

ASSESSING BARRIERS AND FACILITATORS TO PARENTAL VISITATION AND
PARENTING ACTIVITIES DURING INFANT HOSPITALIZATION IN A NEONATAL
INTENSIVE CARE UNIT AND A SPECIAL CARE NURSERY

by

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Abstract

Health and long-term outcomes of neonates hospitalized directly after birth are affected by the work of medical professionals and by parental involvement in care (Vergara, et al., 2006). Research shows that parental involvement in infant care during hospitalization in the Neonatal Intensive Care Unit (NICU) has positive effects on neurocognitive development (Reynolds, et al., 2013), parent-infant attachment (Mehler, et al., 2011), and feeding outcomes (Meyer, Coll, Lester, Boukydis, McDonough, & Oh, 1994). Occupational therapists working with infants in NICUs must consider family situations, priorities, and cultural beliefs in order to facilitate parental visitation and involvement in care (Vergara, et al., 2006).

This study examined, primary barriers that hinder parental visitation and facilitators that promote visitation at the NICU and Special Care Nursery (SCN) in a Level 1 trauma hospital in rural eastern North Carolina. Additionally, parental involvement approaches in infant care during hospitalization were identified. Parent surveys were conducted at the infant's discharge from the NICU or SCN with consenting parents.

Results indicated that the primary barriers to visitation were related to parental factors unrelated to the hospital environment or infant health. Parents reported that living far away, having other children at home, and household responsibilities, and work responsibilities were the most influential barriers. Positive relationships with staff were the primary facilitators to visitation. Overall, parent involvement was more passive in nature, as parents participated in observing the infant, talking or singing to the infant, engaging in eye contact with the infant, and touching or stroking the infant most frequently. Diaper changes, feeding, assisting the staff with procedures and holding was engaged in less often by parents.

Overall, the results indicate that of occupational therapists and other medical professionals must provide support to parents when visiting to promote active participation in infant care. Staff were seen as a facilitator of presence so it is vital that NICU and SCN staff are providing proper education during interactions with parents and inviting parents to participate in direct infant care.

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CHAPTER 1: INTRODUCTION

Infants who require specialized care are often hospitalized in neonatal intensive care units (NICUs). In 2012, there were 77.9 infants admitted to NICUs per 1000 live births in the United States. Compared to the admission rate in 2007, which was 64.0 infants per 1000 live births, the rate 2012 showed a 23% increase in admission (Harrison, & Goodman, 2015). While hospitalized in the NICU, infants are exposed to multiple stressors related to the technologically advanced environment and the numerous medical procedures that are performed daily (Carbajal, et al., 2008; Lester et al., 2011). Infant hospitalization also has a direct impact on parents stress levels. Numerous studies reveal that parents experience heightened levels of distress during an infant's hospital stay (Brandon et al., 2011; Lefkowitz, Baxt, & Evans, 2010; Mackley, Locke, Spear, & Joseph, 2010; Shaw, Bernard, Deblois, T., Ikuta, Ginzburg, & Koopman, 2009).

Many different medical fields are involved in infant care in NICUs. One of these fields is occupational therapy. Occupational therapists support infant health by addressing not only the special needs of the infant, but also the needs of the infant's family. Therapists address the entire context of the NICU by working closely with the infants, parents, and other support NICU professionals. Occupational therapists are knowledgeable about infant needs as well as family circumstances, priorities, concerns, and cultural beliefs (Vergara, et al., 2006).

Occupational therapists who work in the NICU acknowledge that early infant health is impacted by many different factors, including parent involvement (Vergara et al., 2006) which is being investigated along with parent visitation in the current study. Parental involvement in care is not only important for typically developing infants, but also for infants who require hospitalization. Although, infants who are hospitalized receive care from medical professionals, it is imperative that parents also be involved in infant care (Hunter, Lee, & Altimier, 2015). The

following Literature Review (Chapter 2), explores the unique parenting experience during infant hospitalization and the many ways in which infant health is impacted by parent involvement in care.

Statement of the Problem

As the population of infants admitted to NICUs grows (Harrison, & Goodman, 2015), the population of parents experiencing the challenges and unique parenting environment associated with infant hospitalization increases as well. The ability of occupational therapists to work with parents in the NICU to ensure parental involvement depends upon the identification of two sets of factors: factors that may limit parents' ability to visit and factors that promote parental presence during infant hospitalization. Identification of these factors can help occupational therapists and other medical professionals better support parents of infants who are hospitalized after birth. Research must be conducted to identify barriers and facilitators for parental visitation and involvement in infant care.

Purpose of the Study

The purpose of this study was to explore parent experience using a newly developed parent survey to identify barriers to and facilitators of parent visitation in addition to factors that promote parental presence during infant hospitalization in a NICU and Special Care Nursery (SCN) that serves rural eastern North Carolina. This study also explores the ways in which parents are involved in infant care during hospital visits to gain a better understanding of parents' roles during this time. Furthermore, the aim is also to provide useful information to occupational therapists and other health professionals who work to support parents in specialized infant care units by answering the following questions.

Research Questions

- What primary barriers to visitation do parents of hospitalized infants experience and how do barriers experienced by parents with infants in the NICU compare to those experienced by parents with infants in the SCN?
- What primary facilitators to visitation do parents of hospitalized infants experience and how do facilitators experienced by parents with infants in the NICU compare to those experienced by parents with infants in the SCN?
- How do parents who visit their infant during hospitalization participate in infant care and how does participation of parents with infants in the NICU compare to participation by parents with infants in the SCN?

CHAPTER 2: REVIEW OF THE LITERATURE

NICU and SCN Environment

Neonatal units are classified by level of care ranging from lowest level of care (Level I) to highest level of care (Level IV). A Level I unit is considered a hospital nursery and must be able to provide care for healthy newborns born at least 35 weeks gestation. Level II units are called special care nurseries (SCN) and must be able to provide care to infants born at or less than 32 weeks gestation, and weigh 1500 grams or less. The infants in a SCN must have medical issues that are expected to be resolved quickly with continued maturation. These nurseries can also serve as “step-down” units for infants who no longer require the care provided in a Level III or IV unit. A Level III unit is called a hospital Neonatal Intensive Care Unit (NICU). This unit must be able to provide care for infants who require continuous life support and comprehensive high risk care. These units must have variety of pediatric medical specialists and specialized medical capabilities onsite, including advanced imaging and interpretation capabilities, pediatric ophthalmologic services, follow-up retinopathy of prematurity services, pediatric surgeons, and pediatric anesthesiologists. Level III units must also have the capability for transporting infants to higher level units or lower level units. Level IV units must have all of the capabilities of Level III units, but must also have onsite capabilities of surgical repair of serious congenital or acquired malformations (American Academy of Pediatrics, Committee on the Fetus and Newborn, 2012; Hunter, Lee, & Altimier, 2015; Stokowski, 2012).

The NICU at James and Connie Maynard Children’s Hospital located within Vidant Medical Center is a Level III and IV unit. Approximately 44,500 inpatients and 171, 000 outpatients are served overall by Vidant Medical Center each year. Twenty-nine counties in eastern North Carolina are provided with acute, intermediate, rehabilitation and outpatient

services throughout Vidant Medical Center. On average, more than 3,500 babies are delivered at Vidant each year (Vidant Medical Center, n.d.). Twenty-one of the 29 counties in eastern North Carolina that the Vidant Medical NICU serves are designated to be Tier 1 communities; communities included in the top 40 most economically distressed counties in North Carolina (Economic Tiers - North Carolina Rural Economic Development Center, Inc., n.d.). These 29 counties include: Beaufort, Bertie, Camden, Carteret, Chowan, Craven, Currituck, Dare, Duplin, Edgecombe, Gates, Greene, Halifax, Hertford, Hyde, Jones, Lenoir, Martin, Nash, Northampton, Onslow, Pamlico, Pasquotank, Perquimans, Pitt, Tyrrell, Washington, Wayne, and Wilson. Table 2.1 summarizes the economic statistics provided in 2014 that compares data from the entire state of North Carolina to the 29 counties that are specifically served by Vidant Medical Center. Table 2.2 summarizes the population based on race for the 29 counties.

Table 2.1

Economic Statistics in 2014 for North Carolina and for the counties Vidant Medical Center Serves^a

	Poverty Rate for All Ages	Unemployment Rate	Median Household Income
North Carolina	17.2%	6.1%	\$46,596
29 Counties Served by Vidant Medical Center	20.8%	7.4%	\$40,473

^aSource: (2014 Labor Force and Unemployment, 2015; 2014 Poverty and Child Poverty Rates, 2015; 2014 Median Household Income, 2015)

Table 2.2

Race Demographic for 29 counties Served by Vidant Medical Center^a

	American Indian Alaska Native	Asian Pacific Islander	Black African- American	Two or More Races	White
Male	1.01%	1.34%	29.52%	2.33%	65.79%
Female	0.88%	1.57%	31.82%	2.31%	63.41%

^aSource: (North Carolina Office of State Budget and Management, 2016)

Table 2.3

Percentage of Persons with Hispanic Origin in 29 Counties Served by Vidant Medical Center

	Hispanic Origin – White	Hispanic Origin – Non-white	Total
Percentage	6.86%	1.68%	8.54%

^aSource: (North Carolina Office of State Budget and Management, 2016)

The NICU at Vidant Medical Center has approximately 50 patient beds separated into four smaller areas called pods, and three overnight parent rooms where parents can stay on a short-term basis. The NICU pods have twelve bed spaces that have one patient per space but are only separated from the hallway by a draw curtain. There is natural light from the windows at the end of the hall and circadian rhythm lighting illuminates the NICU. Noise levels are kept to a minimum, but the curtain that separate the pod from the hallway does not block all of the noise from groups of medical staff on rotations. The visitation policy allows parents to visit 24 hours a

day seven days a week, but staying overnight or long-term in the units is discouraged unless the mother is breastfeeding around the clock or the infant is in critical condition. However, there are visitation restrictions during influenza season (length of time varies each year). During this time, children under 12 and anyone with signs or symptoms of influenza are not permitted to enter the unit. There is a Ronald McDonald house within the children's hospital and one near-by that offers overnight rooms for parents. (S. Harrell, personal communication, August 24, 2015).

The SCN at Vidant Medical Center is a level II step-down unit that has 21, private, sound-proof rooms. This unit was designed for infants who need time to continue to recover, but no longer require NICU-level care. Often, infants hospitalized in the SCN are feeding and growing, but oxygenation levels are dropping intermittently and their heart rates are not stable enough for discharge to the home environment. Parents are permitted to stay overnight and each room has a pull out chair that one parent can sleep on. The doors to each room close, which increases privacy and decreases noise level. The lighting in the SCN is similar to the NICU, but the windows in each room allow more light to enter the room than what is present in the NICU at times (S. Harrell, personal communication, August 24, 2015).

As described above, the environments of neonatal units can vary greatly depending on the physical features of the hospital and the level of care provided and the accommodating features available to parents. The current study aims to identify the factors that promote and hinder parental visitation and involvement in care in both the NICU and SCN at Vidant Medical Center.

Impact of Hospital Environment on Infant Development

Infants hospitalized in intensive care units develop under altered conditions and are exposed to numerous environmental stressors that can negatively impact neurodevelopmental

progression (Pickler, et al., 2010). Stressors related to the hospital environment include harmful stimuli including excessive noise, light, handling, and painful medical interventions (Carbajal et al., 2008). Furthermore, an infant's environment during hospitalization is also altered by the absence of supportive stimuli, such as holding, breastfeeding, and comforting touch (Hanley, 2008; Lester et al., 2010). The aim of the current study is related to the research supporting positive parent-infant interaction and the identification of factors that impact parent participation in care during infant hospitalization.

Parent Visitation and Involvement in Care Supports Infant Health

Medical care provided by well-educated and trained medical professionals is critical for infant survival during hospitalization. However, parent visitation and involvement in care is also vital to the infant's recovery and long-term outcomes (Vergara, & Bigsby, 2004). One key aspect of parent-infant interaction related to infant health is attachment. Attachment is defined as "a bond that develops between the infant and his or her caregiver over the first year of life" (Case-Smith, 2015, pp. 73-74). There are four patterns of attachment in infants: secure, anxious, insecure-avoidance, and disorganized. Secure attachment guides the formation of a coherent and organized relationship with the parent and is critical to overall child development. Attachment patterns have a significant impact on a child's representation of his or her social world and influences the child's understanding of self (Case-Smith, 2015). Parent interactions with infants that are sensitive and responsive in nature support the formation of a secure attachment pattern (De Wolff & van Ijzendoorn, 1997; Hall, et al., 2015). Furthermore, the attachment process begins early after the birth of the infant. Specifically, when mothers of preterm infants are able to see their infants within three hours after birth, a secure attachment is more likely to form than when there is not early contact between preterm infants and their mothers (Mehler, et al., 2011).

Research supports benefits to early attachment between mothers and infants during the first years of life. Children who had secure attachment to their mothers at 15 months of age have demonstrated better cooperativeness, expressive and receptive language, increased school readiness, and decreased behavior problems than peers exhibiting insecure attachments (Becky & Feron, 2002). In addition, greater emotional and behavioral regulation has been seen in toddlers at 3.5 years of age with secure attachment with mother between ages 12-24 months (Vondra, Shaw, Swearingen, Cohen, & Owens, 2001). Therefore, because the development of a secure attachment affects long-term infant health outcomes, positive parent-infant interaction must occur during hospitalization to promote healthy attachment patterns.

The importance of parental presence in the NICU setting is also supported by research on holding practices. Reynolds et al. (2013) found that parental presence and holding practices in the NICU were associated with positive infant outcomes including a calmer, more predictable affect and the development of more mature and fluid motor skills in children. One specific holding practice associated with improved infant health is Kangaroo Care (KC), also called skin-to-skin care (SSC). KC is the practice of parents holding their infant who is wearing only a diaper and placed directly on the parent's bare chest in an upright, prone position (Case-Smith & O'Brian, 2015). Maternal participation in KC was found to reduce the risk of infant mortality, nosocomial infection, and sepsis, hypothermia, and length of hospital stay. It was also found to increase some measures of infant growth, breast feeding capability, and mother-infant attachment (Conde-Agudelo, Belizán, & Diaz-Rossello, 2011). Furthermore, improved autonomic regulation, state regulation, cognitive development (Feldman & Eidelman, 2003), and enhanced brain development (Scher et al., 2009) are associated with mothers' engagement in KC with their infants. Fewer studies have examined the impact of paternal participation in KC on

infant health. However, prior research has shown positive infant health outcomes emerge as a result of fathers' participation in KC. These positive benefits include: improved temperature and pain, bio-physiological markers, behavioral responses, as well as paternal outcomes, which include parental role attainment, paternal interaction behavior, and decreased paternal stress and anxiety (Shorey, He, & Morelius, 2016).

Feeding, which is another activity that parents can be involved during infant hospitalization, is central aspect of infant care. An infant's ability to eat directly affects length of hospital stay as discharge planning relies heavily on infants' feeding and weight gain. Early mother-infant feeding interactions are also positively correlated with decreases in maternal stress and depression. Specifically, infants of mothers who receive the family-centered interventions displayed significantly less negative feeding behaviors such as grimacing and gagging (Meyer, Coll, Lester, Boukydis, McDonough, & Oh 1994). As evidence on the benefits of breastfeeding in the NICU grows, NICUs have implemented new policies to promote the breastfeeding during infant hospitalization (McGrath, 2012). The current study aims to provide insight to the barriers and facilitators that may relate to mothers' ability to visit the NICU and be active during infant feeding times.

The findings of these studies highlight the benefits of not only parental visitation, but direct parental involvement in care during infant hospitalization and the need for the development of evidence based interventions that are aimed at increasing parental visitation and involvement in care. The current study aims to gain more understanding of how the parent is involved in care while visiting the infant, as well as the factors that promote and limit parental presence and the way in which parents are involved in infant care.

Parenting a Critically Ill Infant

Parenting a preterm infant is different from parenting a full-term infant who is hospitalized. Preterm infants display different behaviors and respond to care in contrasting ways from full-term infants. Preterm infants are typically less attentive, less reactive, display lower levels of engagement and orientation to their mother’s faces, and their facial expressions of emotions are more often difficult to interpret (DeMier et al., 2000; Forcada-Guex, Borghini, Pierrehumbert, Ansermet, & Muller-Nix, 2011).

A meta-synthesis of 14 qualitative research studies on mothers’ experiences of having a preterm baby in a NICU published between 2000 and 2005, revealed five distinct themes that described the mothers’ experiences. These studies of the experience of mothers of preterm report that infants supports the idea that mothering a preterm infant is a “developmental process that is nurtured through close relationship with the baby, professional relationship with the staff, and the internal vigilance and concern of the mother” (Aagaard, & Hall, 2008, p. 33).

Table 2.4

Themes Describing Maternal Experiences During Infant Hospitalization (Aagaard, & Hall, 2008)

Theme	Description
Mother–baby relationship: from their baby to my baby	This theme describes the transition from the feeling of no control, to ownership and a sense of acknowledgement of the infant as “my baby.”
Maternal development: a striving to be a real normal mother	This theme includes the mother’s feeling of alienation as what she is experiencing is different from the typical mothering experience. Furthermore, during infant hospitalization, participation in infant care contributes to the development of a sense of motherhood and aids in the transition of feeling like an outsider to feeling like a real mother.
A turbulent neonatal environment from foreground to background	The mothers’ overwhelmed reaction and attention to the crowded, noisy, and unfamiliar NICU environment is represented by this theme. As the mother becomes more

	acclimated with the new setting, she is able to selectively attend to her baby despite the distraction of the busy NICU environment.
Maternal caregiving and role reclaiming strategies: from silent vigilance to advocacy	This theme encompasses the process mothers undergo progressing from passive involvement to active involvement. Maternal involvement transitions from cares such as touching, holding, and soothing to bathing, positioning, feeding, and diapering.
Mother-nurse relationship: from continuously answering questions through chatting to sharing of knowledge	A positive relationship between nursing staff and mothers is fostered through continuity of care, the acceptance of a partnering role between mother and nurse, and acknowledgement of the mother by the nurse. Positive mother-nurse relationships transition from interactions in which nurses offer education to reciprocal sharing of expertise as the mother becomes familiar with her baby.

Parent interaction with premature infants is often altered due to the medical complications that arise as a result of premature birth. However, previous studies reported mixed findings on parent-infant interaction early after birth of premature infants. Forcada-Guex et al., (2011) reported that mothers of premature infants are more intrusive and controlling during interactions as compared with full-term infants. In contrast, other longitudinal studies reported that mothers of preterm infants were more stimulating and sensitive in the first few months after birth, but by the first year of life positive parenting behaviors decreased and parents of premature infants were much less involved than parents of full-term infants (Barratt, Roach, & Leavitt, 1996; Singer et al., 2003). However, these studies agree that parenting critically ill and/or preterm infants differs greatly than parenting healthy, full-term infants. Thus it is important to gain a better understanding of the challenges related to parental visitation and participation in care during infant hospitalization.

Research studies in the past about parenting a hospitalized infant often do not include the father's perspective or impact on infant outcomes. However, past studies have supported father

interaction as a catalyst to positive outcomes in child development and health. Results from a study investigating the impact of father-infant interaction in 192 families in the United Kingdom, reported that disengaged interactions of fathers with their infants, as early as the third month of life, predict early behavioral problems in children by age one (Ramchandani, et al., 2013). Furthermore, a systematic review of studies investigating the impact of father-child interactions on child development, reported that, overall, when fathers and/or father figures are involved, the amount of behavioral problems in boys and the amount of psychological concerns in girls are decreased. Also, fathers' involvement in the lives of their children supports cognitive development, while lowering incidence of criminal behavior and economic disadvantage in low socioeconomic status (SES) families (Sarkadi, Kristiansson, Oberklaid, & Bremberg, 2008).

A systematic review of the literature published in the years 2000 to 2014 investigated the experience of fathers of infants who are hospitalized report that fathers have five principal experiences (Provenzi & Santoro, 2015). These principles are summarized in the table below (Table 2.5).

Table 2.5

Themes Describing Paternal Experiences During Infant Hospitalization (Provenzi & Santoro, 2015)

Theme	Description
Emotional roller-coaster	This theme includes the fathers' emotional transitions from worrying for the health of the mother during delivery to concern for the newborn's well-being suddenly.
Parental needs	The father's desire to be remain informed about the medical attention the infant is receiving and be recognized by the staff as a father who is eager to participate and be involved in care is represented by this theme.
Coping strategies	This theme includes two coping strategies exhibited by fathers: going back to work to provide for the family and hiding emotions to "stay strong" for the baby's mother.

Self-representation	The fathers' self-identification as protector of the family as well as the "go-between" parent who must return to work as well as visit the baby in the hospital is described by this theme.
Caregiving engagement	This theme refers to the fear and anxiety that fathers often feel which limits caregiving engagement and leads to more passive involvement like singing or talking to the infant.

Fathers have unique experiences during infant hospitalization. Often, fathers are not included in studies of parent involvement or are difficult to recruit for research. The current study includes the perceptions of fathers on visitation and participation in care during infant hospitalization in intensive care.

Infant Treatment in Intensive Care Units: Parental Role

The care team of an infant who is hospitalized is comprised of professionals from many different medical disciplines. In addition to hospital staff, the parents are also vital members of a hospitalized infant's support team. During events that require specialized medical attention, infants receive care from neonatal support professionals. However, after discharge, parents become the sole care providers for the infant. Parent involvement in care during hospitalization is an important aspect that contributes to the health of hospitalized infants. Parental knowledge of the type of care needed by infants and the role of parents during hospitalization is crucial.

The Neonatal Integrated Developmental Care Model (IDC) is the most up-to-date and inclusive model for NICU development and care (Hunter, Lee, & Altimier, 2015). This model includes seven core procedures for family-centered developmental care in the NICU including partnering with families (Altimier & Phillips, 2013). NICUs facilities are now incorporating family members as mutual partners in providing care for hospitalized infants (Case-Smith, & O'Brien, 2015). Furthermore, as a part of partnering with families in the IDC, health

professionals recognize that the family is has the greatest influence over an infant's health and well-being (Altimier, & Phillips, 2013). The former approach of "practitioner as expert, child as patient, and parents as students" is no longer the standard of care in NICUs; now the practitioner no longer talks to the parents, but rather talk with the parents and facilitates the family's active role with their infant and as the NICU team member (Hunter, Lee, & Altimier, 2015, p. 626).

The current study was conducted at the NICU and SCN at Vidant Medical Center. The NICU and SCN do not have a care policy that directly states the use of the IDC model. However, the NICU and SCN promote policies that are comparable to the IDC and are neuroprotective in nature. As explained in previous sections, the Vidant Medical Center NICU and SCN implement measures to protect and foster typical neurodevelopmental progression in patients. The NICU and SCN strive to include parents in care and allow open visitation to families, with the only visitation restrictions to siblings in the influenza season months. Because parental visitation and involvement are an integral part of IDC, identification of the barriers and facilitators of parental visitation is the primary purpose of the current study.

Barriers: Factors That Prevent Parental Visitation and Involvement in Care

Barriers are factors that hinder the ability of parents to visit the hospital and involved in infant care. Barriers can be intrinsic which are related to the parents themselves or extrinsic which are factors related to aspects outside of the parents themselves.

Extrinsic factors within the NICU or SCN facility, including the staff and physical environment, can play a role in the ability of parents to visit their infant or be involved in the infant's care. Parents have reported that if the hospital environment is not "family-friendly," they are less likely to visit and be involved in the care of their infant (Feeley et al., 2013b;

Wigert, et al., 2010). Feeley et al. (2013b) found that fathers who were interviewed experienced many barriers related to the environment. They found the controlled hospital environment to be restrictive of involvement in care. Fathers reported that the type of equipment used, such as incubators, created a physical barrier to involvement in care. Furthermore, fathers felt that the appearance of the NICU was not similar to the home environment, and therefore they were less capable of being involved in infant care (Feeley et al., 2013b). Also, related to the physical environment of the NICU, high levels of noise and illumination have been found to be related to a decrease in parental involvement and visitation (Heinemann, Hellström-Westas, and Nyqvist, 2013). Also, visitation policies that limit the times that parents are allowed to enter the NICU may also limit visitation and participation in infant care (Griffin, 2013).

Extrinsic factors related to the hospital staff can also hinder parental involvement and visitation. Parents reported that general mistreatment by staff hindered their participation in infant care (Wigert, et al, 2010). Ineffective communication between the staff and the parents including the lack of information about the care being provided to the infant was reported in prior studies as a factor that hindered parental involvement in care (Gonya & Nelin, 2013; Ward, 2001; Wigert et al., 2010). Similarly, fathers reported that NICU staff members that did not teach them how to care for their infant or encourage them to provide care were a barrier to involvement in care (Feeley, et al., 2013b). NICU staff can also hinder parental involvement in care in situations where the nurse had taken on the role of the primary caregiver (Broeder, 2003).

The condition of the infant is another extrinsic factor that can affect parental visitation and involvement in care. Prior research has shown that fathers were fearful of being involved in the care of their infant because the infant was viewed as too fragile or small to hold (Feeley, et al., 2013b). Also related to the infant's condition, parental interviews revealed that parents

became upset by their infant's appearance, the infant's behavior or the treatments the infant was receiving and considered these feelings a barrier to visitation and involvement (Gonya & Nelin, 2013). Likewise, fathers have also reported that the infant often did not respond well to when they visited or were involved in care and viewed this as a barrier (Feeley et al., 2013b; Levy-Shiff, Hoffman, Mogilner, Levinger, & Mogilner 1990). Lastly, the severity of the infant's condition and the level of invasiveness of treatment have been reported as a barrier to parental involvement in care and visitation (Feeley et al., 2013b; Latva, Lehtonen, Salmelin, & Tamminen, 2007).

Intrinsic factors, or those related to the parents themselves also play a role in visitation and involvement in care. Responsibilities outside of the hospital, including work (Feeley et al., 2013b; Greene, et al., 2015; Pohlman, 2005; Wigert et al., 2010), care for other children (Feeley et al., 2013b; Franck & Spencer, 2003; Garten, Maass, Schmalisch & Buhner, 2011; Greene et al., 2015; Latva et al., 2007; Wigert, et al., 2010), and home maintenance (Feeley et al., 2013b; Wigert et al., 2010), are factors that have been reported as barriers to visitation and involvement in care. Fathers specifically reported that it was more important for the other parent to be present at the hospital and that they attend to responsibilities outside of the hospital (Feeley, et al., 2013b). The ability to physically get to the hospital has also been reported as a barrier to visitation. Specifically living far away from the hospital (Greene et al., 2015; Latva et al., 2007; Wigert et al., 2013) and not having a way to get to the hospital have been reported by parents as barriers to visitation (Greene et al., 2015; Wigert et al., 2013). Lastly, poor health condition of the parent can play a role in the visitation and involvement in infant care (Wigert et al., 2013). Specifically, maternal exposure to a greater number of potentially traumatic events prior to

childbirth, depression after the infant's birth, and lower maternal anxiety were correlated with lower visitation rate (Greene, et al., 2015).

Barriers to visitation and involvement in care are important to identify and consider because of the impact parental involvement has on infant health as indicated earlier. Hospital staff, including the occupational therapist, can play a role in reducing the barriers parents face.

Facilitators: Factors that Support Parental Involvement in Care

In response to the knowledge of the positive impact of parental involvement in care on infant health, it is important to understand what factors facilitate parental presence. Facilitating factors are those that support parental presence and encourage parental involvement in care while the infant is hospitalized. One study, which investigated the factors that enabled parental presence and involvement in care through the use of qualitative, semi-structured interview reported that KC (skin to skin holding) and the ability to be actively involved in the infant's care gave parents a sense of control and reinforced their motivation to be with their infant during hospitalization (Heinemann, Hellström-Westas & Nyqvist, 2013). Wigert, Berg, and Hellström (2010) also interviewed mothers and fathers who were able to visit their infant during hospitalization in order to identify the factors that encouraged parental presence. The findings showed that good treatment by staff, a family-friendly NICU environment (e.g., a place to sit by the baby's bedside), high-quality care provided to the infant, the ability to come and go freely, receiving regular information about the infant's care, and being invited to participate in care were factors that encouraged parental visitation. Another study investigating the perceptions of both mothers and fathers, found that parents were most concerned with receiving assurance that their infant was being cared for properly and receiving detailed information about the care being

provided for their infant (Ward, 2001). Similar to these findings, another study showed that have found that mothers feel that receiving accurate information and good communication with staff was important, whereas self-related needs were less important (Bialoskurski, Cox, and Wiggins, 2002).

A study that specifically asked fathers of their involvement in the NICU found fathers reported that having twins in the NICU, positive feedback from the infant, positive feelings associated with fatherhood, paternity leave, encouragement from the mother to participate, previous hospital experience, observation of other fathers in the NICU, being able to visit whenever desired, supportive staff, and if the mother could not be present were all factors that encouraged visitation (Feeley, Waitzer, Sherrard, Boisvert, & Zelkowitz, 2013b).

The layout of the NICU facility can also serve as a facilitator of parental presence. Studies conducted specifically on the difference between open-bay NICUs compared to NICUs with single family rooms have found that parents are more likely to visit the NICU and be involved in infant care in the single family room environment (Carter, Carter, & Bennett, 2008; Harris, Shepley, White, Kolberg, & Harrell, 2006). Single family rooms provide more privacy, which contributes to increased parental visitation and involvement (Harris, et al., 2006). Furthermore, parents reported that in single family rooms, there was less overstimulation of noise and light, superior access to their infant's doctor, as well as a higher level of support by the provided by the entire NICU staff (Carter et al., 2008). All of these factors related to the single family room NICU environment increased the parent's ability to be involved in the care of the infant.

The SCN in the current study has single-family rooms and a NICU with several “pods” that accommodate twelve infants each. Parental visitation and involvement may differ between these two settings based on the differing physical features. Parental perceptions of each environment will be collected and the differences between parent experiences will be explored.

The facilitators identified in the studies discussed above were gathered from the reports of parents who were able to visit their infants in the hospital. Factors that are facilitators should continue to be implemented in order to support parental involvement and visitation. However, barriers that impede visitation must also be identified in order to promote visitation and involvement in care of parents who did not visit the NICU or SCN.

Role of Occupational Therapy

Occupational therapists must have specialized education in order to work in NICUs and/or SCNs because of the critical state of the infants and their caregivers in this area of practice. Practitioners in this setting must have advanced knowledge and skills that are obtained through participation in continuing education classes, organized self-study, formal internships, prior pediatric experience, and on the job training facilitated by a mentor (Vergara et al., 2006).

The primary focus of occupational therapists in NICUs is to provide support of infant participation in infant occupations and promote increased occupational performance in these areas of participation (Gorga et al., 2000; Holloway, 1998). Infant occupations include appropriate activities and tasks that are valued in the family’s culture by the culture of the NICU. These occupations are activities in which typically developing infants are expected to participate. Common infant occupations include: exploring, procuring, social interaction, and feeding (Vergara, & Bigsby, 2004). Exploring includes tasks that allow the infant to understand his or

her environment such as visual scanning, oral exploration (“mouthing” objects), postural exploration (rolling, sitting, etc), and listening. The occupation of procuring includes activities that allow the infant to interact with the environment to express his or her needs in order to solicit care from others. For example, an infant may signal a caregiver to provide food by sucking on his thumb or fist to indicate the need to be fed. Social interaction involves tasks such as making eye contact, smiling, cooing, and laughing. Lastly, feeding, which is a basic need of newborns and one of the most naturally occurring occupations, involves signaling for feeds, coordination of sucking, breathing, and swallowing, and oral motor control. Neonatal therapists must be sensitive to the developmental needs of infants hospitalized in the NICU. Therapists must provide interventions that support the progression of expected infant occupations. Infants develop in the context of a family, therefore each of these occupations include a caregiver component. Therapists must provide support to families in order to provide all encompassing interventions to promote increases in occupational performance (Vergara, & Bigsby, 2004)

As stated previously, under Neonatal Integrated Developmental Care Model (IDC), one of the primary roles of the health professional is to involve the family in the care of the infant. The American Occupational Therapy Association *NICU Knowledge & Skills Paper* acknowledges this as a fundamental role of occupational therapists who work in NICUs or SCNs (Vergara et al., 2006). Vergara and colleagues (2006) insist that occupational therapists who work in these units must consider family situations, priorities, and cultural beliefs (Vergara et al., 2006).

Price and Miner (2009) investigated the therapeutic process between a NICU occupational therapist and a mother of an infant hospitalized in the NICU. During the hospitalization, the therapist worked with the mother to increase her confidence in and ability to

provide care to her infant. With the help of the therapist, the mother was able to both contribute to the health and well-being of her infant and form a mother-infant relationship. These findings emphasize the importance for the therapist's knowledge of family patterns and perspectives in order to foster the relationship between parents and their hospitalized infants. Furthermore, the findings support the notion that "therapists must see parents as clients who must learn to nurture and manage their infant's ongoing medical and social needs as a member of the nuclear and human family" (Price & Miner, 2009, p. 68).

Occupational therapy practitioners who practice in neonatal units are concerned not only with the infant occupations, but also with parenting occupations, and parent-infant co-occupations (Vergara et al., 2006). Occupations are the "life engagements that are constructed of multiple activities. Both occupations and activities are used as interventions by practitioners. Participation in occupations is considered the end result of interventions, and practitioners use occupations during the intervention process as the means to the end," (American Occupational Therapy Association, 2014, p. 56). Occupational therapy intervention in the NICU or SCN is based on the knowledge and understanding of these occupations (Vergara et al., 2006).

Summary

As described previously, the role of the occupational therapist goes beyond individualized care of the infant to include individualized support of the family as well. This study aims to identify the primary barriers to visitation and involvement in care and the primary facilitators to visitation and involvement in care. These factors impact the therapist's ability to provide individualized support to the family and promote infant health and wellness. Knowledge of these barriers and facilitators aids the therapists in providing care under IDC model. Furthermore, the parenting activities and parent-infant co-occupations will be explored to gain a

better understanding of parent involvement in care during infant hospitalization. An aspect of support provided by the therapist may be working to resolve the barriers to visitation and involvement in order to ensure family members are interacting with their infant (Vergara et al., 2006).

CHAPTER 3: METHODOLOGY

Design

This non-experimental study included a self-report survey used to measure parents' perspective of facilitators, barriers, and motivational factors that impacted visitation and involvement in the NICU and SCN. The research team was comprised of faculty and students from both the department of Occupational Therapy and the department of Psychology at East Carolina University. These individuals include, Denise Donica, DHSc, OTR/L, Principle Investigator; Meghan Sharp, Study Coordinator; and co-investigators, Lauren Forrest, Christyn Dolbier, PhD, Christy Walcott, PhD. Expedited approval was obtained by the East Carolina University's University and Medical Center Institutional Review Board (*Appendix A*).

Participants

The target population of the study was mothers and fathers who had a newborn hospitalized in the neonatal intensive care unit (NICU) or the special care nursery (SCN) at the James and Connie Maynard Children's Hospital at Vidant Medical Center, Greenville, NC. Using convenience sampling, parents were asked to complete a survey after their infant was scheduled for discharge from the NICU or SCN. The sample was collected based on the following inclusion criteria: (a) being at least 18 years-of-age, (b) being the biological parent of an infant hospitalized for at least 7 days in the NICU or SCN at Vidant Medical Center, and (c) being English or Spanish Speaking. The exclusion criteria were: (a) having an infant who is considered terminally ill, (b) having an infant who passed away while in the NICU/SCN, and (c) being barred from visitation (e.g., due to involvement of Child Protective Services). A fourth exclusion criterion was included during part of the time data was collected: the infant must have

been born at greater than 28-weeks gestation. This exclusion criterion was included initially to prevent burden to parents who may have been approached to participate in existing research on infants under gestational age of 28-weeks. This exclusion criterion was included for the first 69 days of recruitment.

Parent Sample. The sample consisted of 32 parents. Nine of the 32 parents completed both the NICU and the SCN surveys (totaling 18 surveys), 22 parents completed the NICU survey only, and one parent completed the SCN survey only, thus totaling 41 surveys. As the NICU and SCN settings have many differences that may impact the parents’ perspective during hospitalization, the responses generated based on time spent in the NICU (NICU group) and the responses generated based on time spent in the SCN (SCN group) were analyzed separately. The NICU group consisted of 31 parents (10 fathers, 21 mothers). The SCN group consisted of 10 parents (3 fathers, 7 mothers). The demographic data for the 29 counties served by Vidant medical was summarized previously in Table 2.1, Table 2.2, and Table 2.3. Demographic information for these separate groups in the current study’s sample is summarized in *Table 3.1*.

Table 3.1

Parent Demographics

	NICU	SCN
Mean age (years)	27.28 (n=30)	26.78 (n=9)
Race N (%)		
White	18(58.10)	5(50.00)
Black or African American	13(41.90)	4(40.00)
Other	0(0.00)	1(10.00)
Average Household Income	\$38,689.44 (n=25)	\$38,222.22 (n=9)
Employment Status N (%)		
Employed full-time (at least 30 hours per week)	18(58.10)	4(40.00)

Employed part-time (less than 30 hours per week)	8(25.80)	1(10.00)
Not currently employed, looking for work	1(3.20)	3(30.00)
Not currently employed, not looking for work	3(9.70)	1(10.00)
Full-time student	4(12.90)	0(0.00)
Other	5(16.10)	1(10.00)
Marital Status N (%)		
Single (never married)	8(25.80)	3(30.00)
Living with partner	8(25.80)	1(10.00)
Married	13(41.90)	5(50.00)
Other	2(6.50)	1(10.00)
Highest Level of Education N (%)		
High school graduate, diploma or equivalent (GED)	7(22.60)	2(20.00)
Some college credit, no degree	13(41.90)	6(60.00)
Associates degree	4(12.90)	1(10.00)
Bachelor's degree	4(12.90)	1(10.00)
Graduate or professional degree (masters, doctorate, medical, law)	2(6.50)	0(0.00)
Number of children 18 and under (not including most recent birth) (M, SD)	1.14(1.21) (n=28)	1.33(1.66) (n=9)
Number of adults related to you (NOT including you) living with you (M, SD)	1.21(0.92) (n=28)	1.00(0.87) (n=9)
Maternity or Paternity Leave N (%)		
The entire time	14(45.20)	3(30.00)
Part of the time	8(25.80)	3(30.00)
None of the time	4(12.90)	2(20.00)
Not applicable - I was not employed at the time	5(16.10)	2(20.00)
Average length of visits to the NICU/SCN (hours: M,SD)	3.44(3.22) (n=23)	4.43(2.30) (n=7)

Infant Sample. The NICU group included 22 infants and the SCN group included 8 infants. At this time, medical data has not been collected for the entire sample of infants. There are missing data for 5 infants from the NICU group and 3 infants from the SCN group. The medical data available are summarized in Table 3.2.

Visitation data were also collected from the nursing notes from the infants' electronic health records. At the time the results for this study were analyzed, visitation data for 23 parents

(out of 31) in the NICU group were recorded. NICU parents ($n=23$) visited on average 75.3% of the days their infant was hospitalized, and just under half (43.5%) were able to visit at least 80% of the days. Visitation data for the remaining seven parents in the NICU group and the nine parents in the SCN group was unavailable, as this data has not yet been collected by research assistants from the electronic health records.

Table 3.2

Infant Medical Record Demographics

	N	NICU Group M(SD)	N	SCN Group M(SD)
Gestational Age (days)	17	216.41(22.96)	5	211.40(12.52)
Birth Weight (grams)	17	1438.24(593.38)	5	1282.00(384.54)
Length of Unit Stay (days)	16	25.56(5.41)	5	26.00(9.67)
Total Length Of Stay (days)	15	48.40(21.99)	5	60.00(17.22)
Medical Severity (Possible range = 1-7)	15	4.07(1.62)	5	3.50(1.92)
Sex N(%)	17		5	
Male		11(64.70)		4(80.00)
Female		6(35.50)		1(20.00)
Insurance N(%)	16		5	
Private/Employer		4(23.50)		0(0.00)
Medicaid		12(94.10)		5(100.00)
Respiratory Interventions N(%)				
Continuous Positive Airway Pressure (CPAP)	15	10(58.80)	5	0(0.00)
Intubation	10	2(11.80)	5	0(0.00)
Ventilator	6	6(35.30)	5	0(0.00)
Occupational Therapy Intervention N(%)	12	5(41.70)	4	4(100.00)

Instrumentation

Parent Survey. Facilitators and barriers to parental involvement and visitation were assessed through the use of a newly developed parent-report survey (*Appendix B*).

The survey includes the following sets of questions: barriers to visitation/involvement in care, facilitators to visitation/involvement in care reasons/motivators for visiting the hospital, activities parents were involved in when visiting, and demographics. In addition, the survey included questions that assess parental stress which were used in another study and were not be analyzed in the current study. The current study was focused on questions addressing barriers to visitation/involvement in care, facilitators to visitation/involvement, activities parents were involved in when visiting, and parent demographics, and general health data gathered via medical chart review.

The barrier section includes a list of statements that are possible reasons why parents may not visit their baby in the NICU or SCN as found in literature. Statements that included in this section address two different types of barriers: intrinsic barriers, which are related to the parents themselves, and or extrinsic, which are factors related to aspects outside of the parents themselves. The participant is asked “Indicate the extent to which the following things that may keep parents from visiting their baby in the NICU or SCN applies to you.” The statements are rated on a five point Likert scale from “Does not apply at all” to “Applies completely.”

The facilitator section includes a list of statements that are possible motivators or reasons that parents visit the NICU or SCN. The participant is asked “Indicate the extent to which the following things that may encourage parents to visit their baby in the NICU or SCN applies to

you.” The statements are rated on a five point Likert scale from “Does not apply at all” to “Applies completely.”

The survey also includes a section that assesses the parent-infant interaction when visiting the NICU or SCN. The participant is asked to “Indicate how often you were involved in each of the activities parents may engage in with their baby when you were able to visit your baby in the NICU or SCN.” Each statement is rated on a five-point Likert scale from "Never" to "Always" in order to capture the frequency of participant. See Appendix C for the references for each item included in this section. These statements capture the various *co-occupations*, activities that are shared between two or more individuals, between parents and infants that may occur during the early weeks of life (American Occupational Therapy Association, 2014). This section will provide insight into the occupations, or everyday activities that parents of hospitalized infants are involved in when visiting. The involvement during visitation is important because it provides a deeper understanding of the ways parents are interacting with infants, and forming attachments while the infant is hospitalized.

The survey was developed based on the findings of prior research studies (*Appendix C*). The primary studies that contributed to the development of the current survey are explained in further detail below. Researchers from each of these utilized differing methods to gain information on barriers to visitation, facilitators of visitation, and/or activities parents engage in while visiting. Qualitative interviews with open ended questions were yielded information describing the reasons, barriers, and facilitators to visitation expressed by both mothers and fathers (Wigert, Berg, & Hellstrom, 2010), and exclusively expressed by fathers (Feeley et al., 2013a, Feeley et al., 2013b). The trends that emerged from these qualitative studies were included in the barriers, facilitators, and reasons for visiting sections of the current study’s

survey. Other studies used previously developed questionnaires and related parents' answers to these questionnaires to frequency and duration of NICU visitation (Ward, 2001; Greene, et al., 2015). The top ten needs reported by NICU parents identified through the use of the NICU Family Needs Inventory (NFNI) were included in the facilitators section of the current survey (Ward, 2001). Greene and colleagues (2015), compared results gathered through the use of stress and depression inventories to visitation rates and extrinsic factors such as distance from the hospital, which revealed possible reasons why some mothers visited less than others. These reasons were included as items in the barrier section of the current study. Items included in the barriers study were also derived from results of a comparison of frequency of parent visitation to information extracted directly from the infants' medical records including infant health, distance of parent's residence to the hospital, and additional siblings (Latva, Lehtonen, Salmelin, & Tamminen, 2007). The parent-interaction portion of the survey includes parent activities performed while visiting identified through open-ended interviews with fathers (Feeley, et al., 2013a) and through direct observation of parents while visiting (Franck, & Spencer, 2003).

Researchers in the current study collaborated to synthesize the findings of these studies to create a parent survey that would produce quantifiable trends to describe parent experience during infant hospitalization. The studies that provided the most significant contribution to the developed survey were included in the explanation above. Appendix C contains a comprehensive list of the research studies providing support for each item included in the sections of concern for the current study.

The last section of the survey includes demographic information. Information obtained in this section includes parental sex, age, race, ethnicity, marital status, education, employment status and descriptive information related to NICU or SCN visitation including frequency of

visitation and duration of visitation is also included in the survey. Other sections of the survey that are not included in the analyses of the current study are motivating factors to visitation and a parent stress inventory.

Procedure

The procedure for the current study was developed through collaboration of both faculty and students from the Departments of Occupational Therapy and Psychology at East Carolina University (See *Design*). Communication with Vidant Medical Center staff and other East Carolina staff influenced the procedure as well. Devon Kuehn, MD, Director Neonatology Research and Clinical Assistant Professor at East Carolina University, and Sherry Moseley, nurse research coordinator, department of Neonatology at East Carolina University, provided vital information and guidance in creating the procedure for this study. Through this collaboration, the research team was able to identify an appropriate method of screening, recruiting, and contacting parents. Information gathered during meetings with these individuals prompted the research team to contact two Vidant Medical Center social workers. With assistance provided by these two staff members, the best method of initial contact with the potential participants was identified. An occupational therapist, who works in the NICU at Vidant Medical Center, provided support as needed throughout the process of navigating and understanding the NICU and SCN environment and for providing the research team with neurodevelopmental assessments, which may be used to answer future research questions related to self-regulation.

Screening. Weekly review of the infants admitted to the NICU was conducted by the Study Coordinator (SC). Information abstracted from the admitted infant's Electronic Health

Record (EHR) included the infant's name, date of admission, and discharge information. The SC also reviewed the EHR to calculate the date of eligibility (based on length of hospital stay) and to confirm that no exclusion criteria had been met. Data collected via the screening process was stored on the secure ECU server (Pirate Drive) and was only accessible to research team members.

Recruitment. The recruitment process began with the distribution of Permission to Contact Cards (*Appendix D*) and study flyers (*Appendix E*) by Vidant Medical social workers in the NICU during a standard-of-care meeting. Parents who completed the cards either returned them directly to the social workers or dropped them in a locked drop-box located at the front desks of both the NICU and SCN. Research team members with current IRB and HIPAA certifications collected the permission-to-contact cards at least once per week. The research team member who retrieved the cards was responsible for entering in the information provided by the parents on the Contact Log located on a secured network drive. The study coordinator was responsible for assessing eligibility of parents who submitted Permission to Contact cards, according to the inclusion and exclusion criteria. After eligibility was confirmed, scheduling for an in-person consent meeting was initiated by psychology research assistants. Parents were contacted via phone at their preferred telephone number during the times provided on the returned Permission to Contact Card. Parents were contacted a maximum of five times in order to schedule a consent meeting. Consent meetings were scheduled during business hours, when possible, and were typically conducted by a trained occupational therapy research assistant. If requested, reminder phone calls were provided the day before the scheduled consent meeting. In the event a parent was 15 minutes late to a meeting, the research assistant provided a text or phone call to the parent to confirm the arrival time or to reschedule.

Informed Consent. The consent process occurred either at patient bedside or when requested by the parent, in available counseling rooms in the hospital unit. Before reviewing the informed consent form (*Appendix F*) with the parent, eligibility was confirmed. After the research assistant reviewed the consent form with the parent, he or she was given sufficient time to review the form and ask any questions, which were answered thoroughly by the research team member. In the event that both a mother and father were interested in participating, separate consent forms were completed for each individual as they completed the survey individually. Two copies of the consent form were completed; one form was provided to the parent and one form was collected by the research assistant to be stored in a locked filing cabinet in the PI's office. In the event that a parent declined to participate in the study, the parent was thanked for his or her time and the outcome was documented in the log on the network drive.

Enrollment. After the parent agreed to participate and the informed consent forms were completed, the survey passcode, which consisted of the last four digits of the participant's phone number and his/her mother's birth year, was created by the parent. In the event a parent was unable to provide the mother's birth year for the passcode, he or she was instructed to use his or her own birth year. The passcode was recorded on both the thank you flyer provided to the parent and the research assistant's copy of the informed consent form. The survey passcode was provided by the parent at the start of the survey for the purpose of tracking survey completion in order to provide compensation, and to eliminate the need to include personal identifiers on the survey. During enrollment, the research assistant also gathered the following information: participant age, preferred method of survey completion, and mailing address in order to provide compensation after survey completion. Following enrollment, if the infant's other biological

parent had not yet been contacted, the research assistant requested contact information for that individual.

Survey Completion. The surveys were completed based on the date of discharge from either the NICU to home, transfer from the NICU to the SCN, or discharge from the SCN to home. In the event that an infant was scheduled to be discharge to home from the NICU or SCN, parents were eligible to complete the survey near discharge and remained eligible until two weeks post discharge. When an infant was transferred from the NICU to the SCN, parents became eligible to complete the survey based on their experiences in the NICU around the time of a planned transfer to the SCN and remained eligible until seven days after transfer to the SCN. Parents whose infant was hospitalized in both units for at least seven days each were eligible to take both surveys. These timelines for survey complete were created to ensure that after discharge memory of the time during hospitalization remained clear. Also, for infants who were hospitalized in both the NICU and SCN, the timeline ensured that the information provided on the survey reflected the time spent in unit of question.

There were several options parents were given for the mode of survey completion including: (a) in-person at Vidant Medical Center on a password-protected iPad, (b) on the participant's personal device (computer or cell phone), (c) on a paper copy mailed to the participant's home, (d) via phone call provided by a trained research assistant. The online survey was administered using the Qualtrics web-based software provided through East Carolina University. Gift cards valued at \$10 each were distributed in-person or by mail after survey completion. Parents were eligible for up to two gifts cards (one gift card per survey).

During survey administration if questions arose from the participant regarding the survey, the research team member recorded questions and how they were addressed using the Interviewer Question and Explanation Form (*Appendix G*). The form served as system in tracking consistency of interview responses to questions and the frequency that similar questions arose. During weekly team meetings the team members discussed any reoccurring questions and made recommendations for survey revision.

Electronic Health Record Review. A chart review of the enrolled infants' medical records was conducted by a trained member of the study team to extract information pertaining to NICU or SCN admission, medical progress, and hospital discharge. A comprehensive chart review was conducted to collect information pertaining to infant diagnoses, complications, and medical interventions received. Information pertaining to prenatal complications and maternal or infant complications in the delivery room was also recorded. Each infant received a medical severity score (*Table 3.2*) that was determined by a tier of medical diagnoses that range in medical complexity. The Medical Severity Form (*Appendix H*) was used to capture infant medical severity by allowing for a number from zero to seven based on the infants' medical diagnoses. A score of zero was least severe while a score of seven was most severe. This form previously created by researchers in a study aiming to modify the Perinatal Post Traumatic Stress Disorder (PTSD) Questionnaire (Callahan, Borja, & Hynan, 2006). Data related to parent visitation was also collected from the nursing notes in the infant's electronic medical record. Only relevant information for this study from this comprehensive health record review is summarized in *Table 3.2*.

Data Analyses

Descriptive statistics are included to describe the sample of parents who completed the NICU survey and the SCN survey (*Table 3.1*). Descriptive statistics, summarizing the medical information gathered from review of the electronic health record for the infants are also included (*Table 3.2*).

To address the aim of identifying barriers and facilitators contributing to parental visitation and involvement, the frequencies of Likert scale responses were summarized for each item from these sections of the survey. Items in these sections were then ordered based on the mean of the Likert scale responses. Higher averages represented barriers or facilitators that were more representative of the sample as a whole. In order to visually summarize the barriers and facilitators, bar graphs are included. Items related to parent activities performed while visiting were summarized in a similar way to barrier and facilitator items. Parent activities were ordered based on calculated means of Likert scale responses. Higher means represent the parent activities that are more frequently performed by the sample as a whole.

Ethical Concerns

The purpose and content of the study was presented in an honest manner to the participants. The participants were not deceived in any way and were given an opportunity to review the content of the study which is described in the Consent Form (*Appendix A*) before deciding to participate in the study. Participation was voluntary and participants were allowed to end their participation in the study at any time. Participant identity remains confidential and all data is stored on password protected computers.

No physical risks were associated with the participation in this study. Parents either completed the interview in-person or on a personal computer or cellular device. The survey included questions to gain understanding of parents' experiences in the NICU or SCN. If a parent had a traumatic experience in the NICU or SCN, he or she may have become emotional when recalling the events of the time the infant was hospitalized. Parents who may be having trouble coping with the medical issues were reminded that they do not have to take part in the survey if they did not wish to.

CHAPTER 4: RESULTS

The primary aim of the current study was to identify the barriers that hinder parent visitation and facilitators that promote parent visitation during infant hospitalization in a NICU or SCN. Identification of the ways in which parents are involved in infant care when visiting was also of interest.

The tables, which summarize the barriers (*Table 4.1, Table 4.2*), facilitators (*Table 4.3, Table 4.4*) and parent activities (*Table 4.5, Table 4.6*), are color-coded based on self-reported level of agreement with the states provided in the survey. The level of agreement is based on the percentage of parents who selected “completely agree” or “agree very much” for each of the statements. Green signifies that 75% or more parents selected these; blue signifies that between 50 and 74.4 % parents did; yellow signifies that between 25 and 49.9% did; and gray signifies less than 25% of parents selected “completely agree” or “agree very much” for the barrier statement.

What primary barriers to visitation do parents of hospitalized infants experience and how do barriers experienced by parents with infants in the NICU compare to those experienced by parents with infants in the SCN?

A barrier, as defined in this study, is a factor that hinders a parent’s ability to visit the NICU or to participate in infant care during hospitalization. Parents were prompted to rate their level of agreement with eighteen barriers, which potentially hinder parent visitation, provided on the survey. Five point Likert-scale responses (1=does not apply at all, 2=applies a little, 3=applies somewhat, 4=applies very much, 5=applies completely) were recorded.

NICU Group. Thirty-one parents completed surveys about their experiences during infant hospitalization in the NICU. Of the 31 parents, the greatest amount of parents selected “completely agree” or “agree very much” for “I live far away from the hospital” (32.3%), “I had other children at home” (29.1%), and for “I had to take care of my home” (25.4%). These barriers are shaded yellow in *Table 4.1*. Less than 25% of parents selected “completely agree” or “agree very much” for all of the remaining barrier statements, which are shaded gray in *Table 4.1*. This table displays the barriers in descending order of percentage of parents who selected “completely agree” or “agree very much” for each of the barriers. The barriers that had the least impact on parent visitation during infant hospitalization have greater percentages of parents who selected “does not apply at all.” As seen in *Table 4.1*, it is noteworthy that 75% or more of parents selected “does not apply at all” for barriers including, “The medical terms and hospital environment made me uncomfortable,” “It was difficult to communicate with the NICU staff”, “The NICU staff did not encourage me or show me how to care for my baby”, “Information about my baby’s condition was not provided”, “I was not treated well by the NICU staff”, and “My baby did not respond well when I visited (e.g., was difficult, fussy, cried).” *Table 4.1* also includes the mean and standard deviation of the Likert-scale responses selected for each of the barrier statements, but is organized by level of agreement with each barrier statement. Barriers are listed in descending order based on percentage of parents who selected “completely agree” or “agree very much.”

Barriers organized by the mean of responses are included in *Figure 4.1*. This alternative way of viewing the data shows that “I live far away from the hospital” ($M = 2.87$, $SD = 1.408$) was the most applicable overall barrier, which is also the case when ranked by percentage of parents who selected “completely agree” or “agree very much.” However, the second most

applicable barrier according to the mean (*Figure 4.1*) is “I had to take care of my home” (M = 2.84, SD =1.128) (versus “I had other children at home” using the percentage agreement method) (*Table 4.1*). As seen in both *Table 4.1* and *Figure 4.1*, “My baby did not respond well when I visited (e.g., was difficult, fussy, cried)” (M = 1.10, SD = 0.301) was the least applicable barrier to the sample of parents.

Table 4.1

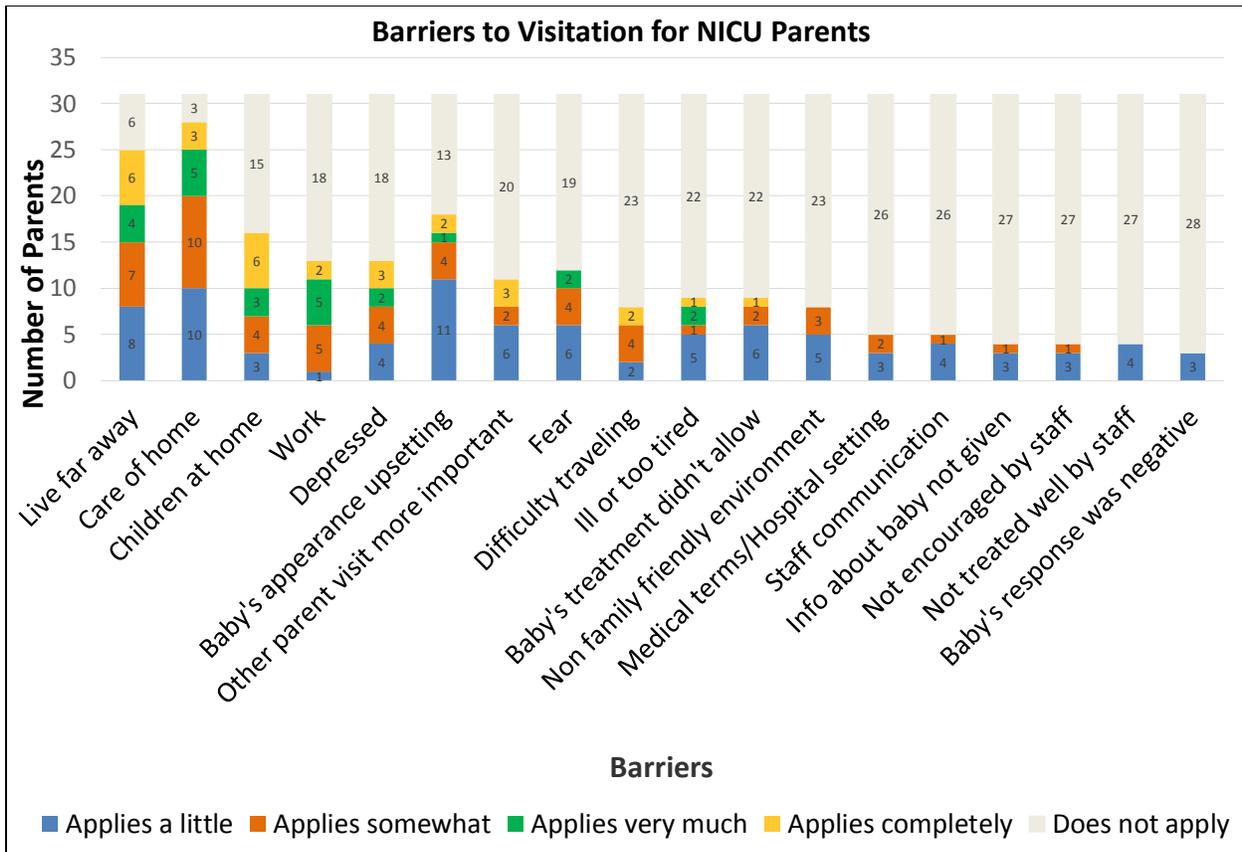
NICU Group Barriers to Visitation

Barrier	N	M(SD)	Applies completely N(%)	Applies very much N(%)	Applies somewhat N(%)	Applies a little N(%)	Does not apply at all N(%)
I live far away from the hospital.	31	2.87 (1.41)	6 (19.40)	4 (12.90)	7 (22.60)	8 (25.80)	6 (19.40)
I had other children at home.	31	2.42 (1.63)	6 (19.40)	3 (9.70)	4 (12.90)	3 (9.70)	15 (48.40)
I had to take care of my home.	31	2.84 (1.13)	3 (9.70)	5 (16.10)	10 (32.30)	10 (32.30)	3 (9.70)
I had to work.	31	2.10 (1.42)	2 (6.50)	5 (16.10)	5 (16.10)	1 (3.20)	18 (58.10)
It was more important for the other parent to be here	31	1.71 (1.24)	3 (9.70)	0 (0.00)	2 (6.50)	6 (19.40)	20 (64.50)
It upset me to see the way my baby looked or acted, or the treatments my baby was receiving.	31	1.97 (1.14)	2 (6.50)	1 (3.20)	4 (12.90)	11 (35.50)	13 (41.90)
I was ill and/or too tired	31	1.55 (1.06)	1 (3.20)	2 (6.50)	1 (3.20)	5 (16.10)	22 (71.00)
I was afraid to be involved in my baby’s care because of the baby’s size or condition.	31	1.65 (0.95)	0 (0.00)	2 (6.50)	4 (12.90)	6 (19.40)	19 (61.30)
I did not have a way to get to the hospital easily.	31	1.58 (1.15)	2 (6.5)	0 (0.00)	4 (12.90)	2 (6.50)	23 (74.2)

My baby's treatment did not allow me to be involved with my baby.	31	1.45 (0.89)	1 (3.2)	0 (0.00)	2 (6.50)	6 (19.40)	22 (71.00)
The NICU environment was not family-friendly (for example, it was noisy; lack of privacy).	31	1.35 (0.66)	0 (0.00)	0 (0.00)	3 (9.70)	5 (16.10)	23 (74.20)
The medical terms and hospital environment made me uncomfortable.	31	1.23 (0.56)	0 (0.00)	0 (0.00)	2 (6.50)	3 (9.70)	26 (83.90)
It was difficult to communicate with the NICU staff	31	1.19 (0.45)	0 (0.00)	0 (0.00)	1 (3.20)	4 (12.90)	26 (83.90)
The NICU staff did not encourage me or show me how to care for my baby	31	1.16 (0.45)	0 (0.00)	0 (0.00)	1 (3.20)	3 (9.70)	27 (87.10)
Information about my baby's condition was not provided	31	1.16 (0.45)	0 (0.00)	0 (0.00)	1 (3.20)	3 (9.70)	27 (87.10)
I was not treated well by the NICU staff.	31	1.13 (0.34)	0 (0.00)	0 (0.00)	0 (0.00)	4 (12.90)	27 (87.10)
My baby did not respond well when I visited (e.g., was difficult, fussy, cried).	31	1.10 (0.30)	0 (0.00)	0 (0.00)	0 (0.00)	3 (9.70)	28 (90.30)

*Gray = 0-24.9%, yellow = 25-49.9%, blue = 50-74.4%, green = 75-100% “completely agree” or “agree very much.”

Figure 4.1



SCN Group. Of the eighteen barriers, only four barriers were rated as “applies completely” or “applies very much.” These barriers included, “I live far away from the hospital”, “I had to work”, “I had other children at home to care for” rated by two parents as “applies very much”, and “I had to take care of my home” rated by one parent as “applies completely” (Table 4.2). All barriers, included the four mentioned above, were rated as “applies completely” or “applies very much” by less than 25% of parents, which is represented by the gray shade in Table 4.2. Overall, more parents tended to disagree than agree with the barriers statements. Specifically, twelve barriers were rated “does not apply at all” by 75% or more of the parents. These barriers included: fear of being involved due to the baby’s condition, being upset due to the way the baby looked, poor response from the baby during parents’ visitation, inability to be

involved due to the baby’s treatments, feeling uncomfortable due to the medical environment, lack of transportation, parent sickness or fatigue, a non-family friendly environment, mistreatment by the staff, lack of information about the baby’s health, lack of encouragement from the staff to participate in care, and difficulty communicating with SCN staff.

Figure 4.2, displays the barriers from most applicable to least applicable according to the mean of the Likert-scale responses. When interpreted based on the means of Likert-scale responses, the most applicable barrier was “I had to take care of my home” (M = 2.50, SD = 1.01). This differs from most applicable barriers based on level of agreeance, as stated above and as seen in *Table 4.2*. The least applicable barriers were “The NICU environment was not family-friendly (for example, it was noisy; lack of privacy) (M = 1.00, SD = 0.00), “Information about my baby’s condition was not provided” (M = 1.00, SD = 0.00), “The NICU staff did not encourage me or show me how to care for my baby” (M = 1.00, SD = 0.000), “I was ill and/or too tired” (M = 1.00, SD = 0.00), “I was not treated well by the NICU staff” (M = 1.00, SD = 0.00), and “It was difficult to communicate with the NICU staff” (M = 1.00, SD = 0.00) (*Table 4.2*).

Table 4.2

SCN Group Barriers to Visitation

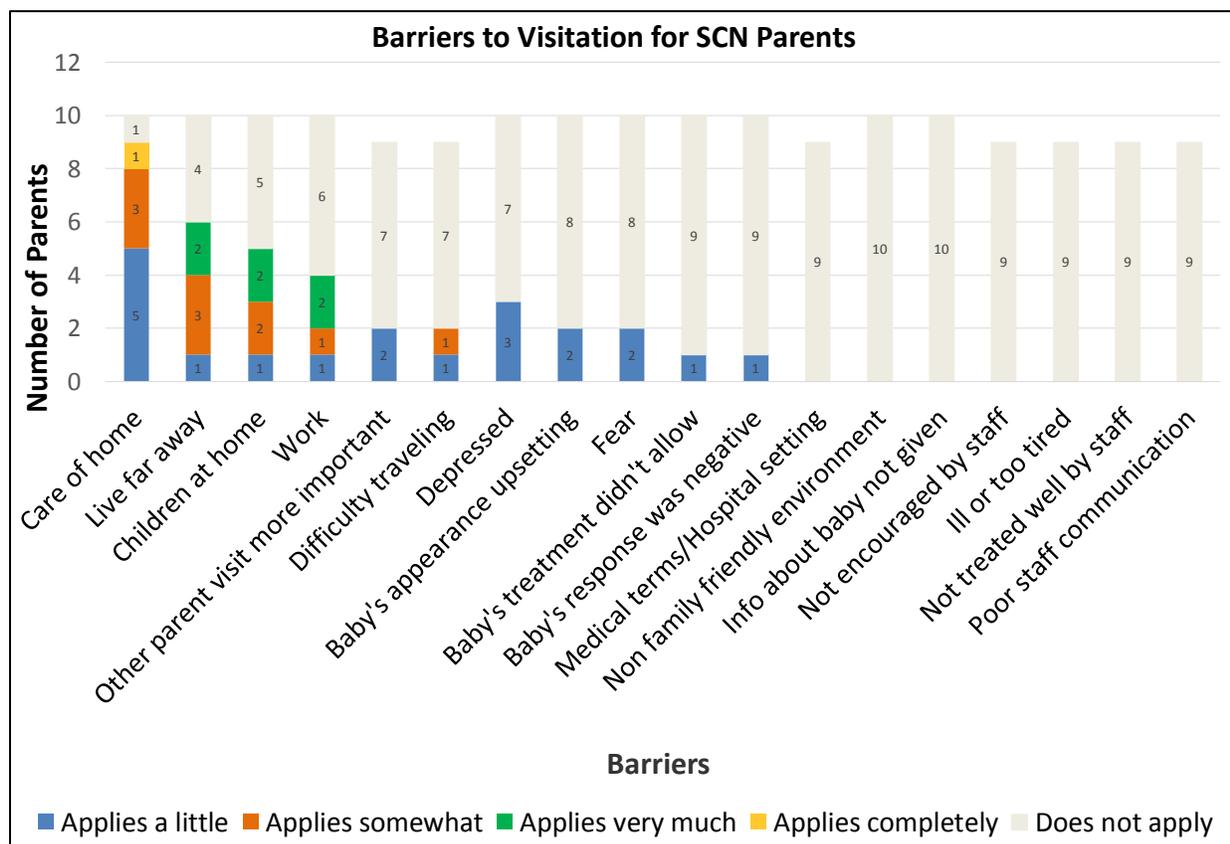
Barrier	N	M(SD)	Applies completely N(%)	Applies very much N(%)	Applies somewhat N(%)	Applies a little N(%)	Does not apply at all N(%)
I live far away from the hospital.	10	2.30 (1.25)	0 (0.00)	2 (20.00)	3 (30.00)	1 (10.00)	4 (40.00)
I had to work.	10	1.90 (1.29)	0 (0.00)	2 (20.00)	1 (10.00)	1 (10.00)	6 (60.00)

I had other children at home to care for.	10	2.10 (1.29)	0 (0.00)	2 (20.00)	2 (20.00)	1 (10.00)	5 (50.00)
I had to take care of my home.	10	2.50 (1.08)	1 (10.00)	0 (0.00)	3 (30.00)	5 (50.00)	1 (10.00)
It was more important for the other parent to be here.	10	1.40 (0.70)	0 (0.00)	0 (0.00)	1 (10.00)	2 (20.00)	7 (70.00)
I felt depressed after the baby's birth.	10	1.30 (0.48)	0 (0.00)	0 (0.00)	0 (0.00)	3 (30.00)	7 (70.00)
I was afraid to be involved in my baby's care because of the baby's size or condition.	10	1.20 (0.42)	0 (0.00)	0 (0.00)	0 (0.00)	2 (20.00)	8 (80.00)
It upset me to see the way my baby looked or acted, or the treatments my baby was receiving.	10	1.20 (0.42)	0 (0.00)	0 (0.00)	0 (0.00)	2 (20.00)	8 (80.00)
My baby did not respond well when I visited (e.g., was difficult, fussy, cried).	10	1.10 (0.32)	0 (0.00)	0 (0.00)	0 (0.00)	1 (10.00)	9 (90.00)
My baby's treatment did not allow me to be involved with my baby.	10	1.10 (0.32)	0 (0.00)	0 (0.00)	0 (0.00)	1 (10.00)	9 (90.00)
The medical terms and hospital environment made me uncomfortable	10	1.10 (0.32)	0 (0.00)	0 (0.00)	0 (0.00)	1 (10.00)	9 (90.00)
I did not have a way to get to the hospital easily.	9	1.33 (0.71)	0 (0.00)	0 (0.00)	1 (11.10)	1 (11.10)	7 (77.80)
I was ill and/or too tired.	9	1.00 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	9 (100.00)
The SCN environment was not family-friendly	10	1.00 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	10 (100.00)

(for example, it was noisy; lack of privacy).							
I was not treated well by the SCN staff.	9	1.00 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	9 (100.00)
Information about my baby's condition was not provided.	10	1.00 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	10 (100.00)
The SCN staff did not encourage me or show me how to care for my baby.	10	1.00 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	10 (100.00)
It was difficult to communicate with the SCN staff.	9	1.00 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)	9 (100.00)

*Gray = 0-24.9%, yellow = 25-49.9%, blue = 50-74.4%, green = 75-100% “completely agree” or “agree very much.”

Figure 4.2



What primary facilitators to visitation do parents of hospitalized infants experience and how do facilitators experienced by parents with infants in the NICU compare to those experienced by parents with infants in the SCN?

A facilitator, as defined in this study, is a factor that promotes parental visitation during infant hospitalization. Parents were asked to rate their level of agreement with eleven barrier statements provided on the survey by selecting “does not apply at all,” “applies a little,” “applies somewhat,” “applies very much,” or “applies completely.”

NICU Group. All eleven facilitators were rated as “applies completely” or “applies very much” by 75% or more of parents. Facilitators rated “applies completely” by 75% or more of parents included, “The NICU medical and nursing staff gave my baby high-quality care”, “I could come and go in the NICU freely”, “The NICU staff answered my questions honestly”, “My baby responded well when I visited”, “The NICU staff gave me information about my baby's condition and care when I visited”, “The NICU staff treated me well” (*Table 4.3*). When the facilitators were ranked in ascending order according to the mean of the responses, the most applicable facilitator was “The NICU medical and nursing staff gave my baby high-quality care” ($M = 4.90, SD = 0.30$), and the least applicable facilitator was “Seeing other parents take care of their baby made me feel like I could do it, too” ($M = 4.01, SD = 1.50$) (*Table 4.3*).

Figure 4.3 provides a visual presentation of the overall influence of each facilitator on the parents during infant hospitalization in the NICU. This bar graph provides the facilitators in order of importance to the parents according to the mean of responses. As described previously, many of the facilitators were rated as “applies completely” or “applies very much.” This is represented in the graph by the amount of yellow and green portions of the bars. Also, the graph

clearly depicts that “Seeing others parents participate” is the only barrier that received “does not apply at all” ratings.

Table 4.3

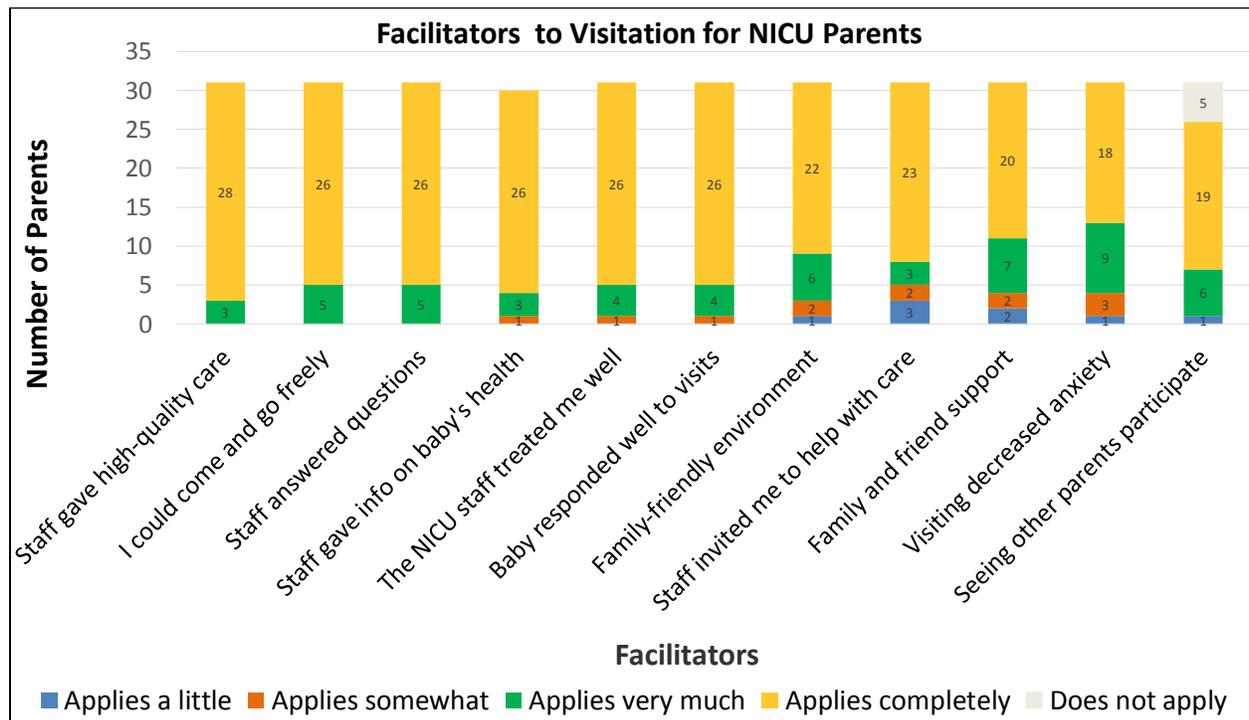
NICU Facilitators of Visitation

Facilitators	N	M(SD)	Applies completely N(%)	Applies very much N(%)	Applies somewhat N(%)	Applies a little N(%)	Does not apply at all N(%)
The NICU medical and nursing staff gave my baby high-quality care.	31	4.90 (0.30)	28 (90.30)	3 (9.70)	0 (0.00)	0 (0.00)	0 (0.00)
I could come and go in the NICU freely	31	4.84 (0.37)	26 (83.90)	5 (16.10)	0 (0.00)	0 (0.00)	0 (0.00)
The NICU staff answered my questions honestly.	31	4.84 (0.37)	26 (83.90)	5 (16.10)	0 (0.00)	0 (0.00)	0 (0.00)
My baby responded well when I visited.	31	4.81 (0.48)	26 (83.90)	4 (12.90)	1 (3.20)	0 (0.00)	0 (0.00)
The NICU staff gave me information about my baby's condition and care when I visited.	30	4.83 (0.46)	26 (86.70)	3 (10.00)	1 (3.30)	0 (0.00)	0 (0.00)
The NICU staff treated me well.	31	4.81 (0.48)	26 (83.90)	4 (12.90)	1 (3.20)	0 (0.00)	0 (0.00)
The NICU staff invited me to help with my baby's care.	31	4.48 (0.10)	23 (74.20)	3 (9.70)	2 (6.50)	3 (9.70)	0 (0.00)
The NICU environment was family-friendly (for example, a place	31	4.58 (0.77)	22 (71.00)	6 (19.40)	2 (6.50)	1 (3.20)	0 (0.00)

for me to sit next to the baby's bed).							
Support from family and friends such as meal preparation, help with household tasks and/or childcare.	31	4.45 (0.89)	20 (64.50)	7 (22.60)	2 (6.50)	2 (6.50)	0 (0.00)
Seeing other parents take care of their baby made me feel like I could do it, too	31	4.01 (1.50)	19 (61.30)	6 (19.40)	0 (0.00)	1 (3.20)	5 (16.10)
I felt overly anxious and visiting helped me feel better.	31	4.42 (0.81)	18 (58.10)	9 (29.00)	3 (9.70)	1 (3.20)	0 (0.00)

*Gray = 0-24.9%, yellow = 25-49.9%, blue = 50-74.4%, green = 75-100% “completely agree” or “agree very much.”

Figure 4.3



SCN Group. All facilitator statements were rated as “applies completely” or “applies very much” by 75% or more parents except, “Support from family and friends such as meal preparation, help with household tasks and/or childcare”, which was rated as “applies completely” or “applies very much” by 70% of the parents (*Table 4.4*). According to the mean of responses for each statement, the most applicable facilitator for SCN parents was “I could come and go in the SCN freely” ($M = 5.00$, $SD = 0.00$), and the least applicable facilitator was “I felt overly anxious and visiting helped me feel better” ($M = 4.00$, $SD = 1.63$) (*Table 4.4*). *Figure 4.4* displays the facilitators organized in descending order by mean. When looking at the graph, it is clear that overall, all of the statements were relatively applicable to the parents, as the portion of yellow (“applies completely”) and green (“applies very much”) is larger than that of the other colors (“applies somewhat, applies a little, and does not apply”).

Table 4.4

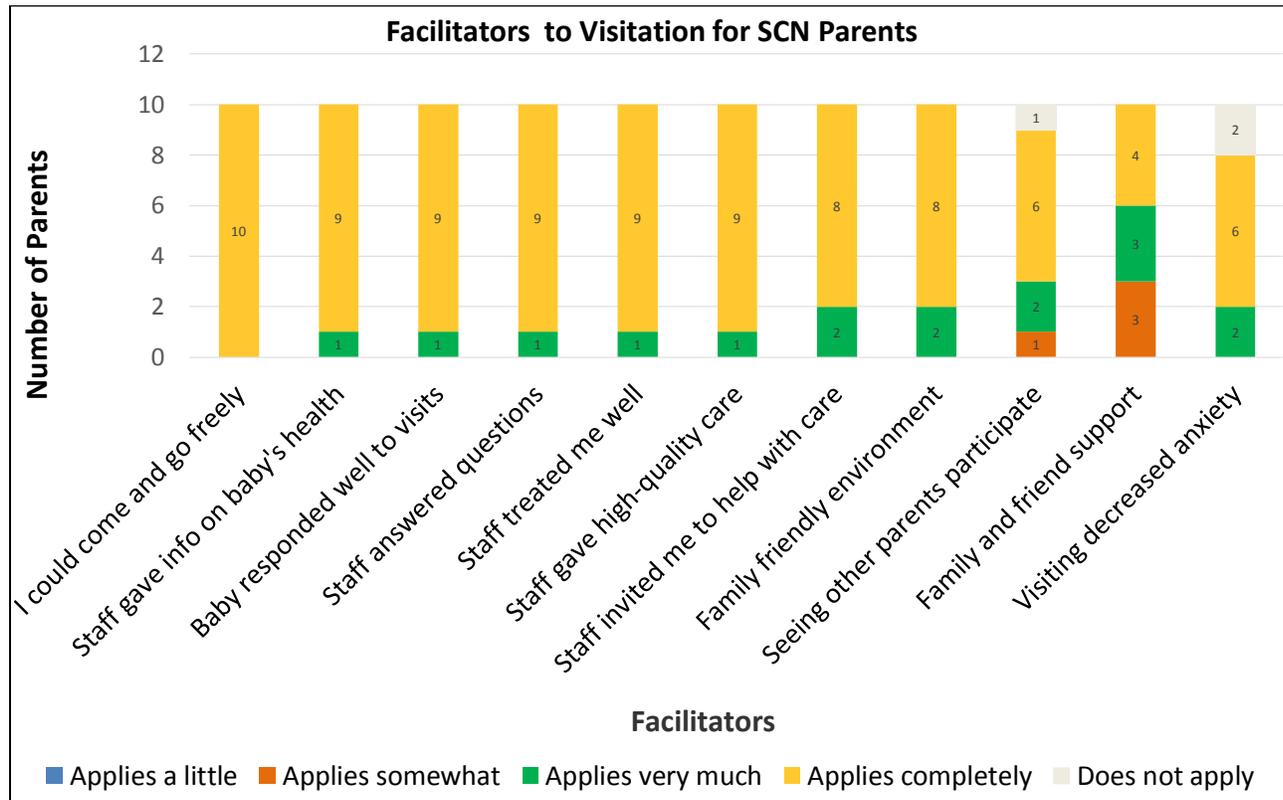
SCN Facilitators of Visitation

Facilitators	N	M(SD) N(%)	Applies completely N(%)	Applies very much N(%)	Applies somewhat N(%)	Applies a little N(%)	Does not apply at all N(%)
I could come and go in the SCN freely.	10	5.00 (0.00)	10 (100.00)	0 (0.00)	0 (0.00)	0 (0.00)	0 (0.00)
The SCN staff gave me information about my baby's condition and care when I visited.	10	4.90 (0.32)	9 (90.00)	1 (10.00)	0 (0.00)	0 (0.00)	0 (0.00)
The SCN staff treated me well.	10	4.90 (0.32)	9 (90.00)	1 (10.00)	0 (0.00)	0 (0.00)	0 (0.00)
The SCN medical and nursing staff	10	4.90 (0.32)	9 (90.00)	1 (10.00)	0 (0.00)	0 (0.00)	0 (0.00)

gave my baby high-quality care.							
My baby responded well when I visited.	10	4.90 (0.32)	9 (90.00)	1 (10.00)	0 (0.00)	0 (0.00)	0 (0.00)
The SCN staff answered my questions honestly.	10	4.90 (0.32)	9 (90.00)	1 (10.00)	0 (0.00)	0 (0.00)	0 (0.00)
The SCN staff invited me to help with my baby's care.	10	4.80 (0.42)	8 (80.00)	2 (20.00)	0 (0.00)	0 (0.00)	0 (0.00)
The SCN environment was family-friendly (for example, a place for me to sit next to the baby's bed).	10	4.80 (0.42)	8 (80.00)	2 (20.00)	0 (0.00)	0 (0.00)	0 (0.00)
Seeing other parents take care of their baby made me feel like I could do it, too.	10	4.20 (1.32)	6 (60.00)	2 (20.00)	1 (10.00)	0 (0.00)	1 (10.00)
I felt overly anxious and visiting helped me feel better.	10	4.00 (1.63)	6 (60.00)	2 (20.00)	0 (0.00)	0 (0.00)	2 (20.00)
Support from family and friends such as meal preparation, help with household tasks and/or childcare.	10	4.10 (0.88)	4 (40.00)	3 (30.00)	3 (30.00)	0 (0.00)	0 (0.00)

*Gray = 0-24.9%, yellow = 25-49.9%, blue = 50-74.4%, green = 75-100% “completely agree” or “agree very much.”

Figure 4.4



How do parents who visit their infant during hospitalization participate in infant care and how does participation of parents with infants in the NICU compare to participation by parents with infants in the SCN?

Parents were asked to provide a rating to reflect how often they participated in eleven activities with the infant while visiting. Parents rated their level of participation in each of the eleven activities on a provided Likert-scale including always (5), often (4), sometimes (3), occasionally (2), and never (1).

NICU group. Observing the baby, talking, singing, and/or reading to the baby, eye contact with the baby, and stroking, touching, or massage were “always” or “often” performed by 75% or more of parents the NICU group (Table 4.5). Observing the baby was participated in

more than any other activity ($M = 4.77$, $SD = 0.62$; $M = 4.90$, $SD = 0.32$) (*Table 4.5, Figure 4.5*). Diaper changes and holding (not Kangaroo Care type) were “Always” or “often” participated less than 75% but greater than 50% of the parents in the NICU group, as represented by the blue shaded barriers (*Table 4.5*). Fewer parents, shaded in yellow, “always” or “often” participated in Kangaroo Care (48.80%), bottle feeding (38.80%) or assisted staff with procedures (30.00%). Bathing or washing the baby’s body or face and breastfeeding were “always” or “often” participated in by less than 25% of parents, as seen by the gray shaded area in *Table 4.5*. Breast feeding was participated in the least ($M = 1.42$, $SD = 0.958$) (*Table 4.5, Figure 4.5*).

Table 4.5

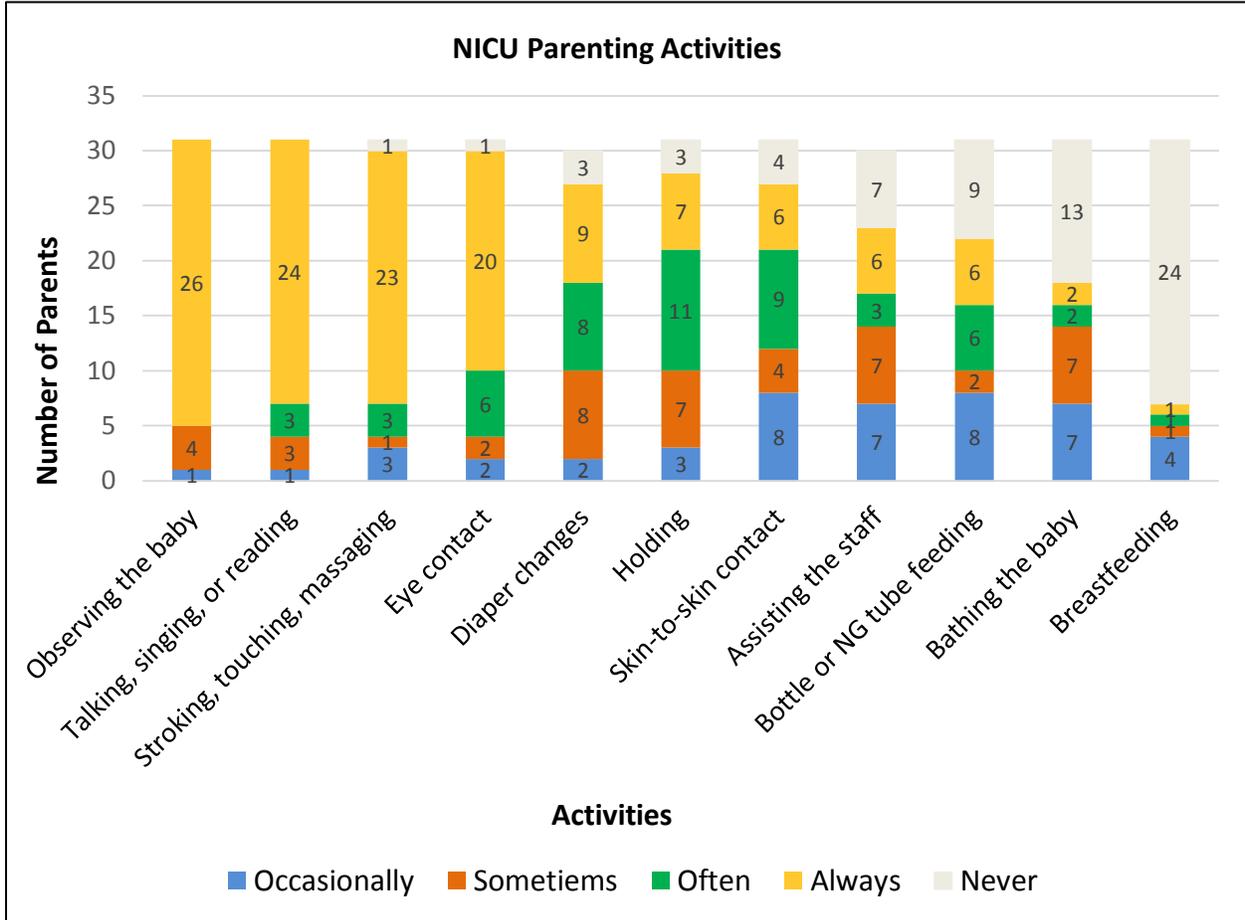
NICU Parent Activities Mean, Standard Deviation, and Frequencies

Activity	N	M(SD)	Always N(%)	Often N(%)	Sometimes N(%)	Occasionally N(%)	Never N(%)
Observing the baby	31	4.77 (0.62)	26 (83.90)	4 (12.90)	0 (0.00)	1 (3.20)	0 (0.00)
Talking, singing, and/or reading to the baby	31	4.61 (0.80)	24 (77.40)	3 (9.70)	3 (9.70)	1 (3.20)	0 (0.00)
Stroking, touching, or massage	31	4.42 (1.15)	23 (74.20)	3 (9.70)	1 (3.20)	3 (9.70)	1 (3.20)
Eye Contact with the Baby	31	4.35 (1.01)	20 (64.50)	6 (19.40)	2 (6.50)	2 (6.50)	1 (3.20)
Diaper changes	30	3.60 (1.28)	9 (30.00)	8 (26.70)	8 (26.70)	2 (6.70)	3 (10.00)
Holding (not Kangaroo care type)	31	3.52 (1.24)	7 (22.60)	11 (35.50)	7 (22.60)	3 (9.70)	3 (9.70)
Skin-to-skin contact (Kangaroo-care or holding the baby against your bare chest)	31	3.16 (1.37)	6 (19.40)	9 (29.00)	4 (12.90)	8 (25.80)	4 (12.90)

Bottle-feeding or nasogastric/gastric tube feeding (with or without nursing assistance)	31	2.74 (1.55)	6 (19.40)	6 (19.40)	2 (6.50)	8 (25.80)	9 (29.00)
Assisting the staff with procedures with the baby	30	2.80 (1.45)	6 (20.00)	3 (10.00)	7 (23.30)	7 (23.30)	7 (23.30)
Bathing or washing the baby's body or face	31	2.13 (1.23)	2 (6.50)	2 (6.50)	7 (22.60)	7 (22.60)	13 (41.90)
Breastfeeding	31	1.42 (0.96)	1 (3.20)	1 (3.20)	1 (3.20)	4 (12.90)	24 (77.40)

*Gray = 0-24.9%, yellow = 25-49.9%, blue = 50-74.4%, green = 75-100% “completely agree” or “agree very much.”

Figure 4.5



SCN Group. Observing the baby, talking, singing, and/or reading to the baby, eye contact with the baby, and stroking, touching, or massage were “always” or “often” performed by 75% or more of parents in the SCN group (Table 4.6). Furthermore, observing the baby was participated in more often by parents than any other activity (M = 4.90, SD = 0.316) (Table 4.6, Figure 4.6). A less amount of time was spent assisting the staff with procedures with the baby, and bathing or washing the baby's body or face, as represented by the blue shaded area (50-74.4%, “always” or “often”) in Table 4.6. Kangaroo care was performed “always” or “often” by even fewer parents (40.00%), as represented by the yellow shaded area. Breast feeding was

“always” or “often participated in by least amount of parents in the SCN group (10.00%), as represented by the gray shaded area.

Table 4.6

SCN Parent Activities Mean, Standard Deviation, and Frequencies

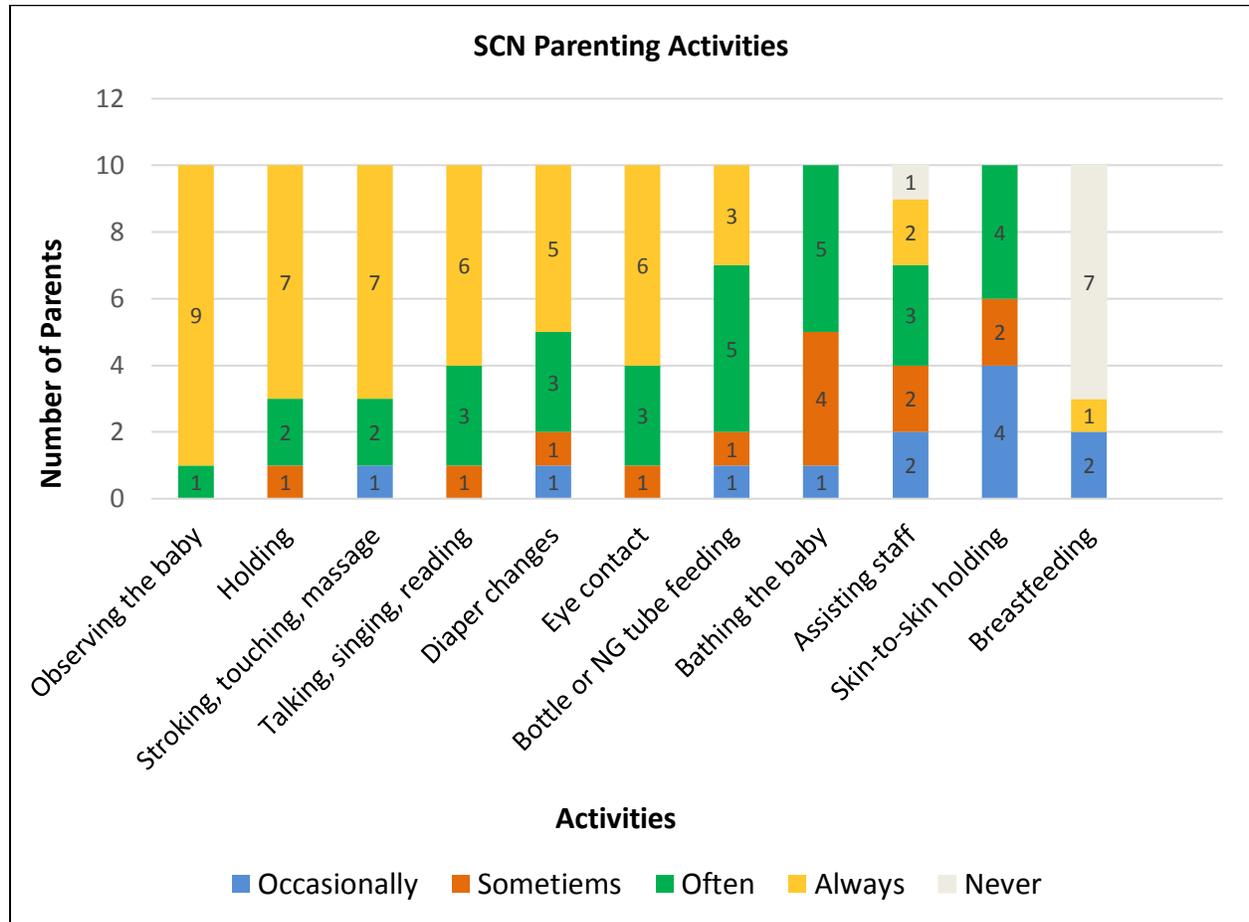
Activity	N	M(SD)	Always N(%)	Often N(%)	Sometimes N(%)	Occasionally N(%)	Never N(%)
Observing the baby	10	4.90 (0.32)	9 (90.00)	1 (10.00)	0 (0.00)	0 (0.00)	0 (0.00)
Holding (not Kangaroo care type)	10	4.60 (0.70)	7 (70.00)	2 (20.00)	1 (10.00)	0 (0.00)	0 (0.00)
Stroking, touching, or massage	10	4.50 (0.97)	7 (70.00)	2 (20.00)	0 (0.00)	1 (10.00)	0 (0.00)
Talking, singing, and/or reading to the baby	10	4.50 (0.71)	6 (60.00)	3 (30.00)	1 (10.00)	0 (0.00)	0 (0.00)
Diaper changes	10	4.20 (1.00)	5 (50.00)	3 (30.00)	1 (10.00)	1 (10.00)	0 (0.00)
Eye contact with the baby	10	4.20 (1.00)	5 (50.00)	3 (30.00)	1 (10.00)	1 (10.00)	0 (0.00)
Bottle-feeding or nasogastric/gastric tube feeding (with or without nursing assistance)	10	4.00 (0.94)	3 (30.00)	5 (50.00)	1 (10.00)	1 (10.00)	0 (0.00)
Assisting the staff with procedures with the baby	10	3.30 (1.34)	2 (20.00)	3 (30.00)	2 (20.00)	2 (20.00)	1 (10.00)
Bathing or washing the baby's body or face	10	3.40 (0.70)	0 (0.00)	5 (50.00)	4 (40.00)	1 (10.00)	0 (0.00)
Skin-to-skin contact (Kangaroo-care)	10	3.00 (0.94)	0 (0.00)	4 (40.00)	2 (20.00)	4 (40.00)	0 (0.00)

or holding the baby against your bare chest)

Breastfeeding	10	1.60 (1.27)	1 (10.00)	0 (0.00)	0 (0.00)	2 (20.00)	7 (70.00)
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*Gray = 0-24.9%, yellow = 25-49.9%, blue = 50-74.4%, green = 75-100% “completely agree” or “agree very much.”

Figure 4.6



CHAPTER 5: DISCUSSION

This study identified the barriers and facilitators of visitation experienced by parents of infants hospitalized in a local NICU and SCN, as well as the parent involvement in care during visits. As the two hospital units have unique environments, the results were analyzed separately. This section explores the similarities and differences between the hospital units for each of the primary aims.

What primary barriers to visitation do parents of hospitalized infants experience and how do barriers experienced by parents with infants in the NICU compare to those experienced by parents with infants in the SCN?

Barriers to visitation for both parents in the NICU group and the SCN group were overall the same. The interpretation of the results are provided in one section that summarizes findings for parents in both groups.

NICU and SCN groups. The common, most applicable barriers to visitation for both NICU and SCN parents were intrinsic factors, or those related to the parents themselves rather than extrinsic factors related to the hospital environment or infant condition. These barriers included distance the parents lived from the hospital, having other children at home to care for, and taking care of the home or household responsibilities. Parents in the SCN group also reported work responsibilities as a major barrier.

As expected, distance from the hospital was reported as a barrier for parents. Vidant Medical Center serves 29 counties in eastern North Carolina making it likely that parents live a great distance from the hospital. The average distance from the parents' home addresses to Vidant Medical Center was 35.3 miles ($SD = 19.5$), and range was 2.80 miles to 69.40 miles.

Living far away from the hospital has also been documented as a barrier to parental visitation in prior literature (Greene et al., 2015; Latva et al., 2007; Wigert et al., 2013). A second common barrier was the responsibility of caring for other children at home. On average, parents in the NICU group ($n = 28$) had 1.14 ($SD = 1.208$) additional children living in their home and parents in the SCN group ($n = 9$) had 1.33 ($SD = 1.658$) additional children living in their home. Providing child care at home has been widely reported in previous studies investigating parental barriers to visitation (Feeley et al., 2013b; Franck & Spencer, 2003; Garten, Maass, Schmalisch & Buhner, 2011; Greene et al., 2015; Latva et al., 2007; Wigert, et al., 2010). The third most applicable barrier was that of household responsibilities. Home maintenance has been reported as a barrier to visitation during infant hospitalization by prior studies (Feeley et al., 2013b; Wigert et al., 2010). Employment was reported as an influential barrier by parents in the SCN. This barrier is supported by findings of prior research studies that have conducted parent interviews yielding qualitative data (Feeley et al., 2013b; Greene, et al., 2015; Pohlman, 2005; Wigert et al., 2010).

Although these barriers were reported as strong barriers by some parents in the NICU groups, according to visitation data, it appears that many parents were able to overcome the barriers to visitation as NICU parents visited on average 75.3% of the days their infant was hospitalized while 43.5% were able to visit at least 80% of the days. Furthermore, due to the requirement that parents be physically present at the NICU or SCN to complete the informed consent process with a research assistant, the sample of parents is likely representative of parents who were able to visit. The in-person consent requirement may have made it difficult to include parents who were unable to visit or rarely visited. Therefore, barriers to visitation for these

parents were not reflected in the results. This limitation is discussed further in the *Limitations* section.

It is encouraging that barriers related to extrinsic factors were not reported by parents. Specifically, statements related to the treatment the baby was receiving, the medical frailty of the baby, and the response of the baby to parent involvement, were not reported as barriers. This is surprising especially for the infants hospitalized in the NICU, who received invasive respiratory treatment. Ten infants in the NICU received Continuous Positive Airway Pressure (CPAP), two were intubated, and six were ventilator dependent (*Table 3.2*). Furthermore, according to the medical severity score used, the average severity score for infants in the NICU was a 4.01 (out of 7). In contrast to the findings in the current study, numerous prior studies have found the health of the infant and the medical treatment to hinder parent visitation (Feeley, et al., 2013b; Gonya & Nelin, 2013; Levy-Shiff, Hoffman, Mogilner, Levinger, & Mogilner 1990; Latva, Lehtonen, Salmelin, & Tamminen, 2007).

Another inconsistency between the findings of the current study and prior literature is related to the differences in the environments of the NICU and SCN at Vidant Medical Center. Research has shown that high levels of noise and illumination (Heinemann, Hellström-Westas, and Nyqvist, 2013), the controlled hospital environment (Feeley et al. (2013b), and a non-family friendly environment to be restrictive of parent visitation (Feeley et al., 2013b; Wigert, et al., 2010). NICU in the current study has pods with twelve bed spaces that have one patient per space but are only separated from the hallway by a draw curtain, whereas the SCN includes 28 private rooms with sound-proof barriers. It is surprising that parents in the NICU group did not report any of the factors related to the medical environment as barriers to visitation. This positive finding may signify that NICU staff are successful in providing a family-friendly, noise reduced

environment which promotes parental presence and is beneficial for infant development (Carbajal et al., 2008).

What primary facilitators to visitation do parents of hospitalized infants experience and how do facilitators experienced by parents with infants in the NICU compare to those experienced by parents with infants in the SCN?

Like the barriers to visitation, facilitators to visitation were largely similar between parents in the NICU group and parents in the SCN group. A summary of the exceptional findings between the groups is provided below. The interpretation of these findings for both groups are described together in one section, as there were minimal difference between the groups.

NICU group. All of the facilitator statements included in the survey were found to promote visitation during infant hospitalization for the NICU group, indicated by 75% or more parents reporting that the statements “applied completely” or “applied very much.”

SCN group. For the SCN group all facilitator statements except receiving support from family and friends were reported as “applies completely” or “applies very much” by 75% or more of parents. The strongest facilitators related to positive relationships and treatment provided by staff members.

NICU and SCN groups. The findings of the current study contrast findings in several prior studies. Specifically, lack of effective communication with staff (Gonya & Nelin, 2013; Ward, 2001; Wigert et al., 2010) and general mistreatment by staff (Wigert et al., 2010) were found to hinder parent visitation. In the current study, these factors were not reported as barriers to visitation, but in contrast, relationships with staff, were reported as facilitators of visitation in the current study. Furthermore, “My baby did not respond well when I visited” was found to be a

barrier to visitation in prior studies (Feeley et al., 2013b; Levy-Shiff, Hoffman, Mogilner, Levinger, & Mogilner 1990), but in the current study the baby's positive response during visits was reported by parents as a strong facilitator of visitation (*Table 4.3, Table 4.4*). This is also surprising, as prior literature have reported that preterm infants are typically less attentive, are less reactive, display lower levels of orientation to their mother's faces, and their facial expressions of emotions are more often difficult to interpret (DeMier et al., 2000; Forcada-Guex, Borghini, Pierrehumbert, Ansermet, & Muller-Nix, 2011). Although infants in the current study may have displayed some of these negative behaviors, parents reported that infant behavior during visitation was a facilitator that promoted their presence.

As described previously, there are many differences between the environment of the NICU and SCN at Vidant Medical Center (see *Literature Review*). Therefore, it is surprising that facilitators related to the environment of the unit did not differ between parents in the NICU group and parents in the SCN group. Prior literature has found that parental presence during infant hospitalization is promoted by a single family room environment (Carter, Carter, & Bennett, 2008; Harris, Shepley, White, Kolberg, & Harrell, 2006). Specifically, single family rooms provide more privacy, which contributes to increased parental visitation and involvement (Harris, et al., 2006). In the current study, parents in both groups reported that the environment was family friendly, which facilitated their presence. Both groups also reported that the ability to come and go freely supported their presence, which is consistent with the open, 24-hour visitation policy of both units.

How do parents who visit their infant during hospitalization participate in infant care and how does participation of parents with infants in the NICU compare to participation by parents with infants in the SCN?

NICU group. Parents of infants hospitalized in the NICU were most involved in observing the baby, talking, singing, and/or reading to the baby stroking, touching, or massage, and making eye contact with the baby (*Table 4.5*). Bathing or washing the baby's body or face, and breast feeding were participated in the least by parents in the NICU group.

SCN group. Observing the baby, holding (not Kangaroo care type), stroking, touching, or massage, talking, singing, and/or reading to the baby, diaper changes, eye contact with the baby, and bottle-feeding or nasogastric/gastric tube feeding (with or without nursing assistance) were most frequently participated in by SCN parents. Breast feeding was the least performed activity performed by parents in the SCN group (*Table 4.6*).

Comparison of NICU and SCN groups. In contrast to the barriers and facilitators reported by parents, there were more differences in the parenting activities reported by parents in the NICU compared to parents in the SCN group. However, there were similarities between the two groups as well. Observing the baby, talking, singing, and/or reading to the baby, eye contact with the baby, and stroking, touching, or massage were the most frequent activities performed by parents in both the NICU and the SCN (*Table 4.4, Table 4.5*). These activities were performed were "always" or "often" performed by 75% or more of parents in both groups. These parenting activities are the most passive and "hand-off" of all of the parenting occupations provided on the survey. During these activities, parents are interacting with the infant, but are not necessarily participating in infant care. However, in the SCN group, the same amount of parents (75% or more) also "always" or "often" participated in diaper changes and bottle-feeding or

nasogastric/gastric tube feeding (with or without nursing assistance), which represents a more active, “hands-on” level of involvement in care for these parents. Assisting the staff with procedures with the baby, and bathing or washing the baby's body or face, was also performed more by parents in the SCN than parents in the NICU group.

It is not surprising that parents play a more active role in infant care in the SCN. Infants in this unit need time to continue to recover, but no longer require more intensive care. Often, infants hospitalized in the SCN are feeding and growing, but oxygenation levels are dropping intermittently and their heart rates are not stable enough for discharge to the home environment. The average infant medical severity score for infants hospitalized in the SCN was 3.50 (SD =1.915), whereas the medical severity score was 4.007 (SD =1.624) for those in the NICU. Furthermore, no infants in the SCN required Continuous Positive Airway Pressure (CPAP), intubation, or mechanical ventilation. It is possible that parents are likely to be more involved in care when infants are healthier and do not require invasive medical treatments.

Although, parents in the SCN were involved in more active, “hand-on” activities, overall, both groups had limited participated in elements of infant care that provides direct, physical assistance to the infant. Skin-to-skin contact (kangaroo-care or holding the baby against your bare chest), and breastfeeding were two of the least frequent parent activities for both groups. Parents in the NICU also rarely participated in bottle-feeding or nasogastric/gastric tube feeding (with or without nursing assistance) or bathing or washing the baby's body or face. Also, although parents reported positive relationships with staff members as a facilitator to visitation, they rarely assisted staff with procedures with the baby. Overall, parental activities were more passive in nature, and implied that nurses and other medical staff were primarily responsible for providing typical care that full-term, healthy infants would also receive (i.e. diaper changes,

feeding, holding, etc.). These findings are consistent with the challenges faced by parents of critically ill or preterm infants. Prior studies have shown that mothers and fathers undergo a process during infant hospitalization to transition from a passive bystander to an active caregiver (Aagaard, & Hall, 2008; Provenzi & Santoro, 2015).

Clinical Application to Occupational Therapy

Occupational therapists in NICUs and SCNs support infant participation in infant occupations and promote increased occupational performance in these areas of participation (Gorga et al., 2000; Holloway, 1998). Beyond providing interventions to infants, occupational therapists in NICUs and SCNs provide education to ensure parents can provide the care ill or premature infants require to promote developmental progress (Vergara et al., 2006).

The current study investigated parent experience during infant hospitalization to gain an understanding of the barriers and facilitators of visitation and the ways in which parents are involved in infant care. Occupational therapists, when informed by the barriers and facilitators that parents face, can provide the support parents need to become an active caregiver before infants are discharged from the hospital.

The barriers identified were related to intrinsic factors, or those related to the parents themselves, rather than infant health or the hospital environment. Occupational therapists must remain informed about the resources in the surrounding counties in which they work to provide support to parents for the barriers parents face outside of the hospital. The facilitators reported by parents were largely related to supportive staff. Occupational therapists who work in NICUs and SCNs can provide educational in-service presentations to other health professionals about the ways in which staff can promote parent visitation and involvement in care. Furthermore, the

most common activities performed by parents in the current study were passive in nature. Parents talked or sang to the infant, engaged in eye contact, observed and touched the baby, but did not as frequently participate in “hands-on” infant care. After discharge, parents become the primary caregivers. Diaper changes, feeding, and bathing become activities that parents are responsible for providing to their infants. Occupational therapists who work in NICUs or SCNs should provide education and training to parents during hospitalization to promote carryover of parenting skills after discharge (Vergara et al., 2006).

The occupational therapist working in the NICU and SCN at Vidant Medical Center is committed to forming a partnership with parents and provided support for the current study after she observed a lack of parental presence during infant hospitalization. Other NICUs in North Carolina strive to provide family center care in NICUs and SCNs. Occupational therapists at Duke University Medical Center provide parent education for all infants born at 28 weeks and less who are hospitalized in the NICU. Therapists provide consultation to each infant and his or her family shortly after birth and then monitor the infant weekly providing further therapies only if needed. Specifically, therapists educate parents on appropriate sensory stimulation, proper holding and handling, and feeding techniques for premature infants. (L. Bonzani, personal communication, September 19, 2016). At the University of North Carolina at Chapel Hill’s Children’s Hospital NICU, occupational therapists provide parent education throughout infant hospitalization as the parent is present at the infant’s bedside. Prior to discharge, when appropriate, parents are provided with educational handouts and demonstration of the therapeutic interventions being provided to the infant (L. Bostic, personal communication, May 17, 2016).

Limitations

The most significant limitation of the study is that the participants are volunteers. The sample gathered is not necessarily representative of the population as a whole. Participants were not randomly selected and, therefore, the results gathered from the study may not be generalizable to the entire population of parents with infants who have been hospitalized in an NICU. Furthermore, because the participants are volunteers the sample may be skewed on any of the demographic questions that are listed in the survey. For instance, there could be more of one race than another or more unemployed parents than employed parents. This would cause the opinion of the groups with more participants to be overrepresented in the results. Furthermore, general limitations with using self-report surveys should be considered. For an example, participants may select responses on the survey that are considered socially-desirable, rather than responses that reflect their true beliefs.

Also, the participants are only gathered from one hospital. This also limits the generalizability of the results to the larger populations of parents as a whole. Many of the counties have a high percentage of low social economic status families which will likely affect the barriers that are found. However, since Maynard Children's Hospital is part of a rural regional hospital that serves 29 counties, there is a better chance of gathering participants of many different demographic backgrounds.

A second limitation of the study is that the survey's internal validity has not been previously tested. It is unknown whether the questions included can actually be useful in identifying the barriers parents' experience. However, the questions that were provided are

based on prior literature which has collected information on barriers to parental visitation and involvement in the NICU (*Appendix A*).

The reliability of the survey has also not been tested. It is unknown whether the survey will be consistent in collecting information about the barriers and facilitators parents encounter. This may have impacted data if participants are interpreting the questions differently from one another. However, the Interviewer Question and Explanation Form (*Appendix F*) was used by research assistants who were present during in-person surveys with parents. This form was used to track questions that parents had when taking the survey. In the event that a question was received from multiple parents, the survey was changed so that the item on the survey was being interpreted in the same manner for all parents. Furthermore, the each item on the survey was based on the findings of prior studies investigating parent experience during infant hospitalization (*Appendix C*).

An additional limitation related to the procedures of the study is that parents were required to be present in the NICU or SCN to complete the informed consent process. This may have affected our sample of parents because those that were unable to visit or did not visit frequently were unable to complete the informed consent process. This limited the ability to investigate barriers to visitation for parents who were truly unable to visit.

At the time the results for the current study were analyzed, parent visitation data and infant medical data collection were being collected and recorded. Therefore, the data reported in the current study are incomplete and conclusions related to infant medical data and parent visitation may not represent the sample as a whole.

Future Research

The current study identified barriers that were primarily related to factors outside of the hospital and most likely beyond parents' control. This is concerning as prior research has shown that parent involvement in direct infant care has many positive impacts on infant health (Reynolds, et al., 2013; Mehler, et al., 2011; Meyer, Coll, Lester, Boukydis, McDonough, & Oh 1994). During visitation, parents have the opportunity to provide positive stimuli to hospitalized infants. However, not all parents are able to visit during hospitalization leaving infants with limited times of supportive care such as Kangaroo Care. Further research should be conducted to explore ways in which the parent role can be fulfilled when parents are unable to visit. For an example, when parents are unable to be at bedside because of factors beyond their control, can a volunteer act as surrogate parent and participate in the parent-infant co-occupations? Also, if it were possible for a volunteer to consistently participate in parent-infant co-occupations, would this have the same impact on infant health as true parent-infant interaction?

Furthermore, future research should be conducted to discern the validity and reliability of the survey. The survey created was the first questionnaire that was designed to yield quantitative data describing parents' experiences during infant hospitalization. Prior studies including in the Introduction have described parent experience using qualitative interviews. After the validity and reliability of the survey has been determined, longitudinal research, investigating parent-child relationships regarding attachment and child behavior should be conducted to determine the long term effects of parent involvement in care during infant hospitalization.

Conclusion

According to the Neonatal Integrated Developmental Care Model (IDC), which is the most accepted care model for NICUs and SCNs, one of the primary roles of the health professional is to involve the family in the care of the infant (Hunter, Lee, & Altimier, 2015). The current study aimed to gain a better understanding of parent experience during infant hospitalization to inform health professionals of the support parents need in order to become an active caregiver.

According to parent visitation data the barriers reported by parents did not have an immense impact on parental presence during infant hospitalization. However, during visits, parents primarily engaged in passive activities more frequently than active activities. Also, although, positive staff relationships facilitated parent presence during hospitalization, these relationships may not have promoted active parental involvement in care.

Occupational therapists have a unique role in providing education and training to parents of hospitalized infants to promote active involvement in care during hospitalization (Vergara et al., 2006; Price & Miner, 2009). Furthermore, occupational therapists' understanding of infant occupations and medical conditions, allow them to provide education to parents and other health professionals about the appropriate ways they can be involved in infant care during hospitalization (Gorga et al., 2000; Holloway, 1998; Vergara et al., 2006). Knowledge of the barriers and facilitators of visitation parents experience guide occupational therapists and other health professionals when aiming to promote parental presence in NICUs and SCNs.

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APPENDIX A



EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board Office
4N-70 Brody Medical Sciences Building · Mail Stop 682
600 Moye Boulevard · Greenville, NC 27834
Office **252-744-2914** · Fax **252-744-2284** · www.ecu.edu/irb

Notification of Initial Approval: Expedited

From: Biomedical IRB
To: [Denise Donica](#)
CC: [Meghan Sharp](#)
Date: 8/18/2015
Re: [UMCIRB 14-000651](#)
Assessing Barriers to Parental Involvement in Care of Infants in NICU and SCN

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 8/17/2015 to 8/16/2016. The research study is eligible for review under expedited category # 5,7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

Name	Description
Informed Consent 7.24.15	Consent Forms
NICU Barriers Survey	Surveys and Questionnaires
Permission to Contact Card	Recruitment Documents/Scripts
Protocol V1 7-24-15 - clean	Study Protocol or Grant Application
Protocol V1 7-24-15 - tracked changes	Study Protocol or Grant Application
Recruitment Flyer	Recruitment Documents/Scripts
SCN Barriers Survey	Surveys and Questionnaires

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

APPENDIX B

WELCOME!

Thank you for your interest in the NICU and SCN Visitation study!

In order to be eligible for this study, you must:

- be at least 18-years-old
- have a baby (or babies) who is/was in the Neonatal Intensive Care Unit (NICU) and/or Special Care Nursery (SCN) at Vidant Medical Center for at least 7 days.

It will take about 15 minutes to fill out this survey.

- Please answer the questions as honestly as you can.
- You do not have to answer any questions you do not want to.
- You can stop answering questions any time you want.
- All of your answers will be kept completely confidential.

If you have any questions before, during, or after taking the survey, you can ask the researcher or call the Study Coordinator or Principal Investigator.

- Study Coordinator: Meghan Sharp, 252-328-4213
- Principal Investigator: Dr. Denise Donica, 252-744-6197

Please enter your study passcode (the last 4 digits of your phone number and your mother’s birth year).

If your most recent birth was a multiple birth (e.g., twins, triplets), please answer all survey questions with regard to all of your babies who were in the NICU.

SECTION 1: NICU VISITATION

1. While your baby was in the NICU, were you able to visit as much as you wanted to?

- Yes
- No

BARRIERS TO VISITING:

2. Please indicate the extent to which the following THINGS THAT MAY KEEP PARENTS FROM VISITING THEIR BABY IN THE NICU apply to you.

	Does not apply at all	Applies a little	Applies somewhat	Applies very much	Applies completely
I had to take care of my home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had other children at home to care for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I had to work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I live far away from the hospital.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I did not have a way to get to the hospital easily.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was ill and/or too tired.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The NICU environment was not family-friendly (for example, it was noisy; lack of privacy).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was not treated well by the NICU staff.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It was difficult to communicate with the NICU staff.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was afraid to be involved in my baby's care because of the baby's size or condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The medical terms and hospital environment made me uncomfortable.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It was more important for the other parent to be here.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It upset me to see the way my baby looked or acted, or the treatments my baby was receiving.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My baby did not respond well when I visited (e.g., was difficult, fussy, cried).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My baby's treatment did not allow me to be involved with my baby.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt depressed after the baby's birth.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The NICU staff did not encourage me or show me how to care for my baby.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information about my baby's condition was not provided.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Were there any other things that kept you from visiting your baby as much as you wanted to? Please describe them below.

3. When visiting your baby in the NICU, about how long were most of your visits? Please estimate the number of minutes or hours per visit on average.

minutes per visit on average

OR

hours per visit on average

- I was not able to visit my baby. (IF SELECTED SKIP TO SECTION 2, QUESTION 7.)

ACTIVITIES WHEN VISITING

4. Please indicate how often you were involved in the following ACTIVITIES PARENTS MAY ENGAGE IN WITH THEIR BABY when you were able to visit your baby in the NICU.

	Never	Occasionally	Some-times	Often	Always
Bathing or washing the baby's body or face	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diaper changes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Observing the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Assisting the staff with procedures with the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skin-to-skin contact (Kangaroo-care or holding the baby against your bare chest)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Holding (not Kangaroo care type)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stroking, touching, or massage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bottle-feeding or nasogastric/orogastric tube feeding (with or without nursing assistance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breastfeeding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eye contact with the baby.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talking, singing, and/or reading to the baby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Were there any other activities you were involved in with your baby?
Please describe below.**

REASONS FOR VISITING:

5. Please indicate the extent to which the following REASONS PARENTS MAY VISIT THEIR BABY IN THE NICU apply to you.

	Does not apply at all	Applies a little	Applies somewhat	Applies very much	Applies completely
I wanted to get to know my baby.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I wanted to help with my baby's care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I wanted to learn how to care for my baby.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I wanted to be in control of my baby's care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My baby needed me to be there.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It was my responsibility as a parent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I wanted my baby to recognize me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being with my baby made me feel positive feelings, such as love and happiness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My baby's other parent could not visit.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Were there any other reasons you had for visiting your baby? Please describe below.

FACILITATORS TO VISITING:

6. Please indicate the extent to which the following THINGS THAT MAY ENCOURAGE PARENTS TO VISIT THEIR BABY IN THE NICU apply to you.

	Does not apply at all	Applies a little	Applies somewhat	Applies very much	Applies completely
The NICU staff treated me well.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The NICU environment was family-friendly (for example, a place for me to sit next to the baby's bed).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The NICU medical and nursing staff gave my baby high-quality care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I could come and go in the NICU freely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The NICU staff gave me information about my baby's condition and care when I visited.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The NICU staff invited me to help with my baby's care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My baby responded well when I visited.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Seeing other parents take care of their baby made me feel like I could do it, too.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The NICU staff answered my questions honestly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt overly anxious and visiting helped me feel better.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support from family and friends such as meal preparation, help with household tasks and/or childcare.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Were there any other things that encouraged you to visit your baby in the NICU? Please describe below.

SECTION 2: PREGNANCY & POSTPARTUM THOUGHTS, FEELINGS, BEHAVIORS

7. Thinking back to when you and the baby's other parent became pregnant, did you want to become pregnant:

- At an earlier time
- At that time
- Did not want to become pregnant at that time, but wanted a pregnancy sometime in the future
- Did not want to become pregnant at that time or at any time in the future

8. Before your baby was born, did you know that he/she was going to need to be admitted to the NICU?

- Yes
- No

9. The questions in this part of the survey ask about ways parents may sometimes feel and act after having a baby.

	Not at all	A little	Some-times	Quite a bit	Very often
Do you have bad dreams of your baby's birth or of your baby's hospital stay?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you have upsetting memories of your baby's birth or of your baby's hospital stay?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you have any sudden feelings as though your baby's birth was happening again?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you try to avoid thinking about childbirth or your baby's hospital stay?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you avoid doing things that might bring up feelings you have about childbirth or your baby's hospital stay (e.g., not watching a TV show about babies, not talking about the delivery)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are you unable to remember parts of your baby's hospital stay?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you lost interest in doing things you usually do (e.g., have you lost interest in your work or family)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel alone and removed from other people (e.g., do you feel like no one understands you)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has it become more difficult for you to feel tenderness or love with others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you have unusual difficulty falling or staying asleep?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Are you more irritable or angry with others than usual?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you have greater difficulties concentrating than before your baby's birth?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel more jumpy (e.g., do you feel more sensitive to noise or are more easily startled)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel more guilt about the childbirth than you feel you should?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION 3: DEMOGRAPHICS & BACKGROUND INFORMATION

10. What race do you identify with most?

- White or Caucasian
- Black or African American
- Alaskan Native, American Indian
- Native Hawaiian, Pacific Islander
- Asian
- Other (please describe below):

11. What is your ethnicity?

- Hispanic or Latino
- Not Hispanic or Latino

12. Where were you born?

- In the United States
- Outside of the United States (please describe where you were born below):

13. Please indicate below how many children 18 and under (NOT including your most recent baby) and adult relatives live with you at home.

children 18 and under (NOT including most recent baby)

adults related to you

14 Have any of your other biological children been hospitalized in the NICU or SCN?

- Yes
- No
- Not applicable – I have no other children

15. In your life, have you ever had any experience (not including this most recent birth) that was so frightening, horrible, or upsetting that, in the past month, you:

	Yes	No
Have had nightmares about it or thought about it when you did not want to?	<input type="checkbox"/>	<input type="checkbox"/>
Tried hard not to think about it or went out of your way to avoid situations that reminded you of it?	<input type="checkbox"/>	<input type="checkbox"/>
Were constantly on guard, watchful, or easily startled?	<input type="checkbox"/>	<input type="checkbox"/>
Felt numb or detached from others, activities, or your surroundings.	<input type="checkbox"/>	<input type="checkbox"/>

When answering the previous question, what were you thinking about?

16. What is your marital status?

- Single (never married)
- Living with partner
- Married
- Separated
- Divorced
- Widowed
- Other (please describe below):

17. Are you living with your baby's other biological parent?

- Yes
- No

18. What is your highest level of education?

- Primary, elementary, or middle school
- High school graduate, diploma or equivalent (GED)
- Some college credit, no degree
- Associates degree
- Bachelors degree
- Graduate or professional degree (masters, doctorate, medical, law)
- Other (please describe below):

19. Which of the following best describes you right now? If more than one applies, you may select both.

- Employed full-time (at least 30 hours per week)
- Employed part-time (less than 30 hours per week)
- Not currently employed, looking for work
- Not currently employed, not looking for work
- Full-time student
- Unable to work due to disability
- Retired
- Other (please describe below):

20. If you were employed at the time, did you take any maternity or paternity leave from work during the time your baby was in the NICU?

- All of the time
- Part of the time
- None of the time
- Not applicable – I was not employed at that time

21. Please indicate below the total combined income you and the relatives you live with had last year from all sources (before taxes). Your best estimate is fine.

\$

household family income from all sources before taxes

Thank you for your time!



APPENDIX C

Evidence Based References for Survey Development

FACILITATORS

Please indicate the extent to which the following THINGS THAT MAY ENCOURAGE PARENTS TO VISIT THEIR BABY IN THE NICU/SCN apply to you.

Response format: 5-point Likert scale from "Does not apply at all" to "Applies completely"

Item	Reference
1. The NICU (or SCN) staff treated me well.	Wigert et al., 2010
2. The NICU (or SCN) environment was family-friendly (for example, a place for me to sit next to the baby's bed).	Wigert et al., 2010
3. The NICU (or SCN) medical and nursing staff gave my baby high-quality care.	Ward, 2001; Wigert et al., 2010
4. I could come and go in the NICU (or SCN) freely.	Feeley et al., 2013b; Ward, 2001; Wigert et al., 2010
5. The NICU (or SCN) staff gave me information about my baby's condition and care when I visited.	Feeley et al., 2013b; Ward, 2001; Wigert et al., 2010
6. The NICU (or SCN) staff invited me to help with my baby's care.	Feeley et al., 2013a; Wigert et al., 2010
7. My baby responded well when I visited.	Feeley et al., 2013b
8. Seeing other parents take care of their baby made me feel like I could do it, too.	Feeley et al., 2013b
9. The NICU (or SCN) staff answered my questions honestly.	Ward, 2001
10. I felt overly anxious and visiting helped me feel better.	Greene et al., 2015
11. Support from family and friends such as meal preparation, help with household tasks and/or childcare.	Feeley et al., 2013b
12. Other (TEXT BOX)	

BARRIERS

“Please indicate the extent to which the following THINGS THAT MAY KEEP PARENTS FROM VISITING THEIR BABY IN THE NICU/SCN apply to you.”

Response format: 5-point Likert scale from "Does not apply at all" to "Applies completely"

Item	Reference
1. I had to take care of my home	Feeley et al., 2013b; Wigert et al., 2010
2. I had other children at home to care for.	Feeley et al., 2013b; Franck et al., 2003; Giacoia et al., 1985; Greene et al., 2015; Latva et al., 2007; Lewis et al., 1991; Wigert, et al., 2010
3. I had to work.	Feeley et al., 2013b; Giacoia et al., 1985; Greene et al., 2015; Wigert et al., 2010
4. I live far away from the hospital.	Callahan et al., 1991; Daniels et al., 1984; Giacoia et al., 1985; Greene et al., 2015; Latva et al., 2007; Wigert et al, 2013
5. I did not have a way to get to the hospital easily.	Brown et al., 1989; Daniels et al., 1984; Giacoia et al., 1985; Greene et al., 2015; Wigert et al., 2013
6. I was ill and/or too tired.	Wigert et al., 2010
7. The NICU (or SCN) environment was not family-friendly (for example, it was noisy; lack of privacy).	Feeley et al., 2013b; Wigert, et al., 2010
8. I was not treated well by the NICU (or SCN) staff.	Wigert et al., 2010
9. It was difficult to communicate with the NICU (or SCN) staff.	Gonya & Nelin, 2013
10. I was afraid to be involved in my baby’s care because of the baby’s size or condition.	Feeley et al., 2013a; Feeley et al., 2013b
11. The medical terms and hospital environment made me uncomfortable.	Feeley et al., 2013b
12. It was more important for the other parent to be here.	Feeley et al., 2013a
13. It upset me to see the way my baby looked or acted, or the treatments my baby was receiving.	Gonya & Nelin, 2013

Item	Reference
14. My baby did not respond well when I visited (e.g., was difficult, fussy, cried).	Feeley et al., 2013b; Levy-Shiff et al., 1990
15. My baby's treatment did not allow me to be involved with my baby.	Feeley et al., 2013b; Latva et al., 2007
16. I felt depressed after the baby's birth.	Greene et al., 2015
17. The NICU (or SCN)staff did not encourage me or show me how to care for my baby	Feeley et al., 2013b
18. Information about my baby's condition was not provided.	Wigert et al., 2010
19. Other (TEXT BOX)	

PARENT INVOLVEMENT

“Please indicate how often you were involved in the following ACTIVITIES PARENTS MAY ENGAGE IN WITH THEIR BABY when you were able to visit your baby in the NICU.”

Response format: 5-point Likert scale from "Never" to "Always"

Item	Reference
1. Bathing	Feeley et al., 2013a; Franck, 2003
2. Diaper changes	Feeley et al., 2013a; Franck, 2003
3. Observing	Feeley et al., 2013a
4. Assisting staff with procedures	Feeley et al., 2013a
5. Skin-to-skin contact (Kangaroo-care or holding baby against your bare chest)	Aucott et al., 2002; Feeley et al., 2013a; Flacking et al., 2012; Franck, 2003
6. Holding (not Kangaroo-care type)	Feeley et al., 2013a
7. Stroking, touching or massage	Aucott et al., 2002; Feeley et al., 2013a; Franck, 2003
8. Bottle-feeding or nasogastric/oral-gastric tube feeding (with or without nursing assistance)	Feeley et al., 2013a; Franck, 2003
9. Breastfeeding	Aucott et al., 2002; Feeley et al., 2013a; Flacking et al., 2012
10. Eye contact with the baby	Feeley et al., 2013a; Flacking et al., 2012
11. Talking, singing, and/or reading to the baby	Aucott et al., 2002; Feeley et al., 2013a; Flacking et al., 2012; Franck, 2003
12. Other (TEXT BOX)	

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We need you!



Participants needed for a research study about what it is like having a baby in the hospital.

You are eligible to participate if you are:

At least 18 years old *and*
Have a baby who has been in the Neonatal Intensive Care Unit (NICU)
and/or Special Care Nursery (SCN) for at least 1 week

In this study, you will:

Complete up to two surveys about what it was like having a baby in the NICU and/or SCN. You will receive a **\$10 gift card** for completion of each survey (maximum of 2).

Interested in participating?

Ask the social worker for the permission-to-contact card.

Research is always voluntary and confidential!

If you have any questions, contact the study team:

- Study coordinator: Meghan Sharp
- Phone: (252) 328 - 4213

APPENDIX F

East Carolina University



Informed Consent to Participate in Research

Information to consider before taking part in research that has no more than minimal risk.

Title of Research Study: **Assessing Barriers to Parental Involvement in Care of Infants in NICU and SCN**

Principal Investigator: **Denise Donica**

Institution, Department or Division: **East Carolina University, Occupational Therapy**

Address: **Health Sciences Building 3305-G, Greenville, NC, 27834**

Telephone #: **252-744-6197**

Study Coordinator: **Meghan Sharp**

Telephone #: **252-328-4213**

Researchers at East Carolina University (ECU) and Vidant Medical Center (VMC) study issues related to society, health problems, environmental problems, behavior problems, and the human condition. Our goal is to try to find ways to improve the lives of you and others. To do this, we need the help of volunteers who are willing to take part in research.

Why am I being invited to take part in this research?

The purpose of this research is to get your input about the kinds of things that make it difficult for parents to visit and help take care of their baby in the Neonatal Intensive Care Unit (NICU) or Special Care Nursery (SCN) and its impact on infant health. You are being invited to take part in this research because you have a baby in the NICU or SCN and are at least 18-years-old. The decision to take part in this research is yours to make. By doing this research, we hope to learn more about what could make having a baby in the NICU or SCN easier for parents. If you volunteer to take part in this research, you will be one of about 100 people to do so.

Are there reasons I should not take part in this research?

You understand you should not volunteer for this study if you are under the age of 18 or do not have a baby currently hospitalized in the NICU or SCN.

What other choices do I have if I do not take part in this research?

You can choose not to participate.

Where is the research going to take place and how long will it last?

The research will be conducted at Vidant Medical Center at your baby's bedside. You can also choose to complete a survey by phone, paper, or online around the time your baby is discharged from the NICU or SCN. You will need to come to the hospital one time during the study to give consent to participate. The total amount of time you will be asked to volunteer for this study is about 20 minutes per survey.

What will I be asked to do?

You will be asked to complete a questionnaire asking you basic information (e.g., education, employment) and questions about the time while your baby was in the hospital. These questions will be

about your experiences while your baby was in the hospital. You will also be asked to give permission for the release of your baby's medical record for use by the researchers only. This information will be about the types of treatment your baby received in the NICU and/or SCN and the length of time they were in the hospital. If your baby receives care at Vidant's Neonatal Follow-up Clinic, this information will also include medical information from these clinic appointments for up to two years.

Research Participant Authorization to Use and Disclose Protected Health Information (PHI)

The individuals who will use or disclose your child's identifiable health information for research purposes include the principal investigator (Dr. Denise Donica), her colleagues on the project, and research assistants working under their supervision. Individuals who will have access to your child's identifiable health information for research purposes include all of the people listed above and:

- Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the Food and Drug Administration (FDA), the North Carolina Department of Health, and the Office for Human Research Protections.
- The ECU Office for Research Integrity & Compliance (ORIC) and its staff, who have responsibility for overseeing your welfare during this research
- ECU institutional officials in connection with duties for monitoring research activity.
- People designated ECU Health Care Components.
- People designated by Vidant Medical Center

The type of information accessed for this research study includes all of the information in your child's medical records at VMC. This medical record may include physician notes and lab, pathology, and radiology results. The information will be used and disclosed in such a way as to protect your child's identity as much as possible; however, confidentiality cannot be absolutely guaranteed. Someone receiving information collected under this Authorization could potentially re-disclose it, and therefore it would no longer be protected under the HIPAA privacy rules (federal rules that govern the use and disclosure of your health information). There is not an expiration date for this Authorization. ECU and VMC are required under law to protect your PHI. However, those individuals or agencies who receive your PHI may not be required by the Federal privacy laws to protect it and may share your PHI with others without your permission, if permitted by the laws governing them.

You may not participate in this study if you do not sign this Consent/Authorization form. You may revoke (withdraw) this Authorization by submitting a request in writing to Dr. Denise Donica (address listed above or donicad@ecu.edu). However, the research team will be able to use any and all of the information collected prior to your request to withdraw your Authorization. You will not be able to see your child's PHI in their medical record related to this study until the study is complete. If it is necessary for your child's care, your child's PHI will be provided to you or your child's physician. The above statements concerning your access to your child's medical record do not apply to this study since no data from this study will be added to your child's medical record.

To authorize the use and disclosure of your child's health information for this study in the way that has been described in this form, you will sign below and date when you signed this form. A signed copy of this Consent/Authorization will be given to you for your records.

What might I experience if I take part in the research?

Because participation in this study is through answering survey questions, there is little to no risk involved to you. Any risks that may occur with this research are no more than what you would experience in everyday life. You should report any problems to the researcher. We don't know if you will benefit

from taking part in this study. There may not be any direct benefit to you, but the information gained by doing this research may help others in the future.

Will I be paid for taking part in this research?

If your baby is in the NICU, you will receive a \$10 gift card for completing the NICU survey. If your baby is in the SCN you will receive a \$10 gift card for completing the SCN survey.

Will it cost me to take part in this research?

It will not cost you any money to be part of the research.

Who will know that I took part in this research and learn personal information about me?

ECU and the people and organizations listed below may know that you took part in this research and may see information about you that is normally kept private. With your permission, these people may use your private information to do this research:

- Any agency of the federal, state, or local government that regulates human research. This includes the Department of Health and Human Services (DHHS), the North Carolina Department of Health, and the Office for Human Research Protections.
- The University & Medical Center Institutional Review Board (UMCIRB) and its staff have responsibility for overseeing your welfare during this research and may need to see research records that identify you.
- People designated by Vidant Medical Center.
- If you are a patient at ECU or Vidant, a copy of the first page of this form will be placed in your medical records.

How will you keep the information you collect secure? How long will you keep it?

Any information that is collected for this study will remain private, will be known only to the researchers and assistants, and will be released only with your permission. No names or other personal identifying information will be on the questionnaire or in any analyses or reports that result from this study. The database storing questionnaire information and information about your infant's health will be on a password-protected, encrypted secure computer server. Your hard copy questionnaire will be stored in a locked filing cabinet in the study coordinator's office in the Department of Psychology and destroyed after seven years.

What if I decide I don't want to continue in this research?

You can stop at any time after it has already started. There will be no consequences if you stop and you will not be criticized. You will not lose any benefits that you normally receive.

Who should I contact if I have questions?

The people conducting this study will be able to answer any questions concerning this research, now or in the future. You may contact the Principal Investigator, Denise Donica, at (252) 744-6197 (weekdays, between 8 AM and 5 PM).

If you have questions about your rights as someone taking part in research, you may call the Office of Research Integrity & Compliance (ORIC) at phone number 252-744-2914 (weekdays, 8:00 am-5:00 pm). If you would like to report a complaint or concern about this research study, you may call the Director of the ORIC, at 252-744-1971 and the Vidant Medical Center Risk Management Office at 252-847-5246.

If you have questions about the sharing of PHI, you may call the University and Medical Center Institutional Review Board at 252-744-2914. In addition, if you have concerns about confidentiality and

privacy rights, you may call the Privacy Officer at Vidant Medical Center at 252-847-3310 or the Privacy Officer at East Carolina University at 252-744-5200.

I have decided I want to take part in this research. What should I do now?

The person obtaining informed consent will ask you to read the following information. If you agree, you should sign this form:

- I have read (or had read to me) all of the above information.
- I have had an opportunity to ask questions about things in this research I did not understand and have received satisfactory answers.
- I know that I can stop taking part in this study at any time.
- By signing this informed consent form, I am not giving up any of my rights.
- I have been given a copy of this consent document, and it is mine to keep.

Infant's Name (PRINT) (PRINT)	Relationship to Infant
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Participant's Name (PRINT)

Participant's Signature	Date
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Would you like to be contacted for future research opportunities?

Yes:

Phone number	Email address
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No

Person Obtaining Informed Consent: I have conducted the initial informed consent process. I have orally reviewed the contents of the consent document with the person who has signed above, and answered all of the person's questions about the research.

Person Obtaining Consent (PRINT)	Signature	Date
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Principal Investigator (PRINT) (If other than person obtaining informed consent)	Signature	Date
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APPENDIX G

Interviewer Question and Explanation Form

Please summarize each question asked, how it was addressed and indicate which part of the interview the question pertained to.

Parent Enrollment ID	Date	Questions Asked	Answer Provided	Corresponding Part of Interview (original directions, question number, etc.)	Interviewer initials
6	1/7/2016	Clarification of barrier to visitation: "I had to take care of my home."	Household responsibilities are like cleaning, doing laundry, any activities you do to maintain your home	Question 1 under barriers to visiting	LSF
7	1/13/16	Does adult relatives living with you include my husband?	yes	Question 13	LSF
8	1/22/16	Does adult relatives living with you include my husband?	yes	Question 13	LSF
15	2/5/16	Does breastfeeding include pumping breast milk and having my baby drink my breast milk from a bottle?	No	Question 3 under Activities when visiting	SJ
16	2/5/16	What does this question mean?	This question is asking you whether or not you were planning to have	Question 7 "Thinking back to when you and the	SJ

			a baby earlier, now, later...etc.	baby's other parent became pregnant, did you want to become pregnant"...	

