (2003) identified premature infants are at risk of not giving normal cues of responses. Mothers' interactions and coping in the hospital related to interactions after discharge related to feeding.

This reinforces that NICU nurses need to assess mothers coping abilities while in the hospital. Rowe and Jones (2010) highlight a significant degree in psychological distress and increase in parental efficacy from pre-discharge to three months later, which supports Bissell and Long's (2003) statement that parental anxiety will dissipate quickly. Jones and Prinz (2005) found a relation between efficacy and psychological distress using Stress Appraisal Measure, Coping Health Inventory for Parents (McCubbin), Parent Satisfaction Scale, Parent Expectations Survey, and General Health Questionnaire.

Parents became very focused on their baby's care, realizing they were the one in charge, the one to problem solve emergency situations, and they became the expert in their baby's care. While parents relied on medical staff in the hospital, now they were the expert. Parents began to make their transition in the hospital to be the primary caregiver, where they started speaking up more, become their baby's advocate, and taking charge. Once home, any concerns that they had in the hospital, became more focused and crystalized. Participants had difficulty identifying their role as parents. Research studies highlight the importance parents make in their transition and adaptation to their role (Boykova et al., 2014; Smith et al., 2009).

Parents in this study approached problem solving and coping in different ways. This was especially evident during the couples' interviews but also from descriptions where one parent was being interviewed but not the other. The code Battles are different for mothers and fathers was developed from this analysis. A study conducted by Mundy (2012) identified needs of parents, specifically at discharge and admission, and differences between mother and father. Parents on admission were more focused on the need for support and hope, whereas at discharge, they wanted more information on transportation (Mundy, 2010). There were no significant differences between the needs of mothers and fathers; however, mothers reported the need to

receive daily information about their infants and to have siblings visit as more important than fathers (Mundy, 2010). It is interesting to note that in this study, the fathers appeared to be strongly and equally protective of the mother and infant.

While most studies focus on the mother's reactions, some include both parents, and even fewer identify the father's perception. In a qualitative study by Kim et al. (2015), the researchers analyzed use of technology health information seeking between mother and fathers of premature infants. Themes from data analysis included "privacy and misinformation, online social networking, learning technology, and choosing a health provider" (p. 44). The study revealed co-partnering of roles versus Parsons' model of extreme gender roles exhibited by both partners (Kim et al., 2015).

One parent was a NICU nurse, so she had a lot of concerns and worries. She realized that her knowledge probably made it harder, and she also realized that she had to let things go. This was an adjustment she had to make in order to manage. Not all parents related their feelings of not being prepared to what the medical staff did or didn't do, specifically one participant indicated that her feelings of not being ready were because she was a single mom and had twins.

Parents had to learn some of their knowledge on their own. They became resilient and sought out help from others who had been through the same experience. Two participants identified that staff didn't cover specific information before discharge that would have been helpful. For instance, the mother with twins stated that no one helped her in how to manage two babies at ones, so she contacted another mom who had twins. She identified things like how to feed twins, how to travel and transport twins, how to bathe twins. Basic daily baby care became a task to learn.

For some parents going home meant they had to be the expert. Managing all things related to their baby's care and dealing with the urgency of responding to any ongoing and unresolved medical issues. Two participants experienced the need to become medical experts, even stating that they brought the hospital home with them. The multiple roles they had to play, just to keep their baby alive, appeared insurmountable.

Parents were in charge, the primary caregiver and focused on many health issues. They became the one to monitor their baby for any changes or problems that might arise. Their learning and support began in the hospital, but also continued once home. Parents reached out for additional help and resources on their own. They had to act and respond on their own, becoming self-reliant. Parents who felt they didn't get enough in the hospital, continued learning once home. One participant described her motivation and desire to learn everything she could. She related that it was hard, and a big responsibility, and revealed that every mother fails one time or another. Even though she knows the stakes were high, she gave herself permission to make mistakes.

After parents realized that their baby was stabilizing and would survive in the NICU, they began their tasks to learn what they needed to care for their baby, and learned as much as they could. Once home, they were faced with what additional concerns might arise. There were still many unknowns, and parents began looking to assess or stay on top of any issues. Concerns for developmental issues and possible further health problems, left parents with the feeling of waiting for the other shoe to drop. They had to follow through with any unresolved issues or concerns. Parents were concerned about further issues such as cerebral palsy, neurological deficits, growth and development. There were still many unknowns. They become the protectors.

While a stressful period for parents is the transition to home and role as independent caregiver, in a study by van der Pal et al. (2014), parents stated that they felt empowered and strengthened in their role as a parent from individualized support and specialized programs of support. According to Peyrovi et al. (2015), empowerment is a powerful aspect of readiness for discharge. Peyrovi et al.'s quasi-experimental study measured mother's perceived level of discharge readiness after a three stage empowerment training program and found statistical significance between emotional readiness in the control and experimental group. Peyrovi et al.'s study was one of the first studies to examine Smith et al.'s (2009) discharge readiness measurement tool.

These results can be applied to the current analysis of parent's experience when they described how they became empowered to care for their baby. In the current study, empowerment began with the subtheme Caring for me, Quest for knowledge, and Customized learning. The implication for the role that empowerment plays in discharge readiness providing the bridge to home, is fundamental in the overarching theme, Adapting to New Family Roles, Finding Normalcy.

Focus 5. What, if any, types of challenges do families have while caring for their premature infant?

Dealing with the preconceived notion of going to have a normal pregnancy is quickly shattered when a mother gives birth to a premature baby with medical issues. While all participants described this adjustment after the preterm birth, the youngest participant was especially articulate and poignant in expressing the shocked reaction and difficulty processing of having a premature baby. The following subthemes; Having the carpet pulled out from under me, Things I lost, Feel like an outsider, Sink or Swim, Quest for knowledge, Caring for me, caring

for my baby, Customized learning, Getting to know baby, Becoming the expert, Ongoing emotions and Adjusted parent role are interwoven throughout the answer to focus five.

This Emotional Roller Coaster Ride was compounded [inferred] having no control of circumstances and unskilled coping mechanisms, for dealing with the ensuing tidal wave of emotions. The lack of control and emotional reactions has been verified in previous studies. Watson (2010) described changes parents go through with the birth of a premature baby, were not prepared for the complex and challenging issues, and described this as a crisis the parents go through. The level of uncertainty, and powerlessness as parents transitioned to parenthood, placed them at risk for dysfunctional parenting. Interestingly, parents in Watson (2010) study described powerlessness and while some reported the nurses were exceptionally helpful, others mentioned they had to behave in a certain manner, as if they were “invited guests” (p. 1467). This was very similar to participants expressing frustrations with limited access to their baby or the unit, feelings of isolation or intimidation, depending on which nurses were working.

Parents in the current study specified they felt support and information helped prepare them for discharge. Doering et al. (2000) made the comparison between support and lack of control in a correlational descriptive study. Results revealed that limited support and lack of control correlated with increased anxiety, depression, and adjustment. These experiences are compounded by the very rapid adjustments Participants’ must make to assimilate all the contrasting emotions. The authors postulated the connection between support and adjustment to parental role is complex. This is also consistent with Mew et al. (2003) who identified the importance of support, stating that parents who received support, experienced less stress and anxiety. These previous findings are validated in the subtheme of Having the carpet pulled out

from under me and it's supporting code of Emotions running wild; and subtheme, Ongoing emotions.

In a study by Whittingham et al. (2014), parents with a premature infant described their need for individualized support that is tailored to help with coping skills and relationships with spouse. Parents reported unique concerns with grief, stress, inability to transition to parenthood, institutionalization, uncertain of infant outcomes, and over nurturing. Confidence was essential to develop into their parental role, especially to increase self-reliance. Raines and Brustad (2012) denoted that parents indicated confidence while in the hospital, but this decreased once home. Parents made the connection between support, resources, and information to their feeling like a parent and able to complete necessary tasks. In a study by Shieh et al. (2010), researchers revealed that maternal confidence increased with specific structured discharge education. While the study by Shieh et al. (2010) also highlighted there was no difference one month out between experimental and control group, the potential for improved growth and outcomes for their baby. These formerly identified findings are valid, in that each Participant experienced each of these aforementioned phenomena in this current research project.

Participants identified how they were separated from their baby, which interfered with bonding. Often parents felt they couldn't visit, or the nurses did not help make accommodations around care for their baby, which created a barrier to learning their babies' needs. Several participants made the connection between spending time with their baby and helping them to feel like a parent. Research studies highlight difficulties parents experienced in transitioning to their role as a parent while caring for their premature infant (Holditch-Davis et al., 2011), and experience role confusion (Affonso et al., 1992; Rikli, 1996). In Things that I lost, perceived barriers have to be worked through and dealt with as valid. Medical staff must be sensitive, aware

and initiate communications of a supporting nature with parents. Barriers are a prelude of blocking the basic and continuing bonding period. This impacted or then compounded or even delayed some of the Participants' feelings of being a parent.

Impact of hospitalization on maternal depression and infant behavior has been identified in studies; however, Vedovvi et al. (2004) indicated that thorough information and support correlated to decreased stress and improved mother infant bonding. Parents reported experiencing emotional responses such as grief, depression, anxiety, and depression. There was little difference between the level of medical complexity, gestation age, birth weight, and emotional responses.

In addition, studies also indicate the separation while in the hospital affects this transition to parenthood (Bernstein et al., 2007). This is consistent with other studies (Boykova, 2008) highlighting parents express similar concerns related to the health and wellness of their baby when transitioning to home. These studies mentioned above, point out the difficulties parents have in assuming their parental role and transitioning to a new normal at home.

In the current study, participants also revealed the level of mental health issues they were experiencing in the adjustment period while in the NICU, and several that had ongoing concerns after discharge. This was especially true for the couple whose infant has severe ongoing medical issues. They described experiencing depression, anxiety, stress, and PTSD after discharge. Furthermore, despite parents being excited for discharge, many parents report anxiety and stress once home (Rabelo et al., 2007), and a correlation exists between mental health symptoms experienced by mothers and level of prematurity, gestation age, and birth weight. Vigod et al. (2010) completed a systematic review on postpartum depression in mothers with preterm or low birth weight infant. Studies supported that mothers experienced postpartum depression; however,

Vigod et al. also divided research articles into preterm and low birth weight into one group and very preterm or very low birth weight into another group. These findings revealed that while mothers with a preterm baby or low birth weight baby at birth are at risk for postpartum depression, mothers with a very preterm and very low birth weight are at risk for increased ongoing depression, especially during the first year (Vigod et al., 2010). Rogers et al. (2013) highlighted that postpartum depression and poor partner relationships correlated to poor attachment, placing infant development at risk but revealed no differences noted when considering acuity or complexity of infants' health status, even after infant has been stabilized.

Participants described how they were looking forward to going home, being together as a family, developing a normal routine. In a phenomenology study by Murdoch and Franck (2011), parents overwhelming sought to have normalcy, learned to care for their infant at home from trial and error, as their infant's status improved their level of confidence increased. The study results identify the need to have professional support which influences parental abilities and confidence. Confidence was also revealed in the current study and related to increased attachment and bonding. Coppola et al. (2007) identified that mothers who were more secure were able to adjust to the needs of a premature infant, whereas mothers who were more insecure became worse at recognizing their baby's needs.

From field notes and peer feedback, discussion about how parents lost the experience of a normal birth and expected parental role with a full term infant, and now had to adjust to a new normal. Parents realized that they were not having a normal pregnancy and delivery; instead they were faced with having a premature infant. This fits in with the theme of the roller coaster ride and things that were lost, where several parents actually articulated this statement throughout the interviews.

From the parents' perspectives, the nursing staff did not take into consideration the unique situation of each parent. There appeared to be a dichotomy of nurses who were perceived as a barrier and other nurses who were supportive and caring. What is it that makes some parents feel that they have an open door to visit and support, whereas others feel they didn't feel they could visit if certain nurses were working? When considering the core question, are parents prepared and were they trained for discharge and transition to home, this study highlights that all but two parents felt they were ready for discharge.

It became evident through discussion with parents that nursing staff was one of the biggest barriers to discharge readiness. This is consistent with a qualitative study, conducted in Columbia, involving NICU staff and their perceptions of what parents need to prepare for discharge (Raffray et al., 2014). Raffray et al. (2014) also highlighted barriers to preparing parents for discharge that includes obstacles to parental visiting, communication barriers, issues with successful breastfeeding, limited resources, and inconsistencies between hospital and community resources. Factors that facilitated readiness included resources for families, customized training and educational material for parents, and promotion of kangaroo care after discharge (Raffray et al., 2014). Analysis of the study by Raffray et al. (2014) also revealed themes comparable to this study such as helping establish parent-infant bond, need for parents to develop skills, and preparing for the transition from hospital to home.

Families in this study looked for support that addresses their specific needs. Pritchard et al. (2008), use of focus groups to help identify parents' preferences in utilization of resources post discharge. Similarities to this study were revealed. Parent's preferred consistent caregivers and well-informed caregivers, increase in detail and quality information on health and developmental needs for their baby. Especially important was the preference to have providers

who focused support and self-efficacy in parents. Parents reported they felt reassured and this helped increase their confidence (Prichard et al. (2008). Amankwaa et al. (2007) also identified a significant association between social support, self-esteem, and increased maternal infant responsiveness. Professional support was a finding in Boykova's (2015) study on the psychometric properties of the Transition model.

Focus 6. What, if any, specific information related to the infant's unique needs was provided during discharge teaching?

There is little research to identify specific needs of parents prior to discharge from the hospital (Griffin & Abraham, 2006). Furthermore, while there are studies that focus on emotional needs of parents after discharge, few studies mention if there is a risk or need assessment prior to discharge or any follow-up afterwards (Wollenhaupt, 2010). The following subthemes, Having the carpet pulled out from under me, Things I lost, Feel like an outsider, Sink or Swim, Quest for knowledge, Caring for me, caring for my baby, Customized learning, Getting to know baby, Becoming the expert, Ongoing emotions and Adjusted parent role are interwoven throughout the answer to focus six.

Given that more and more parents are taking home babies with unresolved medical conditions and require medical technology, there is an increasing need to train these parents. Tearl and Hertzog (2007) demonstrated that parents benefited from specialized and customized training. In their quasi-experimental study, parents became proficient in necessary skills to care for their baby and had increased confidence and increased satisfaction (Tearl & Hertzog, 2007). There is a relationship between quality of discharge teaching, training, and resources and patient perception of readiness for discharge (Weiss et al., 2008). In addition, Zamanzadeh et al. (2013) stressed the need to direct discharge teaching and training goals focused on preferences of

mothers. Formal training, printed material, and person to person demonstrations were preferred methods of training by mothers (Steeple, 1999).

Parents reported they learned best when nurses provided demonstrations followed by opportunities to practice at the bedside. This gave parents the opportunity to really learn their baby. Research has demonstrated that parents develop necessary skills when discharge teaching begins on admission, with the focus on learning their infant's behavior, and receiving both oral and written information (Smith et al., 2012). Browne and Talmi (2012) noted the importance of family focused interventions that improve parent and infant interactions. Parents learn infant cues through education on infant behavior and support from medical providers, leading to being more responsive, sensitive, and interactive to infant needs.

Focus 7. How do families view the overall outcomes for their child?

The following subthemes, Having the carpet pulled out from under me, Things I lost, Feel like an outsider, Sink or swim, Quest for knowledge, Caring for me, Customized learning, Getting to know baby, Becoming the expert, Ongoing emotions, and Adjusted parental role are interwoven throughout the answer to focus seven. Parents are the cornerstone of a successful, happy, and adjusted family. However, with a medically fragile infant, there are so many unknowns, and the sicker the baby is, the less is known about outcomes. During interviews in this study, parents demonstrated optimistic views of outcomes. If there was a chance, even if minimal, they were committed and going to go for it. Having a premature infant requires adjustment of priorities and responsibilities, forming new roles and relationships, and development of a new family.

There are only a few studies in which the relationship between infant outcomes and social support has been explored. In a longitudinal study, McManus and Poehlmann (2011) revealed a

correlation between depressive symptoms in mothers, meaningful social support, and infant cognition. A study by Burnham et al. (2013) highlighted how healthcare professionals identify discharge as a product, or end result of care, whereas parents see this as the beginning of their independent role, especially those with chronic illness or unresolved medical problems. Effective discharge and post discharge support can have long lasting beneficial effects on childhood health outcomes. Despite a rocky and uncertain beginning in the NICU, participants were overwhelmingly positive and had an optimistic outlook about doing whatever they needed to help their child. One participant even stated she was “in it for life.” The literature highlights the difficulty parents have adjusting to their new role, especially in the beginning (Pridham et al., 2001); however, as Bissell and Long (2003) identified in a qualitative study, parents described a level of optimism and excitement as they looked forward to going home.

Parents were open and appeared honest in describing how difficult being in the NICU had been. Within their descriptions of the experience, they shared the toll caring for such a sick baby had taken on their physical and mental health, though none expressed regrets. It was a relief for parents to finally be at home with their child. While several parents expressed that it was stressful and they experienced grief thinking of all the things that could go wrong, most shared the excitement. Golish and Powell (2003) described this contradiction in the shock and grief from loss of an expected normal birth to expressing joy and happiness with their new family as an ambiguous loss. In Golish and Powell’s qualitative study, the joy and grief contradiction parents experienced was evident. Moreover, parents described the overwhelming emotional response, similar to the blindfolded roller coaster description given in this study. Especially noted in Golish and Powell’s study was the specific point that parents made in regard to how to

prepare them for the experience ahead of time, indicating that no amount of information would be enough; however, specific information did help out (p. 327).

Participants talked about different tasks and responsibilities they were doing to take care of their child. These were described with a sense of pride and ownership. It was notable how one specific mother described each of her baby's issues that she was making sure were attended to by medical specialists. She included a rundown of her baby's scar from the shunt that was inserted, talked about the number of eye exams her baby had received, multiple appointments, how the doctors monitored her baby's weight, emphasizing with pride how much her baby had gained.

Another participant shared with pride how much her baby had already improved with the physical therapy they were performing on their baby and could continue therapy at home, versus having home physical therapy visits. Despite the continual attention to care for their unique needs, parents overwhelming revealed how committed and full of pride they were.

Participant 9, the youngest mother, who is also single, also talked with a sense of pride about her own accomplishments in addition to her son's. It appeared that she was growing right along with her baby. Motivation comes into play when talking about outcomes. She described that all her baby has gone through motivates her to do whatever it takes to take care of him. No matter how much of a challenge, it is a worthy sacrifice. There is a warrior spirit in the participants. As mentioned previously, two participants went through a very traumatic experience, which was still ongoing, and they had to learn how to continually be prepared to save their baby's life. They described it as a bleak beginning, and both were well aware the outcome would be uncertain; however, they would give their baby every chance.

Outlook depended on previous experience. Several parents had lost an infant, and while they expressed trepidation for the possibility of another loss, they all shared an overwhelming

sense of hope from the start. One parent shared that their previous loss helped them to cope and gave a sense of hope, though they knew full well their child would face many challenges. In addition, parents were well informed by medical staff the possible difficulties their baby would have throughout the rest of their life; however, they wanted to give their child all the best opportunities they could.

Parents demonstrated how resilient they had become, gained strength from the experience, and remained committed to learn what they needed. Participants also described how they stayed positive and offered advice for other parents. Several participants gave suggestions to share with other parents “to expect the best,” “be prepared for the worst,” “stay positive,” and “it’s all worth it,” and “a worthy fight.” Parents settled into their new routine, adapting to their family, and remained optimistic but realistic. Another participant described the importance of using one’s intuition because parents know their babies better than anyone else. After what parents went through, being at home was a relief. Their new sense of courage and self-reliance was a sort of defiance, causing them to almost dare life to throw something at them because they could handle it after what they had been through to get home. The worthy sacrifice was well documented by parents throughout several of the interviews.

Consistent with this focus, Phillips-Pula et al.’s (2013) phenomenological study examined the experiences of mothers with a premature infant within 6 months after discharge and found mothers expressed an emotional response but also showed determination and willingness to do whatever it took for their baby. In the current study, being discharged was a sigh of relief for parents, almost as if saying they “finally made it.” Even though they were home, there was still much to do, but “we made it home safe and sound.” Parents were thankful that nothing worse had happened; even for the sickest baby, there was a sense of gratitude that as

bad as it was, nothing worse happened. Their new family was all together, and parents reflected ‘this is who we are now.’”

Data Trustworthiness

Trustworthiness is the degree of confidence in data and findings (Lincoln & Guba, 1985). The quality and trustworthiness in qualitative research depends on the researcher providing detailed description and progression of thought process through data collection and data analysis. Multiple sources of data ensured that the researcher captured a thorough and detailed level of understanding from the participants’ experience. This study employed an interpretive phenomenological approach to ensure the meaning, interpretation, and experiences of participants were captured fully. An important aspect of phenomenological research is the ability to develop understanding through participant’s personal view, an emic view, in addition to the etic view, or the perspective of the researcher. Interpretation allows a researcher to reach deeper into a participant’s story, show the meaning and understanding of the phenomenon, and discover a new way of looking at an event or experience (Miles & Huberman, 1994). In the process of interpretation, the researcher of this study used continuous review of transcripts and application of an audit trail and field notes to promote trustworthiness in making clear the meanings and patterns of discharge readiness. Bengtsson (2016) denoted the hermeneutic approach helps to narrow in on trustworthiness; "however, each stage must be performed several times to maintain the quality and trustworthiness of the analysis" (p. 11). In order to address quality and trustworthiness in qualitative studies, Lincoln and Guba (1985) suggested researchers apply techniques of credibility, dependability, confirmability, and transferability.

Credibility

Credibility relates to ensuring accuracy of data and plausibility of the results in a research study. Charmez (2011) suggested methodological strategies to ensure credibility in qualitative research include triangulation, prolonged engagement in the field, and member checking. The researcher established credibility through use of triangulation , prolonged engagement in the field, and member checking.

Triangulation. Triangulation in qualitative research provides the ability to develop in-depth understanding of specific phenomena through multiple modalities (Creswell, 2014). Data triangulation occurred by using a combination of multiple data sources such as transcripts, field notes, and reflective journal recording researcher observations after each interview (Denzin, 2009). Creswell (2014) and Teddlie and Tashakkori (2014) discussed application of triangulation through combining research methods or mixed methods; however, this was not the intent for the current research study, which employed use of multiple data sources to gain deeper insight into the complex phenomenon of discharge readiness. Teddlie and Tashakkori denoted the need to use convergence of data sources along with perspectives of participants. The use of triangulation in this research study included comparing multiple sources of data such as transcripts, reflective journal, field notes, literature review, and feedback from experts and peers.

Reflective journals support trustworthiness and authenticity in qualitative research (Diekelmann, Allen, & Tanner, 1989). The researcher completed a reflective journal after each interview by writing down personal observations of participants, context of interview, researcher-participant interactions, additional comments around participant descriptions, and suggested themes or patterns. While analyzing transcripts, the researcher integrated descriptions in the reflective journal to help develop categories, codes, and themes.

Peer review and feedback was obtained from three different sources to confirm findings. One individual is currently working in a NICU setting and directly involved in preparing parents for discharge; the other is an expert in transition for parents with a premature infant, and the third individual is a health care manager who works with discharge process in hospitals. Feedback was given and gathered to assist in verifying codes and theme development. The process included several back and forth communications and revisions to fully capture participants' experience of discharge readiness.

Prolonged engagement. Prolonged engagement in the field ensures data saturation is accomplished. Data saturation occurs when no new categories are being discovered, and the researcher begins to identify recurring themes (Charmez, 2014). There are two types of saturation, data and theoretical; however, the researcher must decide which one they are using and meet the criteria for each (Morse, 2005). Saturation is also supported by a sample that consists of participants who have knowledge of and represent the specific research topic (Morse et al., 2002). The researcher used data saturation throughout the study by analyzing transcripts, field notes, reflective journal, and peer feedback. The researcher also set out to recruit participants who experienced discharge teaching from a NICU and were caring for their premature infant at home. A total of 10 participants were recruited in the study who had specific experience related to the exploratory nature of this study Recruitment and interviewing continued until the researcher noticed data saturation was reached in that there was enough information to replicate the study and when further coding was not feasible.

There is discrepancy and vague representation in the concept of saturation and a lack of standardization of process or rules in achieving saturation (Bowen, 2008). Francis et al. (2010) conducted a systematic review of research articles between 2006 and 2007, reporting that

researchers used consistency in the definition of saturation, in which “data saturation meant that no new themes, findings, concepts or problems were evident in the data” (p. 1230); however, their findings also revealed little description in how saturation was reached. Bowen (2008) recommended that a researcher use consistency in implementing and describing saturation throughout a study, ensuring efficiency in data collection and thorough data analysis. Use of Creswell’s (2014) six-step hierarchy was used to analyze data. This consisted of a thorough process of organizing, reading, and interpretation of raw data into theme development. As themes were developed, they were confirmed from peer feedback and member checking. Consistency was maintained through record keeping, in order to track theme development.

Interviews were scheduled to allow adequate time to build trust between participants and the researcher. The researcher maintained an open format throughout the interviews so participants could share their experience in detail. As soon as each interview was completed, the researcher began the process of data analysis and coding and categorizing transcripts. This allowed for themes to emerge and expand with each upcoming interview. Data analysis also consisted of including notes from the reflective journal and peer feedback during the process. As common and recurring themes, subthemes, and codes were occurring, the researcher noted this in order to determine saturation. The researcher identified saturation as an ongoing and fluid process in which coding occurred concurrent with interviewing until no new themes were being revealed from the data. This was a fluid process: The entire process was constantly shifting, expanding, and ultimately adding depth to the richness of the data being correlated into themes, subthemes and codes. Furthermore, the researcher applied a systematic search for any disconfirming cases during the study. There were no cases that revealed new data or unique or disconfirming cases.

Member checking. The researcher used member checking, by having participants review transcripts, verify accuracy, and be given the opportunity to add any additional information. While member checking is an established method to ensure credibility (Creswell, 2014), some discrepancy exists among researchers regarding methods of implementation, and different opinions about whether researchers' intention to ensure credibility outweighs concern for participants (Hallett, 2012). Two participants responded and confirmed accuracy of their responses and did not wish to add any additional information to their transcript.

Dependability

Dependability is the stability of data over time through quality assessment procedures and external audits (Lincoln & Guba, 1985). Strategies to establish dependability include enabling an external auditor or peer reviewer and instituting and maintaining an audit trail. Careful record keeping and tracking throughout the research process also helps to establish and guarantee transparency in qualitative research (Creswell, 2014).

Records were kept between transcripts, category and code development, written field notes and reflective journal, and participant and peer feedback. Tables were developed to align field notes and reflective writings with each transcript. Codes and themes were developed using Creswell's (2014) hierarchy of data analysis, and the tables reflected the ongoing analysis of theme development.

Confirmability

Confirmability and dependability are related in use of methods to ensure trustworthiness of qualitative data. Maintaining an audit trail, a written record of all research activities, confirms findings in qualitative research (Carcary, 2009). As previously mentioned, the researcher developed tables to reflect each participants' statements from the interviews, which were

paralleled with categories, codes, and developed themes. Coding was also checked several times for accuracy. In addition, field notes and reflective journal notes were incorporated into each transcript table and further verified by peer reviewers.

Transferability

Transferability in qualitative research is the ability to apply findings in another similar setting. While this is a challenge in qualitative studies, Lincoln and Guba (1985) recommend findings can be applied or transferred to another similar setting or community through persistent observation and engagement in qualitative research studies. Ensuring prolonged engagement in the field assists in yielding rich thick description of the participants experience and setting. Interviews were conducted in the field by the researcher who spent adequate time at the beginning of the interview for participants and researcher to get to know one another. This allowed for trust building and provided an easy transition into narrative inquiry, conduct persistent observations, and the ability to obtain rich detailed description of participant's experience.

Interviews took anywhere from 45 to 100 minutes and were audio recorded. The audio recordings were transcribed into text for data analysis. The researcher listened to the audio recordings several times in order to capture the full meaning, voice inflection, and audible expressions of participants. The researcher also read the transcripts multiple times throughout the analysis period. Field notes were taken during the interview and notes in a reflective journal after each interview were completed. These notes, along with transcripts, were also included in the data analysis, thereby adding to triangulation methods. In addition, peer feedback helped to confirm and verify results of theme development.

Limitations

Qualitative research is based on the unique context and individuals sharing their story about their experience. In qualitative research, application of in depth interviews that reveals rich data and exploring lived experience of the participants is of primary importance. Participants in this study were all Caucasians. Inclusion of a group with ethnic and diverse cultural backgrounds could have helped exploring a broader parental experience.

Recruitment into the study was a challenge for the researcher. The NICU Follow up clinic was only held one day a week, and there were only on average between two to eight scheduled appointments for that day; however, often only half met the inclusion requirement. While recruitment occurred at the clinic, there was not adequate time to conduct the interviews that day, so interviews were scheduled for a later date in the participants' home. Since the study included families with a medically fragile infant, often between recruitment and the scheduled appointment, parents would cancel or ask to reschedule due to their infant becoming ill. In addition, parents were reluctant to commit, especially given their childcare tasks took priority. These factors limited the ability to recruit more parents into the study. There were originally 18 parents scheduled to be interviewed; however, only 10 kept their appointments. While scheduling appointments was a challenge, the researcher also had to travel long distances to other cities to reach participant's home to conduct the interviews.

Implications

Theoretical Implications

Parents went through different stages to prepare for discharge and take care of their baby once home. This adaptation fits definitions of transition and adaptation. In a study by Hutchinson et al. (2012) on parents' experience from NICU to home, findings show the transition parents

make after the unexpected birth of their baby as a process ending with them feeling like a parent. Parents went through four phases, first experiencing fear and uncertainty, to experiencing guilt and feeling emptiness, then gaining confidence though dealing with inconsistencies, and finally experiencing joy and happiness as they went home.

Comparisons from the study by Hutchinson et al. (2012) have many similarities to the experiences of parents in this study; however, the focus was not on discharge readiness. This highlights the complexities of what parents experience transitioning to home and the connection to discharge readiness. Various theories of transition have elements that align with what parents have gone through; however, this study focuses on discharge readiness. Aspects that make up what parents needed were all around support for parents to handle the emotional upheavals that are present as they respond to the unexpected birth, assistance to help parents identify their role and bond with their baby, customized resources and information, and connection with outpatient resources once discharged. Support was one of the primary focuses for participants in this study.

Findings are consistent with previous early studies by Kenner (1988) on a conceptual transition model for parents with a premature baby. Concepts within Kenner's original studies on Transition Theory include the following: information needs, stress and coping, parent and child role development, social interaction, and grief. A Transition measurement tool had been developed and concept testing occurred over the years (Flandermeyer et al., 1992; Kenner & Lott, 1990; McKim et al., 1995). Further development and psychometric testing of the Transition tool was done by Boycova (2015) and expanded the concepts by adding professional support to the original tool. While the current study highlights consistent aspects and concepts of the transition model and tool, the relationship between transition and discharge readiness has not been identified previously.

Theory development on the phenomenon of discharge preparedness within the transition process can add to previous studies on transition and adaptation. How individuals adjust to a traumatic situation is well studied, but for parents with a new baby it is especially critical to understand what they are going through in order to best meet their needs. Parents become the primary caregivers for their new baby, dealing with unknown medical challenges, possibly for life. Their role is unique in their ability to love and nurture their baby, while they are also primarily in charge of their babies' primary health and wellness.

Theory development and study on parent-nursing partnerships would also be helpful. Given that premature infants are often in the NICU for weeks to months, nurses and parents work closely together. This parent nursing relationship requires collaboration and trust. This is the foundation of family centered care, and studies reveal parents feel more comfortable, experience less stress, feel empowered, and experience ease of transition to their role as parents (Van Riper, 2001). This study highlighted the importance in parent and medical staff partnerships and the long lasting influence on parents' wellbeing, while also making parents a crucial part of the health care team.

Implications for Future Research

Further studies are needed to generate new knowledge about discharge preparedness and readiness in NICU parents, help make improvements in quality of care to meet the specific needs of parents, and ensure they are equipped to provide optimal care at home. Recommendations include conducting studies that focus on families living in Appalachia, thus help to shed light on unique needs and how to overcome barriers for families living in rural communities. Studies that identify parents' needs after discharge are also recommended to help focus on areas where follow up education and support are needed. Further studies are also needed to identify

interventions and specific types of support to help parents cope after discharge. Studies that shed light to explain why some families cope better than others following a traumatic event can help providers to support parents to cope and facilitate the transition to home.

Research studies that focus on process analysis could help identify where detailed needs of families and patients get dropped out, similar to research identifying where medication orders and administration errors typically occur. While these unique needs are not as lifesaving and high risk, there might be potential issues from delayed bonding and lack of sufficient training that results in harm or longtime mental health concerns. In addition, research studies that look at the connection between transition, discharge readiness, and mental health are needed, as are more studies on implementation of a discharge nurse and measurement of parent readiness. Studies on nurse and patient satisfaction with implementation of a discharge nurse would also increase knowledge on the effectiveness of discharge readiness.

There is a paucity of research conducted on non-English or limited English speaking individuals, particularly related to discharge readiness for families with a premature infant. Given that there was a large Hispanic population in the local area where the researcher resides, attempts were made to conduct research with this population. Several organizations were contacted; however, it was not possible to conduct research in those settings. The researcher highly recommends that research be conducted in this population in order to gain insight and understanding for how to meet unique cultural needs.

Implications for Practice

Multiple factors go into preparedness for discharge. Features from this study indicate that parents need meaningful support in order to transition into their role as a parent, meet the needs of their baby, and find a new normal. The bridge to their success involves adequate time to bond

with their baby, customized information to learn specific skills to care for their baby, support to become empowered and self-reliant, and adequate time to integrate their knowledge and understanding as they adjust to their new family.

Parents made the connection between being prepared for discharge and confidence by having adequate time to get to know their baby and bond, learning the unique needs for their baby, receiving information in writing about specific resources and follow up appointments, and specifically receiving a discharge summary given to them at discharge. Parents also indicated that they felt prepared when nurses provided a supportive presence at the bedside and talked them through step by step on how to care for their baby. As elucidated throughout this study, for the most part, parents felt prepared for discharge. While previous studies highlighted the gaps in preparing parents for discharge, this study is consistent with current literature, indicating that most parents perceive they do receive adequate support and training; however, there are still areas which need improvement.

Light was shed into possible barriers to achieving their role as parents such as not being able to visit, lack of or inconsistent communication, lack of support, lack of necessary knowledge and skills, and personal physical limitations. Decreased support and perceptions of little to no control correlates with increased anxiety, depression, and adjustment (Dusing et al., 2012). While Dusing et al. (2012) revealed small variations in measured variables, the authors postulated the connection between support and adjustment to parental role as complex. Overcoming these barriers and obstacles to readiness for discharge required the above-mentioned support and adequate information, leading to the bridge to adapt to parental roles and develop a new normal for their family.

The medical field has become very technologically oriented; however, the subtle interactions between medical staff and patients still have a long way to go. The compassionate care aspect of providing patient care is a weak link in the skill level of some medical staff. Asking parents “what would you like, what do you need, what would make you more comfortable, what is your plan?” gives parents an active voice in care plans. Intake information often captures essential demographic information; however, it is not always assimilated into the daily shift changes between staff. Lack of consistent caregivers because of staffing concerns and increasingly busy assignments potentially compromise development of parent-nursing relationships.

Preparedness was associated with parent’s level of confidence in their pediatrician, infant’s level of overall health, and preparations at home. Further information included that parents who reported being prepared also reported that they received adequate instructions and written information on infant care and illness recognition and had sufficient time at the bedside (Smith et al., 2012). Moreover, parents also reported what would help facilitate discharge such as having a nurse that is familiar with the baby and family, receiving consistent information and updates especially on discharge, and explaining the discharge process clearly.

It is well documented in the literature that parents want specialized unique information, based on their situation, as no two situations are alike; however, it is hard to standardize this type of teaching. Developing a plan for discharge and identifying specific goals would help discharge be more organized and allow sufficient time to learn to meet these goals. Hager (2010) described findings in a quasi-experimental study examining readiness for discharge. Hager reported statistical significance in the intervention group who identified goals and barriers to discharge early after admission correlated to increased feelings of preparedness for discharge.

Discharge planning should begin on admission by making the parents a part of the health care team and hospital culture from isolation to inclusion. Nurses and parents need to be held accountable for discharge process on a daily basis. Parents need to be actively involved in teaching and take responsibility for learning. A study conducted by Mills et al. (2006) on discharge readiness demonstrated improvement in discharge process and an increase in parent and staff satisfaction. Preplanning helped to establish transition points to help keep all medical team members consistent and on task. Transition points, both written and verbal communication, were seen to facilitate an effective discharge (Mills et al., 2006). Clear documentation of discharge plan, clarity of staff roles, discharge planning education kit developed for staff, all combined with staff and parent satisfaction (Mills et al., 2006).

While parents might be trained to take care of equipment, nurses need to assess how well they really know their baby. In a study by Smith et al. (2009) with family and nurse dyads, the researchers measured emotional and technical discharge readiness. It is not uncommon for the discharge nurse charged with primary discharge instructions to not be as familiar with the family or patient. This current study does demonstrate that overall parents were prepared for discharge and that nurses reported families as being unprepared more often if they were unfamiliar with the family. In addition, families measured their level of preparedness higher than the nurses, and preparedness was more associated with infant characteristics not maternal or discharge nurse (Smith et al., 2009).

Nurses are in a position to help support parents and identify their current needs, while monitoring their progress toward readiness. Nurses are the gatekeepers to parents being able to visit, learn care, and bond with their baby. Nurses could focus on specific needs for parents on a regular basis, offer support groups while in the hospital, but also connect with community

support groups for parents of premature infants. Daily dialogue and updates on a baby's status could include a brief query on parents' needs, asking three simple questions, "how do you feel today?", "what do you need?", and "what are your goals for today?"

Medical staff, information, resources, and support are all essential to help parents make the adaptation to new family roles and bridge to home. Education for medical staff might include information on the unique needs for the family. There is a need to develop training for nurses on how to assess and identify unique characteristics of parenting and adequate bonding for mother and fathers with a premature baby. In addition, additional training in how to offer mental health support for mothers and fathers may be beneficial.

Some of the questions to ask include if are parents and infants bonding well and assessing whether parents are able to read subtle signs a baby gives off. Priority levels such as acuity levels could be given to parents. For instance, if a parent is young, single, or a first time parent, the parent may require more support. Parents who talked about not feeling prepared felt left out of the care, were intimidated, felt staff did not listen to their concerns, and felt pushed out early, which can be addressed by ensuring that nurses are checking in with parents, being patient with parents while they learn new skills, and helping build confidence by identifying barriers to bonding.

Medical staff need to realize that parents with previous medical experience might technically know what to do, but their experience and knowledge may also cause increased stress because they are aware of all the things that could go wrong. Being educated in the field of nursing does not necessarily guarantee that parents will not experience anxiety or have concerns about taking care of their infant. As described by one participant, it can raise one's anxiety because one is more aware of the dangers. While few studies address medical professional's

responses to parenting a premature infant, Bissel et al. (2003) identified that previous experience can impact how parents approach and respond to a premature birth. Parents with an older child, especially if they were born prematurely, had more confidence in their ability to cope and handle taking care of their baby once home.

The anxiety and stress parents experience can have long term effects and negatively impact their parental role performance and lead to child neglect (Auslander et al., 2003). Auslander et al. (2003), in examining stress levels and anxiety after the unexpected birth of a premature baby, found mothers' and fathers' stress levels to be the same; however, their concerns were not correlated. Mothers were more concerned with developmental issues, whereas fathers were more concerned with difficulty in caring for their child and showed increased anxiety when their child was male. This demonstrates that parents approach their situation very different. Thomas et al. (2009) conducted a study involving fathers with a VLBW infant and revealed fathers feel helpless and powerless when faced with uncertainty. Highlighted in the findings, involved fathers felt more confident with role models, hands on experience, positive reinforcement, personal beliefs and overall health status of their baby (Thomas et al., 2009).

In a study of mother-infant dyads, comparing premature birth, full term birth, and PTSD in mothers, Forcada-Guex et al. (2006) determined that premature birth affects mother-infant interactions and maternal attachment. Premature babies whose mothers have PTSD are more at risk of receiving controlling and distorted parenting interactions (Forcada-Guex et al., 2006). Veddovi et al. (2004) identified the impact of hospitalization on maternal depression and infant behavior. An increase in detailed information and support correlated to decreased stress and improved mother-infant bonding (Veddovi et al., 2004).

In addition, mothers and fathers approach and respond to stressful situations differently so no one uniform technique will work; therefore, medical professionals should identify the unique needs of mothers and fathers. Medical staff need to focus on listening to the concerns of parents and avoid making assumptions about parenting skills just because a parent is a medical professional. In some cases, being prepared might not reflect anything the hospital did or did not do: Life circumstances might make one feel unprepared. The mother with twins felt very unprepared to care for her babies once home. Possibly being aware of all that could happen makes one feel unprepared and more anxious. Therefore, extensive education and skill training for parents prior to discharge is essential.

Nurses provide shelter to parents while caring for their infant and can also help them transition to home through being fully prepared. Nurses can support parents by checking in with them and seeing how they are doing. While the birth of a baby is essentially the beginning of a family, having a premature infant can be a difficult journey. Boykova (2015) tested the transition model and added an essential element, that parents need professional support, to the previous categories. Parents need support to care for their family, but they also need specific support for their emotional needs.

Research is needed that examines the needs for parents of diverse race and ethnicities, especially for parents whose primary language is other than English. While studies across the globe have revealed similar results in the needs of parents preparing for discharge (McKim et al., 1995), few studies explore situations in which parents had infants with high technology needs and did not speak the native language. It is difficult to determine and measure level of preparedness when someone is not fluent in the local language. Communication and training is further complicated by the very complex nature of an infant's diagnosis and needs.

Recommendations for health care staff include providing opportunities to learn about parenting a premature infant with medical needs. Since each infant's needs and parent's knowledge and coping skills are different, each situation should be handled in a unique manner, with customized teaching and resources. Interventional mapping can facilitate discharge and prepare parents with a premature baby, for transition to home. In a systematic review, Brett, Staniszewska, Newburn, Jones and Taylor (2011) identified interventions that support parents in the day to day care for their baby and how to prepare them for home and recommend that health care administrators use such methods to map out interventions that best support parents.

This research study revealed that nursing staff actions and decisions were one of the barriers to parent and baby bonding, by preventing parents from holding their baby, limiting parents' ability to care for their baby, and not coordinating care with parents. Research shows the need for close contact (Johnson, 2005), especially kangaroo care; however, several participants identified that they were not allowed to do kangaroo care.

Challenges and difficulties help build character in individuals, and further motivate them to take ownership of the task that is set before them. However, this is not a reason for medical staff to not step forward and do a better job in providing for the unique needs of parents. The art of listening and the art of interacting are critically important for medical professionals. Training as a diagnostician is equally important as learning to communicate that information to the parents, family, and patients. Specialized training for nurses and medical professionals in communication, specifically in listening to parents' concerns and determining if they really understand what is being taught, is recommended. Because communication plays a major role in medical practice, there should be training and possibly course and certification in communications.

Hands on care can be facilitated by use of simulation for parents. Offering simulation practice for parents that require extensive training would be beneficial in setting up unique scenarios for parents and give them the repeated practice in a safe environment. Those participants who had babies discharged on medical equipment described how they were glad to have practice runs and learned to manage different scenarios, for all eventualities. Participants in the study stated that they preferred a variety of training and information to feel prepared. Subthemes which support the need for unique and specialized training for parents included Begging for more, Caring for me, caring for my baby, Quest for knowledge, Getting to know baby, and Becoming the expert. This is consistent with current research, where Steeples (1999) also highlighted that parents wanted nursing staff, doctors, and specialists to demonstrate skills in person.

Research reveals that parents receive support in the hospital, but often it is lacking after discharge and that few community providers are prepared to meet the needs of medically fragile premature infants (Boykova, 2008). Browne and Talmi (2012) assessed a specialized training program, titled Babies, that helps community professionals appropriately evaluate developmental needs of premature babies and offer support to parents. Results showed that providers felt more confident in assessment and identifying developmental needs for infants, while also developing a collaborative relationship with parents (Browne & Talmi, 2012).

Parents report wanting more information on their infant's condition but often do not remember receiving discharge instructions or information, thus Flandermeyer et al. (1992) recommended follow up contact with families after discharge. This is also consistent with Sheikh et al. (1993) in which results revealed nursing staff and parents agreed on the level of importance in topics of discharge teaching but differed significantly on whether the topic was covered or not,

resulting in parents limited assimilation of material and nursing staff overestimating parents' understanding of discharge teaching.

This study focused on individuals who live in Appalachia, some in small urban areas and other in remote rural locations. Those living in the more remote areas discussed the difficulty finding providers who were skilled in taking care of their infants' needs, especially the family with the most medically complex infant. Furthermore, disparities also exist for mental health providers, especially in Appalachia regions. According to the Appalachian Regional Commission (2017a), mental health providers in Appalachia are 35 percent lower than the national average, with variations in regions as low as 50 percent. Moreover, Hendryx (2008) noted 70 percent of rural Appalachia had significant shortages as compared to 57 percent of non-Appalachian rural areas in the United States. Given that the finding in this study highlight the need for support and the impact of having a premature infant can have on mental health, there needs to be systems in place to assess and provide resources for parents. One area that might benefit families living in remote areas is telemedicine. While not all infant's needs would be met, having access to nurse consultants and specialized providers could decrease potential complications. Marcin et al. (2004) described the benefits of having telemedicine options to help reduce the inequities for those living in rural locations. Two participants described this type of service available to them, whereby a nurse consultant would stay in touch with parents and help identify any specific needs they may have. Health care facilities could include outreach training for community providers in how to help parents and what their needs are. Community health providers who are seeing parents, need a system for further assessment of parents.

Implications for Policy

The primary purpose of policy makers is to improve lifestyle and increase overall health and wellbeing for individuals across the nation. Policyholders are in a position to set up legislation for outreach resources and support. Ongoing funding for outpatient community health resources and adding case managers for state and federal programs that are focused on helping parents with a premature infant could provide additional support for this population.

Given that medically fragile children are living in the community setting, policy makers should provide financial and educational opportunities to support parents who live in rural areas, for example by provision of telehealth. Developing a free service where parents sign up with emergency responders that identifies location and lists specific medical equipment and needs for their child may improve outcomes during critical events, especially for those occurring in rural areas. In addition, programs such as Babies facilitate provider skills in assessing developmental concerns of premature babies, while also supporting parents (Browne & Talmi, 2012).

Another aspect of health improvement through policy makers would be to suggest more funding for home health nursing in rural areas. One specific concern outlined in this study was the challenges getting adequate home health providers and child care workers as a result of rural location. In addition, state legislation should be consistent with the level of care needed and insurance approval for care. While this is not just a policy issue, health insurance companies are regulated by the state in which they provide care. Funding and legislative support for insurance coverage that adequately meets the needs of medically fragile infants is needed especially in light of Congress' failure to renew CHIP-Children's Health Insurance Program. Given the multiple disciplines that provide care for premature babies, legislation to support interprofessional collaboration and interdisciplinary support for parents would be beneficial.

Summary

Further discussion and dialogue with each participant after the initial question provided additional rich narratives and description that captured parents' experience of this phenomenon. It is difficult to talk about discharge readiness and transition to home without also including the experience of being in the NICU and the impact this had on parent's perceptions, adaptations, and adjustment to becoming a family. This study focused on the experience of parent's feeling prepared to care for their infant once home; however, findings revealed that previous experience and expectations had an impact on parent's ability to move through this transition and adapt to new identity as parents with a premature infant.

Parents with a term infant make a transition and adapt as they integrate a new family member; however, the added stress and unknowns of having a premature infant with complex health needs may delay this process. Discharge readiness occurs when parents have access and consistent communication, develop trust and familiarity, and feel supported. Parents also go through a process where they are making the adjustment to their new normal and becoming resilient in the ability to care for their baby.

Analysis above included extrapolating meaning from parents' words; however, further assessment of body language and listening to tone inflection on audio tapes provided additional insight, as described below. Parents who were interviewed while their baby was in the room clearly focused more on their baby than the interview. When describing some of the more difficult experiences of uncertainty, fear, and anxiety, parents appeared to give more attention to their baby, with kisses, hugs, and extra glances. Also, some parents expressed the more emotional side of having a premature baby with medical complications, tearing up, quivering voices, and exhibiting facial expressions of sadness. It further demonstrated the paradox of the

joy of having a new baby and dealing with serious medical, often life-threatening, conditions. The parents found themselves in a state of having to make life-threatening decisions, weighing the amount of suffering their baby will experience, versus giving them the best chance for survival. It is a struggle of the heart and clearly a roller coaster ride with little knowledge of what is around the corner.

Parents of medically fragile infants are balancing dealing with unexpected events and shattered dreams and trying to process what their new family will look like. The goal is to establish a new normal and family routine by adjusting to the unique needs of their baby. Integration of specialized knowledge and overcoming challenges and barriers to create their family rhythm are required. Being prepared for discharge and independent care of their baby is a process that might take several weeks to many months. Parents shared that they felt more like a parent when they were kept updated, informed of their baby's status, and had regular access to their baby.

The overall goal for this study was to add to the existing knowledge, while shedding light on discharge readiness, and fill gaps in the literature. Discharge readiness is tied to the need for parents to adjust to their parental role and find normalcy. In order to establish a new normal, parents navigated through rocky waters and unexpected depths, then found their bearings, discovered their strength and motivation to learn what it takes to reach safe port, and put down an anchor.

Need for further research in areas such as families who do not speak English. Areas of Appalachia have large communities of Hispanic migrant workers. This is especially crucial since the language barrier creates challenges in navigating the health care system, accessing resources

and information, and learning how to care for the complex needs of their baby. However, people living in rural areas do not necessarily have difficulty gaining access to medical care.

Researcher's Reflections

The data collection process was lengthy and required a large investment of time and energy. These included meeting participants at the NICU Follow Up clinic, taking time for introductions and providing information on the study, scheduling interviews, and traveling to individual homes throughout Appalachia. Additionally, the researcher entered into the participants' homes (except for one participant), their personal safe places or environments, with their babies. This process ensured that the participants felt comfortable speaking candidly of their experiences.

The researcher spent extensive time at the beginning of the interview to establish trust and common ground and getting to know each participant by requesting that the participants "tell me a little bit about yourself" and asking them about their baby's story. This set the groundwork and stage to ask the specific research questions if they were not already answered within the telling of their stories.

Another aspect that needs to be mentioned is how the researcher unconsciously (but now with hindsight) provided the participants with a therapeutic environment and maintained a demeanor of objectivity and role as unprejudiced observer. As participants told their story, the researcher observed an emotional response of letting go. Additionally, during several interviews there were instances where strong emotions were evoked and communicated as the participants relived their experiences in the telling.

These emotions were not only raw, but ranged the entire gamut of fear, anguish, guilt, the choices between life or death for their babies, and the joys of the whole process that they lived

through. The researcher found in many instances to be in the position as a listening therapist, which included calming individuals, reaffirming their experience as life changing, and validating their voiced thoughts and perceptions. All of this was not explicitly stated but inferred from the process structure of the conducted interviews.

The researcher was also overcome with how much parents were willing to share their stories, being open and honest with such tender and prideful moments, and revealing how resilient they were. The researcher has a professional nursing and NICU background, working closely for many years in the NICU, especially with parents being discharged. During these interviews, the researcher was filled with feelings of deep compassion for the parents themselves, as the researcher experienced this study from more of the parents' perspective, and helped to close the circle on how parents handle discharge and are coping once home.

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APPENDICES

Appendix A

Research Flyer

Nursing Research:

The purpose of this study is learn about your experiences caring for your infant at home, discover if your family felt prepared for discharge from the NICU, and if you had the resources to care for your infant while at home.

- **Are you a parent with a preemie born in the past two months?**
- **Would you like to share your experience caring for your infant?**

How: If you choose to participate, I will have a one-on-one interview with you to help me gain an understanding of your experience being discharge from the NICU and any issues or challenges you might have experienced. The interviews will take approximately one hour and will either be conducted in the clinic, on the phone, or in your home.

Eligibility: Families who have had an infant discharged from the NICU within the past two months.

Who Will Interview You: Kathy Zimmerman, a doctorate student from East Tennessee State University.

Feel free to contact Kathy with any questions about this research study:

- zimmermank@goldmail.etsu.edu
- 615.513.1770

Appendix B

Demographic Form

Questions to be obtained from the parents:

1. What is your gender? (circle one) Female _____ Male _____
2. What is your age? _____
3. What is your ethnicity? African American_____, Caucasian_____, American Indian or Alaskan Native_____, Native Hawaiian or Other Pacific Islander, Hispanic _____, Asian_____, Other_____
4. What is your marital status? (circle one) Single, Married, Divorced
5. What is the number of individuals living in your household? _____
6. What is your highest level of education, select from one of the categories below.
Below 8th grade_____, 8-12th grade_____, less than 1 year college_____, 1-4 years of college_____, college degree_____
7. What is your income? (select one below)
 - a. 10,000 – 20,000 _____
 - b. 21,000 – 30,000 _____
 - c. 31,000 – 40,000 _____
 - d. 41,000 - 50,000 _____
 - e. 50,000 and above _____
8. What state do you live in? _____
9. What county do you live in? _____
10. What type of location do you live in? Urban_____, Rural_____
11. How far away do you live from the JCCHC NICU follow up clinic?
1 – 10 miles_____, 11 – 25 miles_____, 26 – 50 miles_____, 51 – 100 miles_____, greater than 100 miles
12. How often do you take your infant to the pediatrician? _____
13. How far away is your pediatrician in miles? _____
14. How many times have you had to take your infant to the emergency room? _____
15. How far away is the nearest emergency room in miles? _____
16. Do you give your infant any medications?
Yes_____No_____
17. Number of daily Medications_____
18. How far is the pharmacy in miles? _____

Questions regarding medical information:

1. Infant gestational age at birth_____
2. Birth weight_____
3. Was your infant a; Singleton_____,Twin_____, Triplet_____, Quadruplet_____
4. Discharge weight_____
5. Infant gender_____
6. Length of stay (days)_____
7. Do you have other children? Yes____No____
8. How many children?_____
9. Have you had a preemie before? Yes____ No____
10. Was your infant readmitted to the hospital within 30 days of discharge? Yes_____ No_____
11. Medical Diagnosis of your infant:_____
12. Medically complex (includes any of the following)

- | | | |
|---------------------|----------|---------|
| a. G tube | Yes_____ | No_____ |
| b. Central line | Yes_____ | No_____ |
| c. VP shunt | Yes_____ | No_____ |
| d. Tracheostomy | Yes_____ | No_____ |
| e. Ostomy | Yes_____ | No_____ |
| f. Oxygen | Yes_____ | No_____ |
| g. Apnea monitor | Yes_____ | No_____ |
| h. Home medications | Yes_____ | No_____ |
| i. Home monitor | Yes_____ | No_____ |
| j. Suction | Yes_____ | No_____ |
| k. Ventilator | Yes_____ | No_____ |

Appendix C

Kenner Model of Transition

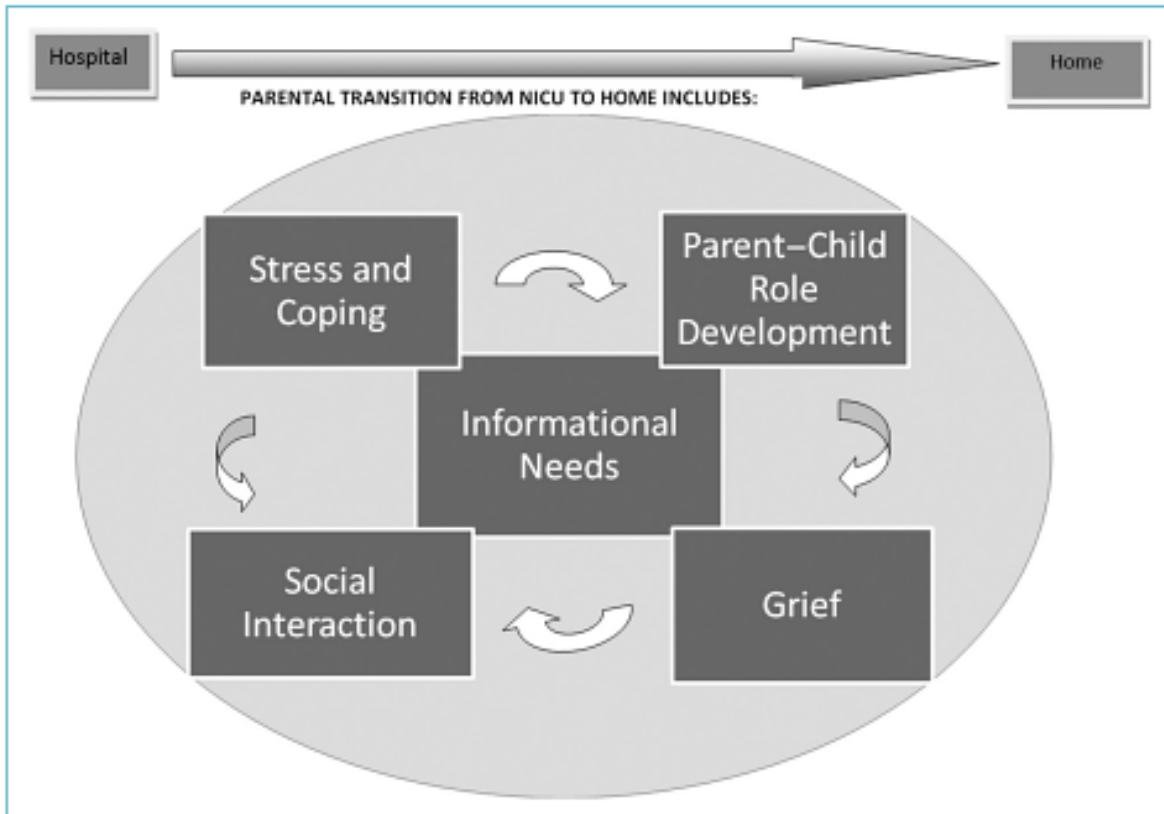
Comprehensive Neonatal Nursing Care, Fifth Edition

Carole Kenner, PhD, RNC-NIC, NNP, FAAN and Judy Wright Lott, DSN, NNP-BC, FAAN

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(see Appendix E)



Appendix D

Demographics of Interview Participants (N = 10)

Participant Characteristics	Number (<i>n</i>)	Percent (%)	
Age range (18 – 40)	18 - 20	1	10%
	21 - 25	1	10%
	26 - 30	7	70%
	> 30	1	10%
Educational background	High School	1	10%
	College	9	90%
Ethnicity	Caucasian	10	100%
Gender	Male	3	30%
	Female	7	70%
Marital Status	Married	8	80%
	Single, never married	2	20%
Income	\$10,000 - \$20,000	3	30%
	\$21,000 - \$30,000	2	20%
	\$40,000 - \$50,000	1	10%
	> \$50,000	4	40%
State of Residence	TN	6	60%
	VA	4	40%
Location	Rural	7	70%
	Urban	3	30%
Distance from NICU FU Clinic	1 – 10 miles	2	20%
	26 – 50 miles	3	30%
	> 50 miles	1	10%
	> 100 miles	5	50%
Pediatrician Visits	1 – 5 times a week	3	30%
	Every other week	4	40%
	Once a month	1	10%
Distance to pediatrician	1 – 10 miles	4	40%
	11 – 25 miles	4	40%
ER Visits after discharge	1 - 2	3	30%
	3 - 5	1	10%
Medications	Yes	8	80%
	No	1	10%
	1 - 3	5	50%
	4 - 6	1	10%
Gestational Age at Birth	23 – 28 week	3	30%
	29 – 32 week	5	50%
Birth weight	11b – 21b	2	20%

	2lb 1oz – 3lb	4	40%
	3lb 1 oz – 4lb 8 oz	2	20%
Discharge weight	4lb – 6lb	4	40%
	7lb – 10lb	3	30%
	> 10lb	1	10%
Infant gender	Male	6	60%
	Female	2	20%
	Singleton	6	60%
	Twin	2	20%
Length of stay	1 – 3 months	5	50%
	4 – 6 months	3	30%
Other children	Yes	4	40%
	No	6	60%
Previous preemie	Yes	3	30%
	No	7	70%
Readmitted within 30 days after discharge	Yes	3	30%
	No	5	50%
Medical diagnosis	Prematurity	8	80%
	ROP	3	30%
	RDS	3	30%
	VP Shunt	2	20%
	Tracheostomy	1	10%
	Ostomy	1	10%
Medical Equipment	Oxygen	1	10%
	Apnea monitor	1	10%
	Suction	1	10%
	Ventilator	1	10%
	Feeding Pump	2	20%

Legend: Pound – lb, ounce - oz

Appendix E

Permission letter from publisher to use Dr. Kenner's Transition Model

Dear Ms. Zimmerman,

Thank you for your permissions request made on August 13, 2017 to use the following:
Comprehensive Neonatal Nursing Care, Fifth Edition

ISBN: 9780826109750

- Transition Model, Figure 35.5 on page 795

This material will be reused in Ms. Zimmerman's dissertation for her doctorate from East Tennessee State University.

We will grant permission, contingent upon the following conditions:

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2. This permission is granted for a **one-time use only**.
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Carole Kenner, PhD, RNC-NIC, NNP, FAAN and Judy Wright Lott, DSN, NNP-BC, FAAN

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Best regards,

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Assistant Editor, Nursing

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Appendix F

Focus Questions that Address Subthemes

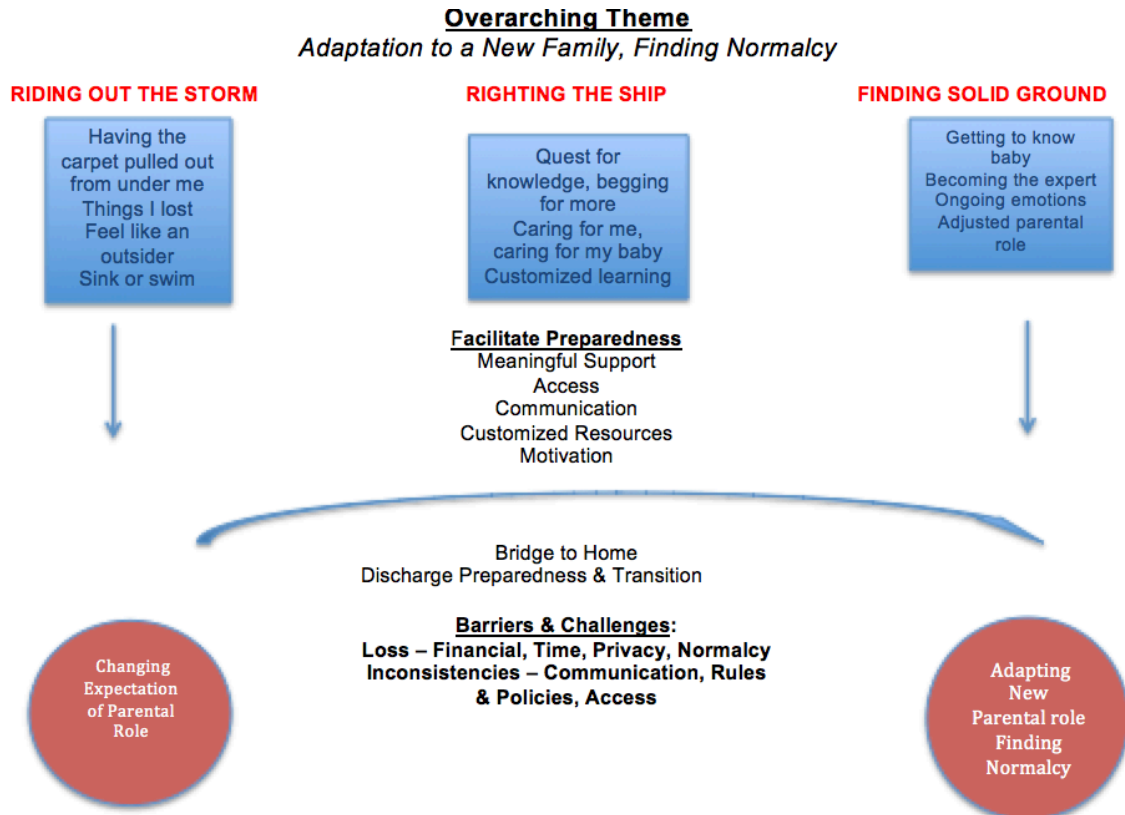
1. How do families perceive their level of preparedness in taking care of their premature infant at home after discharge?
2. What, if any, challenges do families with a premature child face in attempting to access medical resources after discharge from the hospital?
3. What, if any, type of medical and social resources are families with a chronically ill child utilizing?
4. What, if any, concerns do families have related to taking care of their premature infant at home after discharge?
5. What, if any, types of challenges do families have while caring for their premature infant?
6. What, if any, specific information related to the infant's unique needs was provided during discharge teaching?
7. How do families view the overall outcomes for their child?

	1. Riding Out the Storm				2. Righting the Ship			3. Finding Solid Ground			
	1a. Having the carpet pulled out from under me	1b. Thin gs I lost	1c. Feel like an outsider	1d. Sink or Swim	2a. Quest for knowledge	2b. Caring for me, care for my baby	2c. Custom ized learning	3a. Getting to know baby	3b. Becomi ng the expert	3c. Ongoing Emotion s	3d. Adjusted parental role, finding normalcy
Focus 1					X	X	X	X	X	X	X
Focus 2					X	X	X	X	X	X	X
Focus 3				X			X		X		X
Focus 4					X	X	X	X	X	X	X
Focus 5	X	X	X	X	X	X	X	X	X	X	X
Focus 6	X	X	X	X	X	X	X	X	X	X	X
Focus 7	X	X	X	X	X	X	X	X	X	X	X

Appendix G

Adapting to Family Roles, Finding Normalcy

(graphic developed by Kathy Zimmerman)



VITA

KATHRYN A. ZIMMERMAN

- Education: Masters of Science in Nursing, Tennessee State University,
Nashville, Tennessee 2009
Post Graduate Masters in Family Nurse Practitioner, Tennessee
State University, Nashville, Tennessee 2009
Bachelors of Science in Nursing, Tennessee State University,
Nashville, Tennessee 1998
- Professional Experience: Associate Professor, Austin Peay State University, Clarksville,
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Adjunct Professor, Walden University, Minneapolis, Minnesota
2013 – 2015
Adjunct Professor, South University, Atlanta, Georgia 2011 – 2013
Family Nurse Practitioner, Independent Contractor, Middle
Tennessee 2009 – 2017
Family Nurse Practitioner, Mathew Walker Community Clinic,
Clarksville, Tennessee 2010 – 2014
Registered Nurse, Monroe Carell Jr. Children’s Hospital at
Vanderbilt, Nashville, Tennessee 1998 – 2010
- Publications: Zimmerman, K., (2017). Essentials of evidence based practice.
International Journal of Childbirth Educators, 32(2), 37-
42.
Zimmerman, K. (2012). Basics of homeopathy for childbirth.
International Journal of Childbirth Educators, 27(3), 19-
23.
Zimmerman K., & Bauersachs C. (2012). Empowering parents in
the NICU. *International Journal of Childbirth Educators*,
27(1), 50-53.