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Investigating the Needs of Parents of Premature Infants' Interaction in the Neonatal Intensive Care Unit

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Investigating the Needs of Parents of Premature Infants' Interaction
in the Neonatal Intensive Care Unit

by

Maureen A. Rinehimer

Submitted in partial fulfillment of the requirements for the degree

Doctor of Philosophy

School of Health and Medical Sciences

Seton Hall University

May 2017

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Seton Hall University
School of Health and Medical Sciences
Department of Interprofessional Health Sciences and Health Administration

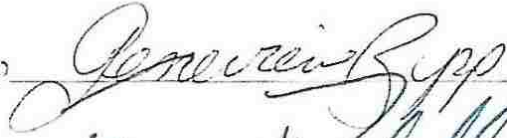
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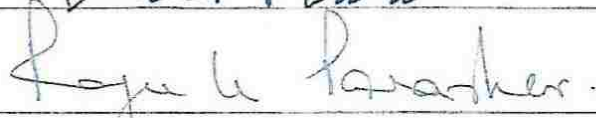
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The chair and any other committee members who wish to review revisions will sign and date this document only when revisions have been completed. Please return this form to the Office of Graduate Studies, where it will be placed in the candidate's file and submit a copy with your final dissertations to be bound as page number two.

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DEDICATION

This dissertation is dedicated to my parents, Catherine and Eugene McGuire who worked diligently with me in childhood, guided me in high school, and encouraged me in college to be the best person possible and a lifelong learner. My mother set an example with her education extending into late adulthood embarking on a new career and area of teaching. This was my father's dream: to have his child receive a doctorate since his education came to screeching halt with deafness from World War II and no ADA to allow education to occur. They set a bar to always strive to be better than they were. I achieved the Ph.D. degree, but can never be better than they were.

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ABSTRACT

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By

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ABSTRACT

Parents and/or caregivers of premature infants provide the interaction needed to promote better outcomes for these challenged infants at risk for developmental delays. This descriptive, exploratory study utilized convenience sampling. Inclusion criteria consisted of parents/caregivers who were at least 18 years of age and older with infants born 35 weeks gestation or less and currently in the NICU. This study focused on the research question: What do parents perceive they need in the NICU to enjoy interacting with their infant in the home? To collect the data needed to capture the perceptions of parent's needs of infants in the NICU, open-ended questions were developed by the Principal Investigator (PI), based upon the Parent Child Interaction (PCI) questionnaire. Devised by the PI in a pilot study, the PCI questionnaire is a reliable and valid tool to investigate what information and needs parents/caregivers have before discharge to gain confidence and enjoy interacting with their infant. A qualitative research approach using a phenomenological approach was taken with five open-ended questions in 21 semi-structured focus groups. Retrieval of the information utilized groups ranging from two to four parents totaling 50 participants. Utilizing a thematic analysis with the PI and an objective second reader to attain trustworthiness of data, seven themes emerged from these intimate focus groups exploring the parent's needs. The emergent themes are: 1) Roles and Responsibilities, 2) Communication and Parenting, 3) Self-Help, 4) Face-to-Face Education, 5) Consistency of Care, 6) Interaction with Infant, and 7) Be Heard. More contact with the infant produces increased confidence. Based on these themes, this study suggests that parents/caregivers feel there is a need for the consistent communication of information by professionals to parents/caregivers as well as by professionals with each other. Additionally, parents/caregivers would like to be perceived as the best source of knowing their infants needs and would like more contact with their infant to

gain confidence in caring for and enjoying their infant after release from the NICU. Imparting information to gain knowledge of how to care for and interact with their infant is perceived to be most effective when done on a one-to-one basis instead of through classes, technology/media, or handouts. This information will promote programming to develop better-informed parents to influence the parent/infant dyad interaction for improvement of the child's overall development.

Keywords: Premature infants, Parents, Needs, Neonatal Intensive Care Unit

Chapter I

INTRODUCTION

Background of the Problem

For most parents, the delivery of their newborn is a memorable experience; however, for the parents of a premature infant born requiring admission to the Neonatal Intensive Care Unit (NICU), it is a stressful situation resulting in escalating feelings of anxiety and distress (Callahan, 2008). Because of the serious medical issues and difficult birth process, the parents initial encounter with their newborn may be observing the infant in an isolate or incubator infiltrated with multiple intravenous lines, respiratory equipment, and leads to cardiac monitors. Because of the fragile state of the newborn, the parents usually may not touch or hold the infant. Additionally, because of the emergency conditions that surround the parents' experience during labor and delivery, a myriad of negative emotions surface such as guilt, sadness, feelings of insufficiency, and the fear of losing their infant (Wiegert, Johanson, Berg, & Hellstrom, 2006). These emotions frequently increase while both the premature infant and family receive care in the NICU.

Preterm infants are operationally described as infants less than 32 weeks gestation and/or less than 1,500 grams at birth (Richie, 2002). In the United States each year, there are approximately four million births with 12.5% of those involving preterm or premature births (Cooper et al., 2007; Martin, Hamilton, Osterman, Curtin, & Matthews, 2015). The Institute of Medicine and the National Institutes of Health (2005) reported a 30% increase in premature births over the previous 25 years. According to Aagaard, Uhenfeldt, Ludvigsen, and Fegran, (2015),

The preterm birth rate has increased between 1990 and 2010 with an average of 0.8% annually in almost all countries. Morbidity among critically ill newborn and preterm infants varies widely from no late effects to severe complications such as visual or hearing impairment, chronic lung disease, growth failure in infancy and specific learning impairments, dyslexia and reduced academic achievement. (p. 124)

Additionally, the frequency of premature births of less than 37 weeks gestation has increased to over 500,000 per year in the United States (Cooper et al., 2007). With this increase in the premature population, there also has been a concomitant increase in complex medical problems in 20-40% of the premature born infants. These problems include patent ductus arteriosus, respiratory issues such as bronchial-pulmonary dysplasia, and intestinal issues such as necrotizing enterocolitis (Verma, 2003). These types of medical complications require specialized care from health-care personnel in the NICU in addition to parental care.

Before the current technical advances in neonatal care, premature infants weighing less than 1,500 grams rarely survived (Goldberg-Hamblin et al. 1998). Since the 1980s, thanks to the availability of advanced medical technology, medical management in the NICU has improved significantly, resulting in the survival rate of greater than 85% of infants weighing less than 1,500 g. Currently, there is a 14% survival rate in premature infants with a birth weight of less than 500 grams born at 22 weeks gestation, and 76% survival rate in infants with a birth weight of 750 grams at 25 weeks gestation (Ritchie, 2002). As a result, the numbers of premature infants and families dealing with these infants and their needs have grown dramatically: their interactions thus warrant further investigation.

Statement of the Problem

Regardless of the approaches currently used in the NICU to care for the preterm infant, it is clear that before discharging the infant the parents need to be provided structured information from many NICU staff members (physicians, nurses, physical therapists, occupational therapists, speech therapists, respiratory therapists, and social workers) to effectively care for their infant (Sheikh, O'Brien, & McCluskey-Fawcett, 1993). Interventions focused to improve parents' coping skills have not progressed as well as the medical advances of medication, respiratory equipment, and surgical techniques. A review of the literature concerning interventions in the NICU and at home did not find a clearly defined, theoretical framework used in the NICU (Melnik, Feinstein, & Fairbanks, 2002). This has resulted in considerable variation in the length and types of interventions, parent-infant interactions, and positive coping skills outcomes extending over months after the infant's discharge.

Thus, the question remains: when and how should parents be involved in the care of their child in the NICU? Based on available literature, it is important to emphasize parent-infant interaction throughout the NICU experience. Empowering parents to make decisions and interact with their infant while at the NICU allows them to achieve some control in the NICU and perhaps relieve some of their feelings of powerlessness. Helping families to be comfortable when interacting with their infant may instill confidence for years after discharge from the NICU (Brown, Pearl, & Carrasco, 1991).

Current literature shows the lack of a program to assist or guide parents in the NICU to enjoy interacting with their infant and to help them smoothly transition from the NICU to home with documented positive developmental outcomes of the infant. Premature infants have specific needs that differ from a full-term infant. Als (1986) noted that the premature infant shows

atypical reactions to external stimuli and a decreased ability to remain behaviorally organized. She further suggested that premature infants benefit from a specialized NICU program that focuses on developmental care.

Als (1982) created the syndactyl model in which the infant has five subsystems of function: autonomic, motor, state regulatory, attentional/interaction, and self-regulatory. The focus of the model is the continuous interaction of those subsystems, which are shaped by the environment ranging from conception, maternal intrauterine environment, parental extra-uterine environment, and world at large at 52 weeks gestation. The interactions direct the infant's physical signals and behavioral responses to the environment and serve as the basis of the Newborn Individualized Developmental Care and Assessment Program (NIDCAP). These subsystems must be balanced through environmental modifications, for example, how an infant is handled or positioned and the amount of noise and light causing over-stimulation and stress to the infant. The caregiving is adapted individually to increase the infant's stability. At birth, the developmental schedule follows the state appropriate for the individual infant's gestational level.

Purpose of the Study

The purpose of this study was to understand the parents' need for information during their stay in the NICU that will help them to become confident to care for and interact with their infant(s) at home. The goals of the study were two-fold: a pilot study to develop a survey, and the implementation of the survey. Because of the absence of a published survey to explore the perceptions of what parents of preterm infants feel they require to deal with their infant prior to discharge from the NICU, it led this researcher to a pilot study to generate a survey. The pilot study consisted of 2 phases: development of a survey using a Delphi process, followed by a second phase to validate and estimate the reliability of the survey (see Appendices F1, F2, F3).

The PI produced a valid and reliable tool for use in the NICU entitled Parent Child Interaction (PCI) Survey (see Appendix F4).

Upon completion of the pilot study, the second and final phase of the study was to use the PCI survey. The intention was to have a mixed methods study. “However, due to participant recruitment challenges with the survey design approach, the data collection methodology changed to focus groups using qualitative methods. Open-ended questions were developed from the survey to use in focus groups to ascertain what information the parents’ need and the most effective method to distribute information to fulfill their needs to care for their infants at home. The information derived from parents in the focus groups will be helpful in setting up educational programs in NICUs.

Research Question

RQ1: What do parents perceive they need in the NICU to enjoy interacting with their infant once at home?

Significance of the Study

As infants in the NICU are surviving and developing, parents of these newborns need information about how to enjoy and interact with them. Parents’ interaction is important to foster the infant’s health and development. The influences on the environment of the development of an infant, including the quality of caregiver-infant relationship and individual care in the NICU, influences brain development (Bonnier, 2008). Thus, it is beneficial for parents to be informed consumers in the NICU to interact well with their infant(s) in contributing to the newborn’s overall development. The perceptions and input of parents are needed to develop educational programs in the NICU.

Most research focuses on preterm infants less than 32 weeks gestation and/or less than 1,500 g at birth (very low birth weight). The concept of prematurity involves biological immaturity for extra-uterine life. Maturation is the process of achieving full development or growth. Infants that are born preterm have immature organ systems that often need additional support to survive. The degree of maturity, therefore, is the major determinant of mortality and morbidity (the short- and long-term complications) of preterm birth.

Operational Definitions

There were four main constructs used in the survey instrument for this study: confidence, knowledge, parent-child interactions, and stress. It is important to operationally define these traits.

Confidence. Confidence is attributed to when parents feel comfortable in performing infant caring skills, they verbalized that they feel they can help their infant in times of need (Murray & Joseph, 2016).

Knowledge. Knowledge is the comprehension of factual information committed to memory or learned. Beyond the accrual of knowledge, there are different levels of understanding that stem from further processing of the knowledge Parental knowledge acquisition itself can be conceptualized as part of the adaptive and coping process. Parents do in fact find that coping with the hospitalization is made easier when they know about and understand the basic details of their infant's condition and care (Loo, Espinosa, Tyler, & Howard, 2003).

Parent-child interaction. This interaction is the activity of the parent-child dyad, which includes bids for the other's attention and responses to the bids (Pridham, Lutz, Anderson, Reisch, & Becker, 2010).

Stress. Stress is a significant experience that provokes a sense of misgiving, nervousness, emotional tension or pressure, and separation anxiety with the experiences of parents with infants in an NICU (Heidari, Hasanpour, & Foolad, 2013).

Conceptual Framework

As preterm infants shift from the warm and safe maternal womb to the challenging world, they adapt their biologic/behavioral mechanisms to the new environment (Sameroff, 2009). Sameroff suggested that the transition of the parent/infant progressing from the NICU to home with the multitude of environmental and behavioral factors requires internal and external adaptations. Cho, Holditch-Davis, and Miles, (2008) looked at empowerment strategies utilized by mothers and noted that mothers who learn how to interact with their infants early, later develop better coping skills to handle the infant's illnesses, to interact with health professionals, and in developing parenting skills. A survey of the literature revealed four theories that encompass these constructs.

The first theory was Arnold Sameroff's 1975 transactional model of development theory, which points out the importance of the interaction of the infant with the environment, including the parents. Additionally, the author proposed that infants actively interact with their environment as opposed to a cause and effect relationship. Since 1975, the graphic depiction of this model has evolved several times. Sameroff, with colleague Chandler, continued to develop this model with the bidirectional effects of the child and the environment on development (Sameroff, 2009). Further discussion of this theory involved the child and environment with the addition of context over time (Magee & Roy, 2008). Sameroff described this model as a constant reaction/relationship interaction and adaptations of the infant with the experiences in the environment as the infant matures. This model also places emphasis on discontinuities, meaning

that the child and parent mutually change the typical method of doing things (Meyer, Lester, Boukydis, & Bigsby, 1998; Sameroff, 2009).

As a complement to the transactional model, a second theory, life span theory, supports the importance of parent-infant development in the NICU. According to Schultz and Heckhausen (1996), primary and secondary controls are the basic concepts of this theory. Primary control pertains to changing the external environment to fit the needs of the individual. Secondary control refers to the process of internalizing the changing environment to increase the intensity of primary control. The goal is that the infant develops a balance of the primary and secondary control.

According to Schulz and Heckhausen (1996), neonates have the ability to produce behavior and event contingencies referred to as *primary-control striving*, which pertains to motivation of attaining goals over an extended period of time. In addition, a primary parameter of the life-span model of successful aging is that parents have the challenge of providing diversity (dynamic process with different contexts and environments) and selectivity (focus efforts on adapting) for their infants. The diversification and selectivity develops the infant's ability to overcome unsuccessful attempts in life. As a result of providing diversity, some "convergence between the inherent abilities of the child and the investment of time and effort is demonstrated, which refers to the investment of providing a variety of experiences over time" (p. 705).

Schultz and Heckhausen (1996) further described compensatory primary control as assistance given by others to lessen the effects of failure or losses of an individual's motivation. Compensatory primary control is required if an individual cannot work towards a goal independently, as noted with the life of infants and the elderly. The life span theory of control

encourages individuals, such as premature infants, to attain primary control of “resilience of self” (p. 710). Furthermore, the parent as the external scaffold for the infant helps to provide the foundation to selectively develop primary control. Thus, the authors concluded that as infants grow and develop, secondary control begins to develop as they learn and explore new ideas and movements, and ultimately, a conception of self.

The third theory, a resource-based model of Dunst and Trivette, proposes that families need to access information within their community to help relieve the parent’s stress (as cited in Shonkoff & Meisels, 2000). Once the family is discharged from the NICU, use of *early intervention services* provided by the state is recommended. Early intervention is based on the premise that the earlier an infant interacts with their environment, the greater their ability to positively engage with their environment compared with those who interact later. There is a need for further support to investigate the factors affecting the transition of the parent-infant dyad from the NICU to home and early intervention services.

Families and healthcare providers play a significant role in the external factors that affect a premature infant. Ramey et al. (1992) proposed a need for prevention programs that take into consideration the alterable biological factors such as birth weight and behavior—factors that include the education of the mother and her participation in intervention education. Thus, the fourth theory, Guralnick’s (2001) developmental systems model, provides a framework for infants and children in the community entering the early-intervention programs. According to the author, many of the underlying domains are similarly representative of the needs of infants and parents preparing to exit the medical model in a NICU to go home and begin utilizing community services. This theoretical model guides an early intervention program based upon a multi-component interactive system. “A strategic point in this model is that families are the

primary influences on the outcomes of children” (Shonkoff & Meisels, 2000, p. 197). Ramey et al. (1992) posited that genetic and contextual factors such as gender and ethnicity use these influences to affect cognitive development of an infant.

Similar to the Ramey et al. (1992) model, Guralnick’s (2001) developmental systems model consists of four categories of environmental stressors associated with family interaction: information on interpersonal needs, family distress, resource needs, and confidence needs. These factors directly influence the parents’ interaction with their infant and ultimately affect the infant’s outcomes (see Figure 1). Guralnick also discussed the environmental factors that affect families and ultimately the child’s outcomes (see Figure 2).

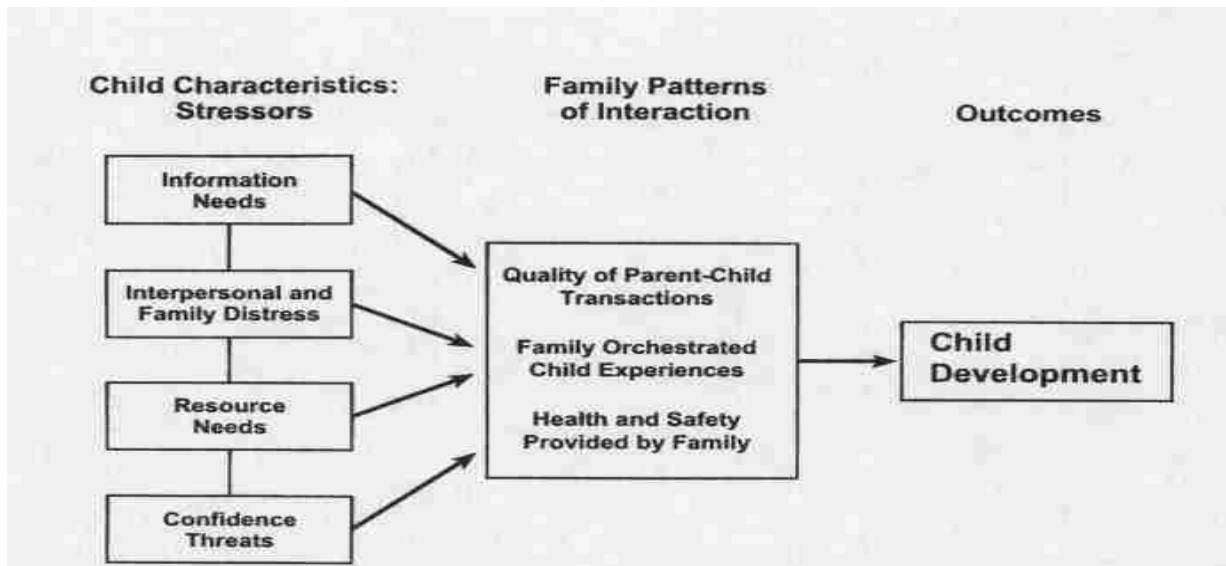


Figure 1. Guralnick's developmental systems model family stressors. Guralnick, 2001

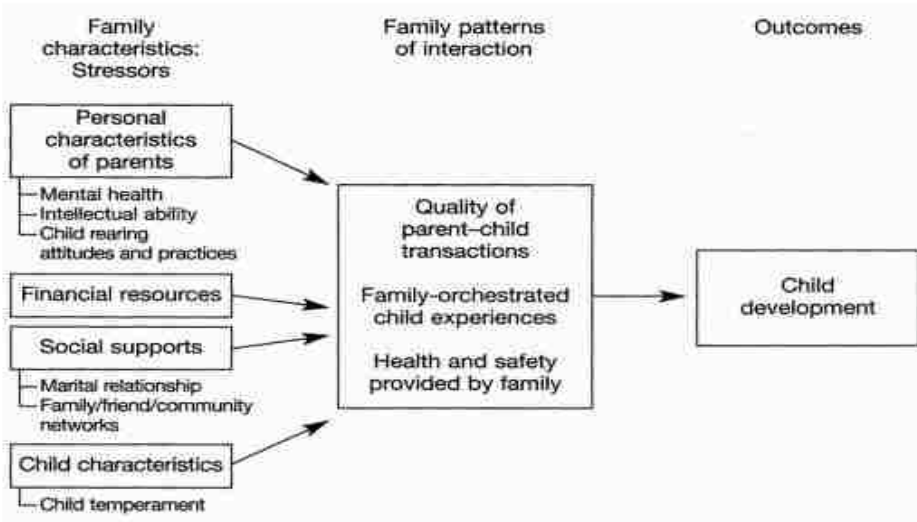


Figure 2. Guralnick's developmental systems model environmental factors. Guralnick, 2001

Guralnick (2001) discussed how parallel professional domains with professionals working independently of each other and without family input exert pressures on families with fragmented services for infant developmental outcomes. Furthermore, the author indicated that integration through collaboration involving families is needed for a more coordinated system when working with infants and families.

The final component of the developmental systems model is inclusion, a seamless transition of the infant toddler program to the preschool program or preschool to kindergarten. This is also true for the transition from the NICU to the community. The assessment of stressful factors related with the family's characteristics must be done with great sensitivity. In particular, Guralnick noted that familial characteristics might offer great risks to an infant's development related to environmental factors, families, and options for services available, which includes early-intervention programming (Guralnick, 2001).

The common and compelling thread of information in the four theories is that families greatly affect the infant's development at all stages of life, even at conception. So how does one begin to address the families' needs in the NICU to promote good infant developmental outcomes while the parent-infant dyad is in the NICU? The knowledge of the medical staff is an integral part of the environment that affects the premature infant. By understanding developmental care, knowing the needs of both premature infants and parents, and providing the appropriate services and information to parents and infants while at the NICU, the health professionals, including nurses, will help decrease the stress and anxiety of the parents and allow them to begin enjoying more interactions with their infant. Through exploration of knowledge-sharing and effective methods of instructing the parents, so they can retain the information imparted to them at the NICU, nurses may help to build an integrated system that promotes parental readiness to take their infant home by increasing parent's confidence, developing good interaction skills, and encouraging appropriate infant developmental outcomes for the child's adjusted age (Forcada, 2006).

Chapter II

REVIEW OF LITERATURE

Individual care of infants emphasizes the importance of parents' interaction with their infant and how they provide a major contribution to their infant's neurodevelopment (Als, 1982; Lawhon, 2003; Treyvaud et al., 2009; Vanderveen et al., [2009](#)). Browne (2011) reported that developmentally supportive care has developed to improve neurodevelopmental outcomes of high-risk newborns.

In recent years, infant research has focused on how the infant's brain organizes and responds to sensory stimulation through all five senses in early infancy. For instance, they are able to visually attend to sights (Lickliter, 2011). When we discuss how parent interaction is important while an infant is in the NICU, it is wise to remember this quote by Lickliter, "For concerns with care of the preterm infant, plastic changes across brain systems and related behavior vary as a function of the timing and nature of changes in experience" (p.7).

The premature infant is treated in NICU across one of five levels of acuity of the infant's illness, Levels 1 through 3C (National Guideline Clearinghouse, 2009) as shown in Figure 3.

NICU Levels

Level 1. Unit stabilizes infant until transfer to a facility providing intensive care.

Level 2. Infants are moderately ill with problems expected to resolve.

Level 3A. Infants weighing less than 1,000 grams, more than 28 weeks, critically ill or requiring surgery.

Level 3B. Infants weighing less than 1,000 grams, 28 weeks or less, critically ill, requiring surgery, or requiring advanced respiratory care such as high frequency ventilation, have access to pediatric medical and surgical sub-specialists on site or close by and advanced imaging with interpretation on an urgent basis.

Level 3C. Infants with all the needs of Level 3B but within a facility that provides extracorporeal membrane oxygenation (ECMO) and surgical repair of serious congenital cardiac malformations that require, cardiopulmonary bypass.

Figure 3. NICU five levels of acuity of an infant's illness. National Guideline Clearinghouse, 2009

With each higher level of care is a more seriously involved infant requiring more medically necessary isolation and less parent-infant interaction. Regardless of the level of care, all parents of NICU infants describe feelings of powerlessness to help, hold, care for the infant, shield the infant from pain, and allow other family members to visit as primary sources of stress (Cleveland, 2008; Shaw et al., 2006). Since parents have the ability to facilitate their infant's well-being and development, any stress and anxiety experienced by a premature infant's parents early in the stay in the NICU increases his or her difficulty to interact with the infant as the premature infant continues to grow and develop (Davis, Edwards, & Mohay, 2003b; Minde, Whitelaw, Brown, & Fitzhardinge, 1983; Willis, 2008).

The Newborn Individualized Developmental Care and Assessment Program (NIDCAP)

NIDCAP is a form of developmental care in a NICU based on the synactive theory built upon years of animal studies and concerning the serial development of sensory, cognitive, and

motor functions in the fetus (Als 1982, 1986; Nelson & Bedford, 2016). Using this form of interaction of the NIDCAP principles, it has been suggested that the care of infants in the NICU become more individualized, infant focused, family friendly, and concerned with overall development. The goal of NIDCAP is to empower the family to learn appropriate skills to adapt the environment for developmentally supportive care (Westrup, 2005). The NIDCAP theory can be described as ongoing integration of the autonomic, state organizational, attentional, motor and self-regulatory systems for premature infants (Als, 1982, 1986; Lickliter, 2011).

According to Als (1982, 1986), developmental care is utilized in NICUs with the understanding that following the synactive theory helps to improve infant regulation and minimize stress through adaptations to the environment, strategically planned handling, and developmentally appropriate interactions with the preterm infants for the overall development of the subsystems . Using the NIDCAP format, specially trained staffs of the NICU (i.e., nurses, physical therapists, occupational therapists, speech therapists, social workers, teachers, physicians) observe the behaviors of the premature infant's behaviors within the context of the environment (physical props, clinical staff, and family involvement) during care giving. The interventions derived from these observations are individualized to an infant's specific reactions to stimuli within the environment.

Lawhon (2003) noted that the family is vital to the infant's development within the family centered care (FCC) approach. FCC provides an individualized care plan and adaptation to the environment for effective interaction with the premature infant in the NICU. The ultimate goal is to foster family-friendly goals specially designed promote the least stressful environment for each infant.

Als et al. (2003) further supported her ideas with data indicating that developmental care showed improved motor development and weight gain, and may alter brain function and structure; thus, causing a decrease in infant stress levels. A year later Als et al. 2004 reported that there is an increase of the frontal regions of the brain during the development of preterm infants. This study supports the earlier findings of greater frontal lobe vulnerability to unexpected environmental experiences and stimulation by the caregivers.

In a randomized clinical trial, the first in vivo evidence of enhanced brain function, Als et al. (2004) detected significant effects of developmental intervention using the NIDCAP intervention on neuro behavior, electrophysiology and brain structure. The authors found that low risk preterm infants that receive the developmental individualized approach to care are better adjusted at 2 weeks corrected age using the Assessment of Preterm Infants Behavior and Precht Neurologic Examination of the full term newborn infant. Corrected age is calculated by subtracting the number of weeks born before 40 weeks of gestation from the chronological age (Committee on Fetus and Newborn, 2004). The effect of the NIDCAP intervention continued for 9 months as determined by the behavioral performance on the Bayley II Infant Scale (Als et al., 2004).

Additionally, Als et al. (2003) reported that the Parenting Stress Index, the Mother's View of the Child (MVC) and Parent Domain scores suggests mothers that participate in the developmental care approach in the NICU feel more competent as a parent and find that daily life situations caring for their infant are less stressful. Based upon the study, NICU programs focus on providing effectively ongoing support and education to families of a preterm infant while in the NICU, which may support the family's transition from NICU to home care. The studies by Als et al. (2003) and Als et al. (2004) support the need for more involvement of

parents with premature infants and offer various theoretical considerations regarding parent, environment, and infant interactions.

Positive interaction between infants and their parents is vital for the development of understanding and reacting to behavior cues (White-Traut et al., 2013). In the NICU, infants are separated from their parents, which obstructs parent-infant interaction and can be disadvantageous to the infant. In this study, care in the NICU was established on the basis that only NICU professionals with special skills could provide the majority of care for the infant (Obrien et al., 2003). As described by the authors, “parents remain relegated to a supportive role, and some have described themselves as voyeurs who are ‘allowed’ to visit and hold their infants” (p.2). Therefore, parents feel anxious and unprepared to care for their infants after discharge. This is in stark contrast to the regular nursery where care is provided by parents from birth (Luptona & Fenwick, 2001). The authors asserted that parents become distraught when they feel restricted in their interactions with their infant and unable to develop a bond, even if the infant is only in the NICU for a short time. Loving touch and interaction are not as important as nursing, but rather if the mother “showed interest” in their infant and learning about the infant’s care.

According to White-Traut et al. (2013), interventions in the NICU addressing parents’ needs consist of helping mothers reduce anxiety. Most programs in the NICU promote the interventions for the improvement of the infant’s development of neurobehavioral functioning and regulation. The premature infant and parent’s experiences within the NICU help them cope with the daily experiences, so that families may confidently transition from the NICU to home. Frequently, during the transition from acute NICU care to home phase, parents begin to experience feelings of anxiety, as they do not feel equipped or have the adequate knowledge to

confidently care for their infant(s). Consequently, as the infant is approaching discharge their parent's level of anxiety escalates (see Figure 4).

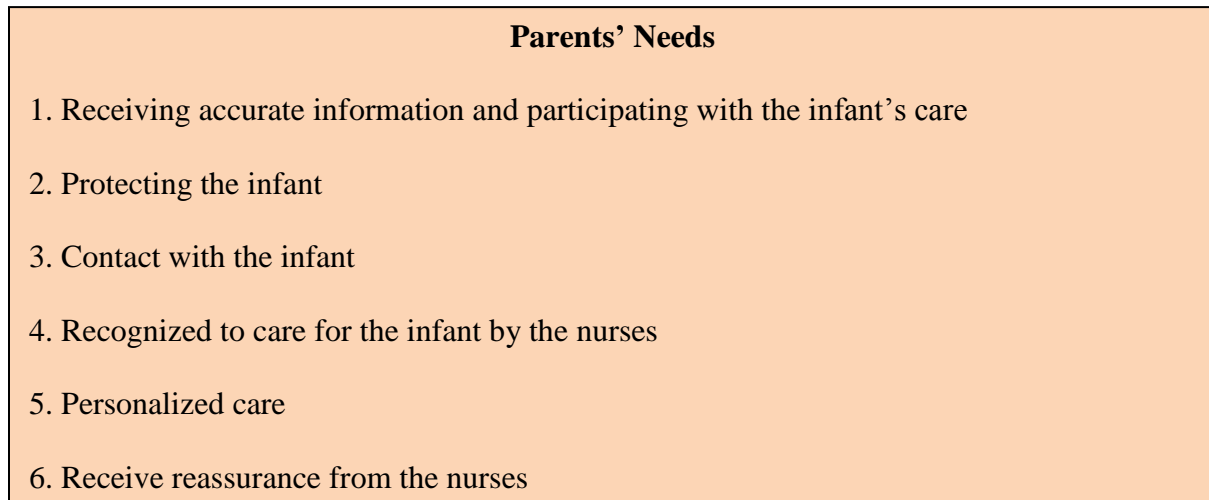


Figure 4. Parents' needs identified by White-Traut et al., 2013.

Incremental Learning

One way to accomplish the task of reducing parental stress is to give the families information in increments to prepare to take their infant home. Feeley et al. (2008) and Zelkowitz et al. (2008) used the Cues and Care trial tests, a brief intervention, designed to reduce anxiety and develop sensitive interaction skills among mothers of very low birth weight (VLBW) infants. By intervening at the level of maternal distress and maternal interactive behavior, it may be possible to promote a better parenting environment and optimize child developmental outcomes. However, there was no pre-intervention survey to identify the shortfalls of the parents. In addition, according to Cooper et al. (2007), parents need to feel confident caring for their baby. Some parents report being supported initially by their spouse followed by family members, nurses, physicians, and a nurse family specialist. Mothers feel more confident and less stressed

when they have an opportunity to talk with a specialist before delivery concerning what to expect of a premature infant.

From the information compiled by Cleveland (2008) in a systematic review, there are six needs of parents: (a) accurate information and inclusion in the infant's care, (b) vigilant watching-over and protecting the infant, (c) contact with the infant, (d) being positively perceived by the nursery staff, (e) individualized care, and (f) a therapeutic relationship with the nursing staff. The author also reported four nursing supportive measures noted in the literature. The four behaviors are (a) emotional support, (b) parent empowerment, (c) an environment that welcomes parents to participate with their infant's care as part of the nursing policies, and (d) educating parents with a chance to practice new skills. A significant amount of literature indicates that there is a need for support from the nurses (Goldberg-Hamblin, 1998; Kowalski Leef, Mackley, Spear, & Paul, 2006; Lawhon, 2002; May et al., 2000). However, Cleveland pointed out that effective collaboration of multiple disciplines is needed to support active decision-making of the parents regarding the care of their infant.

Despite the majority of literature concerning parent-infant interaction, which revolves primarily around nursing, the parent-infant dyad is also greatly affected by health professionals. The key word of Cleveland's (2008) comments is "collaboration" for better parent-infant outcomes. To promote collaboration with the environment and optimize an infant's developmental success, the relationship of the parent-premature infant dyad is vital (Feldman, 2004). The sequence of the birth of a premature infant with the abrupt termination of a pregnancy, a devastating birth experience, and a long hospitalization of the infant in an incubator creates a difficult environment for a parent to comfortably interact with his/her infant (Tallandini & Scalembra, 2006).

Understanding the behaviors and daily routines of a premature infant helps parents to cope with the care of their infant when discharged home (Smith et al., 2009). Parents of premature infants benefit from guidance of the NICU staff to understand and effectively deal with their infant's needs during their stay in the NICU and after discharge (Wielenga, Smit, & Unk, 2006). Consideration of the parent's perspectives with a focus on the parent-infant dyad and interactions provides the staff with an abundance of information for training parents in preparation for home care (Slattery, Flanagan, Cronenwett, Meade, & Chase, 1998; Wielenga et al., 2006). Healthcare providers need to understand the importance of promoting positive experiences for parents beyond the NICU, which enhances parent's abilities after discharge in the home in order to decrease stress, increase parent confidence level, and promote increased ease of care of the baby to foster child development and parent child interaction.

Traditionally, when premature infants progress from being acutely ill to the intermediate nursery section of the NICU in preparation for discharge, the family may receive inconsistent information on how to care for their child when at home. Sheikh et al. (1993) surveyed 34 nurses and 45 mothers of infants treated in the same NICU. The purpose of the study was to investigate information obtained through surveys of parents on 43 topics that parents may or may not receive information on regarding their baby's discharge from the NICU.

At 4-6 weeks after discharge, a questionnaire was given to parents of infants who were discharged consisting of 43 items. The parents were asked if they received the information and how important it is as discharge information. These same items on the parent questionnaire were then given to the nurses as a written survey to rate the topics of information regarding their importance for parents to know. For each topic, nurses were asked about the importance of

information parents need to know before discharge of their infant from the NICU. The nurses ranked them in order as shown in Figure 5.

Information Needed by Parents after Infant Released from NICU

1. Gather staff reports of the standard teaching protocol for discharge
2. Identify the topics that nurses hold important to teach parents
3. Identify who is responsible to present certain topics to families
4. Collect data from parent concerning the preparation for discharge with their infant

Figure 5. Importance of information related to parental infant care after release from NICU by Sheikh et al., 1993.

Sheikh et al. (1993) found a disparity of perceptions of what the nurses and parents indicated as the important information to know. In addition, parents did not remember learning the information that was reported by the nurses as being covered. For example, the results indicated that 67% of the nurses that were surveyed reported that the topic ‘infants crying too much’ was instructed to the parents, yet only 9% of the parents remembered receiving this information. Other topics of instruction, such as awareness of normal and delayed growth and development, had similarly discrepant results. The study supports the concept that parental stress hinders parental learning because of the medical issues surrounding prematurity.

NICUs in the United States are beginning to embrace Family Centered Care (FCC) intervention as a standard of care (Cooper et al., 2007). Through FCC, it is suggested that parents of infants are the primary caregivers in the NICU and become empowered with information and skills to collaborate with healthcare providers to care for their infant. The benefits of FCC include decreased length of stay, improved parent-infant bonding, improved preterm infant health and safety, better family satisfaction, and a decreased number of lawsuits. Hence, FCC

reduces the stresses of the infants of the NICU and incorporates the families with the infant's care and decision-making (American Academy of Pediatrics Committee on Hospital Care, 2003; Cooper et al., 2007; Smyington, 2003).

Based on the study by Cooper et al. (2007), 54% of 502 NICU staff members surveyed indicated that NICU Family Support (NFS), also known as FCC, improves the quality of care of the premature infants in the NICU. Eighty one percent of the nurses who completed the survey reported that the increase in quality of care is due to "more informed parents" (Cooper et al. 2007, p. s33). The authors proposed that the positive effects of NFS on FCC, such as being able to speak with the NFS person and also changing the unit culture, produces decreased parental stress level, an increased comfort level, and improved parenting confidence. This is the result of the ability of parents to make decisions and become informed caregivers. However, 58% of parents in the Cooper et al. study reported being confused and ill prepared at discharge because information was presented during the final week before the infant was discharged from the NICU. Nonetheless, 74% of the staff reported that discharge planning begins at admission. Cooper et al. asserted that information presents a substantial discrepancy of observations between the parents and staff on discharge instructions.

Recall bias may be a limitation to the Cooper et al. (2007) study because the staff was asked to rate degree of perception retrospectively. Also, the authors did not use pre- and post-project strategy to determine overall change. Another limitation was the difference of the number of staff (48%) and family (13%) survey responses obtained. They indicated that it could have been the result of not having the families complete the survey before the infant was discharged.

Timing of Learning

The timing of presenting information appears to affect the retention and usefulness of the instruction provided by the healthcare providers (Sheidkh et al., 1993). In a randomized control trial of 260 families with preterm infants from two Level III NICUs, Melnyk et al. (2006) reported that parents who receive early educational behavioral intervention during the NICU admission process demonstrate improvements in their mental health. The randomization was made by 4-week blocks of time chosen and based on the mean length of stay of low birth weight infants during the previous year. There were four phases of intervention, which provided information about infant behaviors and how parents can interact with an infant in the NICU. The intervention program began 2-4 days after the infant's admission with the fourth phase at 1-4 days before discharge. During the study, parents were asked to complete self-administered questionnaires concerning parent-infant interaction during the hospital stay, 7 days after discharge and at 2 months corrected age. As a result of this intervention project, Melnyk et al. concluded that parents develop more confident parent–infant interactions needed for critical parenting skills, and the premature infant's length of stay is reduced by 3 days.

In addition to a family centered care approach described previously, Developmental Care (DC) has been used in many NICUs. The (DC) approach uses a broad class of intervention strategies designed to minimize infant stress. DC includes the control of the environment, modulation of sensory stimulation, clustering care in the NICU, and positioning the infant to decrease stress through containment similar to the interaction of parents with the infant in the uterine environment (Smyington, 2003). Findings in this review of 36 articles indicate there are limited benefits from developmental care for preterm infants. However, the authors indicated that

this meta-analysis is limited due to the great variation in outcomes and limited randomized control trials for each outcome.

Within individual areas of study, there are some positive outcomes such as decreased length of stay as reported by Fucile, Gisel, and Lau (2005). This randomized controlled trial (RCT) utilized an oral stimulation program consisting of stroking the peri- and intra-oral structures of 32 preterm infants before the initiation of oral feedings to promote amplitude of expression of sucking for overall improved feeding performance.

In another RCT by Gatts, Wallace, Glasscock, McKee, and Cohen (1994), around the third day of life until discharge, preterm infants weighing 1,000–2,000 grams were exposed to vestibular and auditory stimulation using an adapted mattress. This mattress provided smooth varied motions simulating what a fetus experiences during the third trimester in utero while the mother is walking and at rest. It also produces a sound reflecting a mother's pulse for 24 hours. The authors found that the experimental group infants had a decreased length of stay, were nipple fed earlier, had decreased incidence of apnea, and performed better on the Brazelton Neonatal Behavioral Assessment Scale, which supports the hypothesis that appropriate amounts of stimulation may assist maturation of the preterm infant.

In the RCT White-Traut et al. (2013) study, the authors discovered that the experimental infants that were 23-26 weeks gestation and received 15 minutes of vestibular, auditory, visual, and tactile stimulation twice a day and 5 days per week from 33 weeks to discharge had a decreased length of stay compared to a control group.

Boyce, Cook, Simonmeir, and Hendershot (2015) conducted a study using infants 32 weeks and younger and under 1,200 grams without syndromes. The authors completed an in home interview 1 month post discharge from the NICU and between kindergarten to second

grade. Assessments comprised of maternal interviews videotaping mother-child interactions and school readiness child outcomes using the Conners Rating Scale and subscales from the Woodcock Johnson-III and the Caregiver-Infant Interaction Rating Scale. Mother-child interactions were videotaped during a feeding interaction in the home at the time of the first assessment. Ninety nine percent of the infants received early intervention services during their first year, averaging 14.7 home visits. The authors reported a significant effect of gestational age on the mother's responsiveness when feeding the infant. It was reported that mothers respond to older gestational-age infants more sensitively than to younger gestational-age infants. As hypothesized, maternal sensitivity during infant feeding experiences is positively related to mutual parent-child enjoyment.

These results of these studies suggest that it is not only the infant risk factors following a premature birth that influence development through the early school age, but also the mother-child relationship that contributes to the child's development (Boyce et al., 2015).

Influence of Parent and Stress on the Triad

Parental stress is an important factor that affects a parent's ability to care for their premature infant (Davis et al., 2003a; Davis et al., 2004; Herrera et al., 2004; Singer et al., 1999; Singer et al., 2003; Singer et al., 2010). In comparison to full term infants, parents of preterm infants report that their experience with their infant continues to be more stressful, produces anxiety, and is maladaptive throughout their first year of life (Davis et al., 2003a; Davis et al., 2004; Singer et al., 1999).

As a part of a prospective longitudinal study over an 8-year period, Singer et al. (2010) used a sample consisting of mothers of very low birth weight (VLBW) infants that were either low-risk or high-risk less than 1,500 grams with bronchial pulmonary dysplasia (BPD) and

requiring oxygen greater than 28 days. Maternal stress and its effect on the interaction of the mothers with their premature infants were also investigated.

The study utilized partial stratification of subjects to investigate the effect of social class and medical risk factors on the stress and coping outcomes. Term infants without a diagnosis served as the control group. Groups were equally matched in race, social class, gender, maternal education, and marital status. The methodology consisted of the mother completing the Brief Symptom Inventory (BSI) self-report questionnaire at the infant's feeding evaluation at 1, 8, and 12 months corrected age periods. The BSI measured overall psychological distress. Test-retest reliabilities ranged from 0.68 to 0.91. They indicated that validity is demonstrated through the scale's relationship to content scales and cluster scores of other measures of psychological distress. The authors also reported that they based validly for infants on previous studies sensitive to infant risk status and development during the first 3 years of life. Three researchers coded the Nursing Child Assessment Feeding Scale (NCAFS) and rated the mother/caregiver's interaction with the infant from a video taken of a mother-infant dyad during feedings. Spearman rank order correlations were utilized to assess the relationship of severity of maternal psychological symptoms with each maternal and child behavior and summary score (Singer et al., 2010).

Singer et al. (2010) asserted that mothers of high-risk VLBW infants are less prone to utilize withdrawal avoidant coping strategies, including denial, mental disengagement, and behavioral disengagement than mothers of term children. High-risk VLBW mothers have greater personal strain, greater family and social influence, and greater financial stresses compared to term mothers. Mothers of low-risk VLBW children have lower parenting stress than those of high-risk VLBW children, but neither differs from term mothers. Mothers of high-risk VLBW

children are less likely to use avoidant coping, denial, and disengagement than mothers of term infants. Mothers of high-risk VLBW children have greater family and social impact, social strain, greater personal strain, and greater financial strain compared to mothers of term infants. Other factors affecting stress and coping include: multiple births relating to maternal social isolation, lower feelings of mastery, and less child acceptability and attachment. Additionally, at age 8, mothers of high-risk VLBW children compared to low-risk VLBW children are less likely to use denial and mental disengagement coping than term children. Mothers of both high-risk and low-risk VLBW infants do not advance their education and have greater concern for their infant's health. Higher maternal education is associated with lower stress. Lower child IQ and social economic status (SES) predicts higher stress for all others mothers in all domains (Singer et al., 2010).

The Singer et al. (2010) study identified that the behaviors of mothers toward their infants improve over time. Based upon their findings, the authors suggested that interventions are needed to help mothers of VLBW infants teach and work with their infant to stimulate the infant as he or she develops. Singer et al. stressed that interventions should focus on the assessment of the mother's psychological distress and the difficulties brought about by the less responsive interactive behaviors of VLBW infants. The authors also asserted that maternal distress is a major factor influencing the interaction of mothers of VLBW infants (Singer et al., 2010).

The results of this study comparing VLBW infants with term infants indicate that at 1 month of age, the mothers of high-risk infants develop more cognitive and social emotional growth fostering parenting behaviors. However, by 8 and 12 months, there are no group differences. Furthermore, the results of the study indicated that mothers of high-risk VLBW infants displayed significantly greater stimulating interactions for cognitive development with

their infants than mothers of term infants at one month ($p < .001$). There is no significant difference in stimulating interactions for mothers of low-risk VLBW infants ($p < .10$) between groups at 8 months ($p < .89$). Maternal stress was significant after controlling for infant risk status and age and their interaction ($F = 9.7, p < .002$) (Singer et al., 2010).

Dudik-Shriber (2004) indicated that parents of premature infants have a variety of types of stressors such as the infant's physical appearance, which affects the parent-infant interaction. Using the Parental Stress Scale: Neonatal Intensive Care Unit (PSS: NICU), the authors investigated the frequency of stressful incidents of 162 parents of infants in Level II and Level III NICUs. The PSS: NICU was given to the parents on the initial day of contact with the author. Dudik-Shriber utilized Cronbach's alpha coefficient to determine the internal consistency reliability coefficients for three subscales and for the total scale. The internal consistency for the entire scale was .94 and .89; for sights and sounds, subscale was .80 and .73; for relationship with baby/parental role, subscale was .90 and .83; for baby looks and behaves, subscale .92 and .83; thus indicating a high correlation of the subscale scores ($r = .88$ to $.96$). To determine the construct validity each of the parents' scores on the PSS: NICU, subscales were compared with the State Trait Anxiety Inventory using the Pearson Correlation Coefficient, which demonstrated significance at $p < .05$.

The most significant results from the Dudik-Shriber (2004) study indicate that the highest levels and greatest frequency of stress stem from the parent's physical interaction and relationship with the baby as indicated in 32 out of 47 items on the PSS: NICU. The authors concluded that mothers have higher overall stress than fathers. Other significant findings predictive of stress included marital status (unmarried mothers had increased stress.), parent's age (younger aged parents had more stress), and infant's length of stay (infants who stayed

longer in the NICU had more stress). However, due to the lower than expected mean stress occurrence, overall stress scores, and information in the literature, parents appeared satisfied with the care of their infants in the NICU, thereby easing their stress with a trusting environment. However, as noted in previous studies, home maternal stress significantly affects the infant's risk status and the interaction between infant and mother.

Similarly, Lahner, and Hayslip (2003) contended that mothers of higher risk infants report greater distress after discharge when remembering their NICU experiences compared to how they felt while they were there. These memories experienced during the post discharge period of time have a highly negative influence on the parent when caring for their infant and decreases the feelings of attachment between parent and infant. As the infant approaches 18 months old, the flashback type memories appear more often and are more graphic. Mothers react by exhibiting avoidance behavior toward the infant affecting the interaction of the mother with the infant.

To promote decreased stress and anxiety and increase confidence of caring and interacting with the infant in the NICU and at home, there appears to be a need to understand how the NICU staff may be able to work with parents of the infants during their stay in the NICU prior to discharge. The importance of a parent feeling confident to care for his or her premature infant has been the topic of many investigations. For example, Zahr (1991) described confidence in care giving as the mother's perception of her ability to care for and understand her infant. Mothers of premature infants, in a study by Goldberg-Hamblin et al. (1998), expressed that they felt less confident with parenting, increased difficulty coping with a more difficult infant and doubtful when managing potential problems at home.

Researchers report that mothers with more confidence have better interaction with their infants and see their infants as less difficult to care for (May & Hu, 2000). A factor that influences maternal confidence is the ability to understand the infant's cries and other forms of communication (Singer et al., 2003). However, mothers of premature infants report that they receive fewer cues from a preterm infant as opposed to a full term infant (Leavitt, 1998; Singer et al., 2003; Worchel & Allen, 1997). As parents become more knowledgeable of their infant's cues and communication, they are able to enjoy and interact better with their infant, thus improving the infant-parent dyad.

According to Gray et al. (2013), parents of preterm infants compared to full term infants have significantly more stress at age 1 year, which contributes to dysfunctional interaction with their preterm infant. In the study, the authors did not indicate if any education for parent-infant interaction was provided in the NICU for the mothers of preterm infants. Gray et al. suggested that stress and dysfunctional interaction is affected by the mother's behavioral depression status.

As the percentage of premature infants surviving with significant health concerns are discharged to home with augmentative medical needs, such as respiratory care and equipment, frequent clinic and specialists office visits and surgical procedures, there is a critical need to focus on the coping skills of parents caring for these infants during the infant's continuing growth and development. Information obtained from parents can be useful in helping professionals design and implement interventions for parent-infant interaction to reduce parental stress, provide emotional and social support, and increase parents' knowledge to care for and stimulate the infant-parent dyad interaction.

Herrera et al. (2004) concluded that maternal depression negatively affects the quality of interaction between mothers with and without depression and their full term infants. In the study,

face-to-face interactions of mothers with infants (72 mother-infant dyads) were analyzed, specifically the frequency and quality of touch. The content of the mother-child directed speech was also analyzed. The observation sessions included the infant-mother dyad playing with a zebra stuffed toy for 5 minutes. The 10 month-old infant sat in an infant seat in a room with two cameras. Coding was devised around frequency of touch of mother to infant, relative frequency of infant vocalizations, and frequency of maternal speech.

The results of the Herrera et al. (2004) study indicated that depressed mothers of 10 month-old infants lift their infant more than the control group and 6 month-old infants (Herrera et al., 2004). The authors concluded that touching is an essential form of communication between a mother and an infant to compensate for a lack of verbal or facial expression. Additionally, they found that infants of depressed mothers also demonstrate more self-touching (touching their own skin), which was observed in other studies of children of depressed mothers as a form of self-comforting. Moreover, depressed mothers of 6 month-old infants incorporate less informative (direct statements interpretations, questions, or non-emotional) speech. Conversely, depressed mothers of 10 month-old infants have informational speech when interacting with their infant and tend to provide more negative touch than non-depressed mothers.

The Herrera et al. (2004) study pointed out that informing parents about the developmental aspects affecting interactions, such as the content of speech and touch, are important factors regarding mother-infant interaction to facilitate the care of their infant at home. The authors concluded that mothers of infants need to know and understand the adequate use of touch and content of speech to respond appropriately to the behavioral cues of infants and to prevent infant's self-regulatory responses.

There is evidence to indicate that with the correct type of touch promoting mutually regulated parent-infant system (maternal and environmental conditions) provides positive effects for health growth and development of parent-infant interaction. Based on the dynamic systems' perspective, individual paths of organized development with small variations in the initial circumstances may result in significant disturbances to the parent-infant relations and the infant's development (Feldman & Eidelman, 2007).

The happiness and wellbeing of families in the NICU have become a focal point of care during the past two decades (Cooper et al., 2007). In the study, the authors used a national sample of online household panel members to analyze parents' satisfaction using information from a survey of 76 questions developed by the authors and pre-tested for comprehension using 15 subjects before commencing with the sample of 502 culturally diverse parents of children (383 Caucasian, 62 African-American, 46 Hispanic, 15 Asian, and 25 others). The inclusion criteria consisted of parents of children who were: less than 30 months-old, born less than 36 weeks gestation, and who were either in the NICU or recent graduates of the NICU. Based on information gathered from the surveys, the authors reported that there is a growing need for a strong and efficient discharge education by health care professionals with enough information to make certain that parents feel confident to meet the needs of their infant as they transition to home.

The study by Cooper et al. (2007) further contended that healthcare professionals in the NICU adequately prepare parents to care for their infant. However, the authors hypothesized that more should be done to ensure that parent's needs are met in the NICU and transitioning to home. To test the hypothesis, the authors conducted a survey of 76 questions given to parents regarding family centered care subject matter such as parental NICU involvement,

communication, information, and transition to home needs. They asserted that 37% of the parents received preparation for the transition home during most of their stay in the NICU. The parents were asked to name one thing that they would change concerning how the staff prepared them for home. Parents reported that they would like more information and more hands-on practice with experience in the NICU (as cited in Bern et al., 2007). Eighty-five percent of parents indicated that after their infant was discharged from the NICU, they relied on the primary health care provider as their primary source of information. Also, nearly 66% of the families who turned to family and friends as their second most common information source were African-Americans followed by Hispanics at 41%, and Asians at 33% (Cooper et al., 2007).

Based upon the literature, interactions affect the development of infants and corresponding responses to stimulation. Parents of premature infants require support in developing effective interactions with their infants. In an attempt to investigate the supports available to parents in the NICU that would foster interactions, Ward (2001) performed a descriptive study. The author used the NICU Family Needs Inventory to identify the perceived needs of parents of premature infants. The participants consisted of 52 parents of infants 28-41 weeks gestation in a Level II and Level III NICU.

From the study, the 10 most important and least important need statements were identified. The participants reported assurance and information-related needs as the most important, while support needs were ranked as least important. Fathers (mean of 49.10, $p = .003$) and mothers (mean of 59.38, $p = .003$) categorized support, information, and assurance needs as significantly less important. To help meet the needs of parents of NICU infants, the author suggested informing parents of the infant's treatment plan and procedures, answering parents'

questions honestly, actively listening to parents' fears and expectations, and assisting parents in understanding infant responses to hospitalization (Ward, 2001).

Ward's (2001) study determined there is a need for replication of this study to conceptualize the difference of needs between mothers and fathers, and a need for collaboration of services through early involvement of the parent-infant dyad to prepare for the infant transitioning from the NICU to home and community services. In support of the findings, research by Meyer et al. (1998) at Women's and Infant's Hospital of Rhode Island examined an intervention model that purported to intervene early to maximize the quality of the life of the high-risk infant and a parent's life. This program by Meyer was based on four domains of family psychological intervention as noted in Meyer et al. (1994): infant behavior and characteristics, family organization and functioning, care giving environment, and home discharge/community resources.

Meyer et al. (1994) evenly distributed 30 families of premature infants to either family-based psychological interventions or a standard care control group. Standard care consisted of medical and nursing treatment of the infant and the intervention of a social worker. The intervention group received standard care plus individualized care by one individual care manager who interviewed the families using the Clinical Interview for Parents of High Risk Infants (CLIP) (Meyer et al., 1994). In addition, several questionnaires (PSS: NICU, Maternal Self Report Inventory (MSRI), Beck Depression Inventory (BDI), and the Family Environmental Scale (FES) and demographics were given to the mothers of both groups measuring stress, depression, and self-esteem before and after intervention. Upon completion of the questionnaires, the mother-infant dyads were then videotaped during feedings. The first 15 minutes of the

feeding were coded, measuring the mother-infant feeding behaviors and the quality of maternal interactive behaviors.

The results indicated a significant group by time interaction effects on stress on PSS: NICU sights and sound subscale ($p < .05$), infant appearance ($p < .05$), and the total Stressor Scale, ($p < .05$). At discharge, mothers in the intervention group had less overall stress and depression (11%) compared to the control group (44%). Regarding the feeding observations, the intervention mothers showed less frequent interruption of feedings ($p < .001$), less attempts to stimulate their infants' sucking with a positive affect ($p < .01$), more infant smiles and sensitivity ($p < .001$), and more vocalization ($p < .001$). This model provided a strategy to help parents know their infant and to feel prepared to take their infant home with less stress, improved self-esteem and less depression (Meyer et al., 1994; Meyer et al., 1998).

At discharge, the improved maternal qualities of the intervention group such as increased smiling at her infant and increased vocalizing to her infant provide a good indication that mothers may be more confident to care for their infant at home. The questionnaires utilized in this study provide significant information towards the outcomes of interest with the parent-infant dyad and interaction (Meyer et al., 1994; Meyer et al., 1998).

In a randomized control study of 260 families in two Level III NICUs, Melnyk et al. (2006) investigated the efficacy of an educational behavioral program known as Creating Opportunities for Parent Empowerment (COPE). Group One, the experimental group ($n = 147$) families, was involved in the 4-stage COPE program. In all phases of this program, families received written and audio taped instructions.

1. Phase I presented the portfolio to keep records of characteristics and milestones of the premature infants.

2. Phase II provided activities to foster interaction and caring for their infant(s).
3. Phase III included the characteristics of infant states, the best times for interaction and the parent role for a smooth transition to home.
4. Phase IV was delivered in the parent's homes one week after the infant's discharge.

During this home visit, the authors provided the parents with activities to encourage cognitive development. The comparison group ($n = 113$ families) was provided with a series of four audiotapes and written information given simultaneously, which addressed hospital services, discharge information, and immunizations. The variables of the study included maternal/paternal emotional outcomes; maternal/paternal functional outcomes, such as quality of parent interaction with infant in the NICU, and the process of coping and infant outcomes such as length of stay. Parents were given self-report measures at baseline at each of the phase II through phase IV (2-4 days after the first intervention) one-week post NICU discharge, and at 2 months corrected age. Validity was established with all of the following measurement tools with the Cronbach Coefficient values noted such as:

- The Trait Anxiety Inventory (0.90 - 0.95)
- Beck Depression Inventory (0.63 – 0.90)
- Parental Stressor Scale (PSS-NICU) (0 .90 – 0.94 – 9.96)
- Index of Parent Behavior-NICU (0.83 – 0.86)
- Interaction with Infant-NICU
- Involvement in Infant Care-NICU (NA)
- Sensitivity to Needs of Infant-NICU (NA)
- Parental Beliefs Scale (0.90 = 0.93)
- Manipulation Checks (NA)

- Length of Stay (NA)

Based on the results of self-report questionnaires, Melynk et al. (2006) determined that the COPE program positively affects parental outcome factors such as decreased stress, better parent-infant interaction in the NICU, and greater coping skills. These positive results, as evidenced by a decreased length of stay (LOS) of 3.8 days, saved \$5,000 per infant. The documented effects of the interventions were only available through 2 months corrected age. A limitation of this study included that the study was conducted in only 2 Level III NICUs in the northeast United States, which do not generalize in other institutions. Another limitation was the sample consisted of relatively healthy and larger premature infants.

In a study published in 2009, Melynk and Fenstein indicated that through the use of the COPE program, there is a decreased length of stay, removing 8 days in the NICU and a decreased net savings of \$9,864.00 per infant. However, according to the authors, ongoing research is needed to determine the effects of the program and cost outcomes over time up to three years post discharge from the NICU.

The quality of maternal interaction with a premature infant is predisposed to various complications and attributes of the mother and infant. Veddovi et al. (2004) sampled 42 well preterm infants 28-34 weeks gestation with age appropriate weights. The authors investigated the level of depression and interaction of these infants with their mothers at postnatal age of 56 days (mean post-conceptual age of 39 weeks) and at 1 year corrected age. The study utilized several parent-infant behavioral competencies questionnaires such as The Neurobehavioral Assessment of the Preterm Infant (NAPI), Griffiths Mental Development Scales, Bayley Behavior Rating Scale, Knowledge of Infant Developmental Inventory, Ways of Coping Questionnaire,

Edinburgh Postnatal Depression Scale, Parenting Stress Scale, and Monash Mother-Infant Interaction Scale. The authors did not present reliability and validity information.

The results of the study showed a 67% participation rate of the mothers. The mothers who did not participate reported that they would increase their stress by remembering the delivery and did not want to prolong the memories of the NICU experience. The results suggest that maternal competencies such as ways of coping, knowledge of infants, depression, and mother infant dyad interaction are significant for infant development and mother infant interaction outcomes. Previous knowledge of infant development from babysitting experience and exploring information concerning infant development positively affects the infant's development, maternal adjustment, and mother-infant interaction at 12 months post-natally. The preterm infant's development at 12 months is significantly predisposed by the mother's ways of coping with the preterm experience and not the infant's preterm characteristics. Additionally, the authors indicated that the mothers who seek social support from friends and family alone may need more emotional and informational support from NICU staff. Further, there is an association between infant drowsiness and the first time mother's higher levels of stress (Veddovi et al., 2004).

Thus, a combination of these supports may be helpful for infant development. The authors also suggested more studies are needed to understand if increased emotional support would be beneficial to further improve mother-infant interaction and coping. This may imply that parenting can be influenced by a combination of formal and informal teaching moments. (Veddovi et al., 2004).

This poses a question if healthcare providers in the NICU may affect the level of stress, thus influencing the parent-infant dyad interaction. Connecting parental stress and infant

behavior supports the transactional model to emphasize mother infant interaction as the blended result of the individual and the contextual experience. The idea of combining the individual with the experience mirrors the life span model in that the parents individually provide stimulation similar to the use of contextual experiences and parent interaction in the transactional model of development. Based on these findings, more information is needed to contribute to the understanding and provision of the support for parents to provide effective stimulation and interaction with his/her infant upon discharge. It is important to consider the limitation of this study. According to the authors, the sample in the study was not a high-risk sample. The sample consisted of well, preterm babies at 28-34 weeks. The participation rate of mothers was 67% (Veddovi et al., 2004).

Cho et al. (2008) furthered this work by observing how the infant-mother dyad may differ due to the severity of infant's medical complications and age of prematurity. The study consisted of three groups: 108 preterm infants (mean age 28.9 weeks old) and their mothers, 67 medically fragile infants (mean age 33.9 weeks old) and their mothers, and 83 infants with a positive serum reaction for HIV (mean age 38.3 weeks old) and their primary caregivers. The authors concluded that mothers with medically involved infants had depressive symptoms for one to two years affecting infant mother interactions. Other researchers have found that mothers of preterm infants have higher levels of depression with less attentiveness to their infants.

The authors videotaped the infants interacting with their mothers at 6 and 18 months corrected age. From these tapes, they determined that the level of maternal depression symptoms varied between genders and between groups of medically at risk infants. Upon completion of the videotaping, the infant-mother dyad completed the Home Observation for Measure of the Environment (HOME) and the Center for Epidemiologic Studies Depression Scale (CES-D).

Inter rater reliability was .85 - .95 for the premature infants. Internal consistency for the three HOME subscales was .42 - .69 (Cho et al., 2008).

Additionally, the authors investigated how interaction behaviors varied depending on if the depression symptoms of mothers were normal or elevated. Analysis using t tests at 6 and 18 months of [$t(1.51) = 2.31, p = .03$ and $t(1.57) = 2.58, p = .01$] respectively, indicated that depressed mothers of medically fragile infants are less attentive and place more limits on their infants than mothers of premature infants. Some of the parents experienced depression that lasted 6 months, which significantly affected interactions with their infant. In support of the findings, Cho et al. (2008) reported that in other studies, mothers of preterm infants had an increased rate of depression. In many cases, the depressive symptoms decreased at 6 months. However, mothers of preterm infants continue to be depressed for 2 years after the infant's birth.

The statistical power of this study was .80 based on the repeated measures that posed a limitation. Another limitation was the internal consistency of mother-infant interactive variables such as infant social behaviors and mother attention because the results were below .70. Analysis included t tests at 6 and 18 months that helped to determine the interactions between mothers and premature infants did not change based on the presence or absence of maternal depressive symptoms. Groups of medically at risk infants are significantly less attentive to stimulation ($t = 2.58, p < .01$) and showed more restrictiveness with the infants at 6 months corrected age. Longitudinal analysis of maternal depression and infant gender through the use of general linear mixed models determined whether the interaction of mothers and their medically at risk infant differed (Cho et al., 2008).

Based upon these findings, it is important to guide parents in ways to develop strategies to deal with the problems that premature infants encounter for good quality interaction and infant

outcome (Als, 2003). As shown in studies with animals, there is evidence to indicate that the timing of stimulation is crucial for positive development (Liu, 2007). Presently, since there are no standardized norms, we can only speculate what the normative ranges of the amounts of sensory stimuli are for the preterm or full term newborn. Thus, instructing parents and caregivers on how much or when to interact with their infant, needs to be based upon the cues of the infant as opposed to the nurses schedules. This requires instruction and understanding of an infant's behavioral cues (Lawhon, 2002).

Lawhon (2002) performed an exploratory study investigating individualized nursing intervention for parental and infant competence to ensure positive outcomes. A multiple case descriptive design was utilized with a convenience sample of 10 infants and parents (fathers and mothers). The inclusion criteria consisted of infants with a birth weight of less than or equal to 1,500 grams and less than or equal to 32 weeks gestation, mothers who were 18 years of age and no history of illicit drugs, infants with no genetic malformations, mothers of single birth, and infant admitted to a level III newborn intensive care unit. Mothers and infants were videotaped while interacting in a care session.

Analysis of the individualized nursing intervention was accomplished by measuring three levels of effectiveness: the ability of parents to appraise their infant's behavior critically (audiotape transcripts), parents' ability to integrate critical appraisal into a supportive approach to handling during interaction (coded videotape), and enhanced parent and infant competence (Scoring of the Nursing Child Assessment Feeding Scale [NCAFS] and the Assessment of Preterm Infant's Behavior [APIB]). No reliability or validity information was available from the study. For the first level of effectiveness to occur as measured by the parents' ability to appraise their infant's behavior critically, the results of the study determined that the NICU staff needs to

further facilitate the emerging competence of the parents (Lawhon, 2002). Clinically, this can be used as a guide in the NICU nursery to promote inclusion and participation of parents in the care of their infant.

Recently, alternate forms of providing information for parents have been investigated. Using a clinical scenario, Chuo, Sherman, Drain, and Kulikowski (2007) investigated the possibility of providing web-based information to families of infants in the NICU. To create the web program, the authors used a generic clinical scenario with a complete health record of a premature infant. The software included events that are typical for a neonate within a specific time-frame. The scenario was further personalized to the particular infant to help educate parents during three phases of the infant's hospital stay in the NICU: admission, interim, and discharge.

During the interim period when tests were completed, the results were reported on the software for healthcare providers to see immediately. This allowed the healthcare provider to alter or add information based on parents' responses and also provided additional information from peer reviewed sources to match the infant's particular circumstances. Due to the availability of technology and the informatics system design, communication occurred in a timely fashion. In addition, messages regarding the results of events were sent to the physician and parents of via cell phones. Consequently, healthcare providers and the parents could stay up-to-date and be involved with the infant's care. This method of communication provided:

1. Information to parents before meeting with the infant's physician in the NICU,
2. Additional information for clarification of parent's questions
3. Expedited communication between the physician and parents of important, unanticipated issues (Chuo et al., 2007).

A knowledge repository with evidence-based information concerning neonates was given an information weight score and matched with the infant's personal history to compute a relevance score. A staff member approved the information and relevance score were in order to send the information to the parents. In general, in this prototype model, using a relevance score and an algorithm, stresses how early and continuous information to the parents is highly effective in a NICU setting to instill confidence (Chuo et al., 2007). These authors continue to investigate improving the accuracy of the relevance score to date.

There are some limitations and needs for refinement of the system design to address. They include intercultural and language issues, validation of knowledge resources, HIPPA and security, parental literacy, added work for the overtaxed physician workload, and sending information to patients "on the fly."

In a longitudinal correlational study, Douchette and Pinelli (2004) investigated the relationship of family coping, family resources, and family strains on family adjustment post-birth of sick infants 24-41 weeks gestation. They approached 120 families initially, but only 71 families were involved in the study. Questionnaires including The McMaster Family Assessment Device, which is considered highly reliable and valid to measure family function with an internal consistency with Cronbach alpha of 0.86 and reliability coefficient of 0.81 for mothers and 0.89 for fathers. By administering two known self-report family assessment measures, Family Unit Inventory and FACES II, concurrent validity was assessed. Another tool used was the Family Inventory of Resources for Management (FIRM). This instrument had an internal reliability (Cronbach alpha) of 0.89 and a reliability coefficient of 0.93 for the total scale. Validity checks of the FIRM to the Family Environment Scales had moderate correlations ($r = 0.15$ to 0.46). Family Crisis Oriented Personnel Evaluation Scales reliability for the entire score was 0.85 for mothers

and 0.82 for fathers. The authors reported that no additional validity tests were given. The final measure used in the study was the Family Inventory of Life Events (FILE). The overall reliability was 0.81 (Cronbach alpha) with a 0.77 for mothers and 0.75 for fathers. Validity assessment of the FILE to the Family Environmental Scale using Pearson's correlation of the subscales varied from no correlation to moderate correlation ($r = 0.00$ to 0.42). Predictive validity yielded low to moderate correlations ($r = 0.01$ to 0.28).

All of the questionnaires were mailed to participants to assess family adjustment, family resources, family coping, and family strains respectively. The research questions addressed:

1. The difference of parents' adjustments between the acute phase in the NICU and following the NICU experience
2. Mothers' and fathers' adjustment, resources and strains of first time parents and non-first time parents
3. Coping strategies that parents used and if there were differences between mothers and fathers in the acute phase and at 18-24 months post NICU experience
4. Differences of families with healthy infants and infants with ongoing health problems at 18-24 months

Data analysis included descriptive statistics, paired t tests, multivariate/regression analyses, and hierarchical linear modeling (HLM) using SPSS-PC and HLM software (Douchette & Pinelli, 2004).

The results of the study indicated that mothers use more coping mechanisms, including negative ones. There is a moderate positive correlation between family life events and strains and family adjustment scores. This suggests that the family adjustment scores improve in relation to

the infants' improvement. Family strains related to life events are not associated with the family's ability to adjust at home (Douchette & Pinelli, 2004).

There is a significant relationship of the family resources for esteem, communication, and mastery and health for mothers with $t(1) = -2.48, p = 0.016$, and for fathers with $t(1) = 3.26, p = 0.002$, and $t(1) = 2.87$. There is a moderate positive correlation between family life events and family adjustment scores ($r = 0.30, p < 0.05$). Additionally, there is a significant relation among family resources, esteem, communication mastery, and health for mothers and fathers. The families' adjustment seems to improve over time, according to the mothers, but not the fathers, which may be due to mothers experiencing more depression and stress. Furthermore, there are gender differences indicating that fathers used fewer resources, and fewer positive coping mechanisms, had greater difficulty with psychological adjustment, and experienced more strained reactions of events (Douchette & Pinelli, 2004).

There was no statistical significance to the family adjustment at 18 to 24 months when infants have ongoing health problems. Thirty eight percent for fathers and 42% for mothers reported that their infants had ongoing health problems. The ongoing health problems were associated with the significantly poorer family adjustment scores in fathers ($t(69) = 2.05, p < 0.05$) but not significantly with mothers ($t(9) = 0.28, p > 0.05$) (Douchette & Pinelli, 2004).

The authors concluded that educational programs should focus on assessing the family as a unit. During the acute stage in the NICU transitioning to home helps to decrease the time parents need to adjust to any special needs of their infant (Douchette & Pinelli, 2004).

The limitations of the Douchette and Pinelli (2004) study noted the potential for bias, with the parents using the self-administered questionnaire with social desirability when responding and collaborating with other parents. The timing of when the questionnaire was

administered, due to the time for convenience, was given at 18-24 months, which created a limitation. The particular time when the questionnaires are given may produce recall bias as well as an inconsistent point in time.

Another limitation was identifying with a population with similar characteristics. There was a non-diverse population consisting of families with high incomes, English speaking, married and well educated parents from one tertiary center in Ontario. This did not necessarily represent other NICUs or a varied population.

Taking into account the stress of mothers, some studies have reported that mothers of premature infants experience symptoms similar to posttraumatic stress syndrome (PTSS). PTSS negatively affects their confidence and ease of care of their infant (Holditch-Davis, Bartlett, Blickman, & Miles, 2003). The authors further investigated the relationship of PTSS to maternal and infant variables within a group of 34 mothers with high-risk premature infants. At 6 months corrected age, they employed semi-structured interviews using open-ended questions with 30 mothers of high-risk premature infants.

The results of the study showed that all 34 mothers had at least one post-traumatic symptom (not part of the inclusion criteria), 12 had two symptoms, and 16 had three symptoms. Approximately 80% of the mothers indicated that they have flashbacks of the traumatic birth of their premature infant and subsequent experiences in the NICU. These memories are associated with an increased behavioral response such as overprotection of the child and a constant fear of the child dying. There were significant statistical results correlating the number of posttraumatic stress disorder-like symptoms of the mother and child characteristics present at enrollment. The results showed maternal depressive symptoms $r = .32$, $p < 0.05$, maternal stress about the NICU

(PSS: NICU) $r = .42$, $p < 0.05$, and at 6 months corrected age, the maternal worry about the child $r = .44$, $p < 0.01$ (Holditch et al., 2003).

As a result of the study, Holditch et al (2003) reported that more research is needed to predict ways to provide better support in the NICU from nurses and other health care providers for mothers who exhibit avoidance behaviors in the NICU. They stated that this psychoeducational support improves maternal coping and lead to better parenting and prevention of PTSS symptoms.

Kowalski et al. (2006) conducted a study of 101 parents of infants less than 32 weeks gestation, admitted to a Level III regional NICU between August 2002 to September 2003, and who spoke English. The authors used a 19-item questionnaire developed by two of the authors. Content validity was assured by giving the survey to six health care professionals, three parents, and two epidemiologist's before the study. The questionnaire was modified from the comments and suggestions. The purpose of the study was to investigate what sources of medical information were most helpful for a parent, who provides the information, and the parent's expectations about receiving clear information.

In the study, parents reported that they preferred and relied on personal communication with the medical team as opposed to using the Internet. Parents identified a need to learn more by receiving information from individuals that they have developed a trusting relationship or have a personal contact as opposed to the Internet. For example, the parents valued frequent encounters with the neonatologists to improve the communication. Parents also acknowledged that nurses provide them with most medical information. The evidence supports that the NICU staff, specifically nurses and the neonatologists, need to collaborate during rounds with the parents to help bridge any gaps of communication (Kowalski et al, 2006).

Parents of premature infants need to learn more about premature infants and how to care for them. Some hospitals offer a variety of programs for parents of premature infants. However, it is often difficult to determine the efficacy of the parent support program (PSP), which requires selective choice of services that will meet the needs and are useful to parents.

In an effort to review the overall usefulness and utilization of a program during a 2-year evaluation period, Hurst (2006) created a parent support plan for 303 families. The author investigated some support services for parents in the NICU such as group support, one-on-one with veteran mothers of premature infants, and telephone support. Sixty percent of the 477 participants were mothers, 30% were fathers or grandparents, and 10% were other family members.

Hurst (2006) devised a parent support survey (PSS), using a Likert scale to examine the participants' perceptions of the support services. The scale consisted of 13 declarative statements asking the participants to provide their opinion about the services. It also asked about information concerning weekly parent support groups, one-on-one hospital visits by a veteran parent of a premature infant, demographics, and what they found helpful about the parent support program.

The survey was distributed to a sub-sample of 44 families with premature infants (mean age = 32.1 weeks gestation) when the infant's mean age was 11.5 months (range 3-21 months) chronological age. The survey was created to assess participants' perspectives on whether support services provide the emotional/information support and facilitate involvement in their baby's care. A consensus was achieved by a group of healthcare professionals and veteran parents concerning the areas of evaluation of the survey. The response rate was low at 23%. Descriptive statistics and qualitative content analysis were used for data analysis (Hurst, 2006).

The results of the survey indicated that 89% of the parents use the hospital visitation portion of the program (veteran parent in the NICU available for one on one consultation available on Sundays). Forty-three percent of the participant parents attended the meetings 2-9 times, 30% of the survey participants attended the parent support group 2-9 times, and the telephone support line was used by 10% of the participants. In general, 35% of the participants used two of the available support services. Most participants ($n = 40$) reported that the PSP was helpful. They emphasized that being supported by the same volunteer throughout the hospitalization was very helpful. Twenty-three parents indicated that the PSP was helpful by providing support “to work through their feelings” (Hurst, 2006).

Overall, the Hurst (2006) study promoted the use of a mixture of parent support programs providing parents an option of the type of support they are comfortable using. The individual needs of the parents and particular problems that the infants experience in the NICU are the key factors to be addressed when planning a parent support group. Furthermore, the author asserted that there is a need to investigate the content of the material used to support parents and the effectiveness of providing these forms of support to prepare families to transition to home.

Brazy, Anderson, Bexcker, and Becker (2001) conducted a two-phase descriptive, cross sectional design study investigating the process used by parents to obtain information and support when their infant is in the NICU. The first phase of the study consisted of an interview of four fathers and fifteen mothers of infants weighing less than 1,500 grams at birth in the NICU to determine their informational needs. The second phase consisted of a questionnaire mailed to 138 families. Sixty-four families completed the questionnaire, which asked parents about the following:

- Resources most often used to obtain information

- Experiences as parents of premature infants
- Amount of hours they invested investigating information at different stages of pre-pregnancy and post-delivery
- Use of computers

Both phases based questions on the experiences during four phases: prenatal, acute (after birth before transferring to intermediate care), convalescent (moving to intermediate care) and discharge.

According to Brazy et al. (2001), before delivery, parents learn best on an individual basis through instruction by the mother's physician, nurse, and neonatologist. During this stage, the parents' confidence in the person providing a positive perspective and accurate information is paramount. The author asserted that as the parents become more confident with their knowledge base, they become more aware of how they can best facilitate learning. If a parent is instructed before or just after the delivery, often times they are unable to absorb the information due to being in a state of shock. Thus, the timing of the delivery of information to families is important for effective learning to occur.

The study described four stages as well as the methods and information needed in each stage. The four stages include:

1. Prenatal
2. Acute
3. Convalescent (preparing to go home)
4. Discharge

As the parents evolve through the four stages, their informational needs also change. Their needs for information initially focus on the concerns of maintaining a pregnancy. However, these needs turned toward infant health during stage 2 and 3 and coping in stage 4 (Brazy et al., 2001).

According to Brazy et al. (2001), from interviews with the participants, similar themes became evident as advice evolved for other parents of infants in the NICU such as “a) get as much information as you can get, b) get involved with the care of your infant, and c) understand that having a premature baby may be the most stressful and challenging experience of your life” (p. 46). In terms of information sources, 71% of parents ranked the nurses as providing the most information; however, 56% listed the preferred source of information received by the neonatologist as opposed to 49% preferring the nurses.

During the acute phase of the infant’s illness/recovery, 63% of parents relied on their spouse and 40% on family. During the infant’s days preparing to go home, 71% of parents listed the nurses as the best source for information and 52% listed their spouse, companion, or family. During the time before discharge and being discharged phases, the mothers primarily sought out self-initiated learning and use of non-human resources. Twenty nine percent of the parents reported that they had difficulty leaving their infant in the hospital. During the discharge phase, 70% of the mothers utilized their spouse and 52% family to obtain information (Brazy et al., 2001).

Throughout each of the four stages, the needs of the mothers change. Each stage gradually prepares parents for the next stage, and ultimately, to find information and obtain emotional support post discharge. It is understood that there is a need to understand what information, by whom and when best presented to support the needs of the families to help decrease stress during all the stages. Ultimately, parental stress is decreased and using

intervention strategies improve parent interaction and the premature infant's developmental outcome (Brazy et al., 2001).

It is important to present evidence-based information concerning the care of a premature infant to the parents in family friendly language. Swartz (2005), in a metasynthesis, indicated that group prenatal care has been shown to be effective intervention for parental infant interaction. The author argued that after discharge from the NICU, a form of post-discharge peer support should continue. It serves as an excellent resource for parents. The metasynthesis discusses the quality of the parent-child interactions, which should be assessed continuously for future interventions. Swartz suggested that parents of preterm infants develop better coping skills when provided with evidence-based clinical care, guidance, and education in anticipation of events at home based on the principles of family-centered care.

In a pilot study in a Level III NICU, a research team from Montreal, Canada, Freely et al. (2008), assessed the feasibility and acceptability of an intervention to decrease anxiety and develop sensitivity among mothers of very low birth weight infants. The authors utilized a convenience sample of 24 mothers in single group pretest and posttest design with assessments post-intervention of infants one-half month old and at 6 months of age. Promoting mother-infant interaction was the focus of intervention in the study, with the mothers being taught how to identify cues from their infant and how to recognize and deal with their own anxiety.

The intervention program in the study began 4 weeks post-birth and continued 2 to 4 weeks post-discharge. As a result of the intervention program, the authors discovered that 20 of 24 mothers or 83.3% attended all six sessions. Seventy percent of the mothers were satisfied with the program. The mothers indicated that the most helpful topics are infant behavior and appearance, infant communication cues, and infant feeding behavior (Freely et al. 2008).

There were several questionnaires used in the Freely et al. (2008) study such as outcome measures given given to the mothers. The importance of the developmental care or family centered care is emphasized to promote parent confidence in their roles with their infant and to promote better developmental outcomes of the infant (American Academy of Pediatrics Committee on Hospital Care, 2003).

In the past two decades, a multitude of technical and environmental advances have occurred in the NICUs throughout the United States. Great advances in technology have produced wonderful life saving devices that have enabled more premature infants to survive longer and with greater developmental outcomes. Advances in NICU care such as developmental care and architectural changes for subdued lighting and reduced noises have also fostered decreased stress levels in the premature infants (Van der Pal et al, 2008). However, the literature suggests that parental stress and lack of confidence to care for a preterm infant affects the baby's outcomes and the parent-infant dyad. Therefore, better understanding the needs of parents of premature infants may provide the strategies needed to relieve stress and anxiety in the NICU and during the transition from the NICU to post discharge.

From the literature, there is a need of a tool to investigate the needs of the parents in the NICU before discharge of their infant. This researcher developed a questionnaire for parents in this situation. A pilot study was conducted in two phases using the Delphi technique to produce a parent questionnaire and develop a tool with content validity, reliability, and internal consistency. IRB Approval was obtained from Seton Hall University (see Appendix A and Appendix B).

Through the Delphi Technique, a valid and reliable tool emerged after three rounds using health professionals in neonatal care and parents of former premature infants discharged from the

NICU as the panel of experts. Participants who fit the inclusive criteria were recruited from the NICU where this primary investigator (PI) is employed and from a request of therapists in a national neonatal society. The parents were recruited from the NICU where the PI works and by distributing flyers in the waiting rooms of Pediatric Physical Therapy departments.

At the conclusion of the two phases of Delphi Technique (see Appendix I and Appendix J), a reliable (see Appendix K) and valid tool (see Appendix L), the Parent Child Interaction Scale (PCI) was available (see Appendix M. From this tool, the PI and the dissertation committee for this study reviewed the questions that were used in focus groups with parents of infants currently in the NICU for at least 10 days that met the inclusion criteria.

Chapter III

METHODS

This study involved three phases. Initially, as noted in the literature review, there is a need to develop and validate a tool to investigate what parents of infants born less than 33 weeks gestation in the NICU need to feel confident and to enjoy their baby when he or she is discharged and is now at home. This was accomplished in pilot study for this study (see Appendix I). The PCI Questionnaire, which was developed and assessed for validity and reliability during the pilot study, was used. Parents who assisted with the validity portion of the pilot study answered all questions on the questionnaire. From the information expressed by the participant parents during the development process of the PCI Questionnaire, the PI was inspired to conduct a more in-depth study of their comments. The comments were varied, yet generally expressed concerns with their needs and how the needs were not being met before going home from the NICU with their infant.

With the PCI Questionnaire found to be valid and reliable, this study moved into phase 2 where it was the PI expectation to survey 150 parents of NICU infants; however, due to an insufficient amount of returned questionnaires in 6 months, the research team re-evaluated the process of securing data and it was determined that phase 2 would be aborted and that a focus group process of data collections would be employed (phase 3). The methods, analysis, and research findings presented only pertain to the focused group outcomes.

Research Design

A descriptive, exploratory study was conducted to answer the research question: What do parents perceive they need in the NICU from healthcare providers to promote a positive parent

child interaction? This study was designed to accomplish the task of exploring the perspectives of parents and caregivers of infants in the NICU using an interpretive phenomenological approach. This approach allowed the investigators to learn the “essence” of parent’s experiences (Polit & Beck, 2012).

Utilizing focus groups, qualitative research methods were used to discover themes and patterns from the statements of the parents of premature infants. The PI used the information derived from a non-experimental valid and reliable tool, the Parent Child Interaction (PCI) questionnaire, to probe responses via a structured survey. As previously mentioned, this tool was developed by the PI to be used with parents whose infants were born less than 33 weeks in the NICU; however, the questions for the focus groups were extrapolated from this questionnaire to be used with parents of infants who were born below 35 weeks gestation still hospitalized in the NICU.

Before initiating this descriptive design study, ethical approval was obtained from the IRB of Seton Hall University, South Orange, New Jersey. (see appendices A, B, C, D, F, and H) The demographic questions were devised to meet the needs of this study (see Appendix N). Demographic information of the sample provided facts about the participants concerning the age, level of education, and marital status within this study. An advantage of using focus groups is that the researcher can access group interactions and discussions (Saks & Allsop, 2007). Specifically, the focus group process in this study offered parents an opportunity to share their perspectives about their needs in the NICU to confidently care for and enjoy their infants after they are discharged and sent home. Focus groups are time efficient, benefit from the responses of others, and inspire participants. Some disadvantages of focus groups can be the fear of

expressing themselves in front of others and the culture of the group may foster group thinking (Polit & Beck, 2012).

Exploratory research designs are utilized to analyze a phenomenon of interest and investigate capacities, including how it identifies with different elements of the study (Portney & Watkins, 2009). Face-to-face mode is the method of choice as opposed to online and telephone focus groups. This is an acceptable social situation for people to sit together and voice opinions with back and forth conversations (Roller & Lavrakas, 2015).

Participants

Upon approval by the IRB (see Appendix H), focus group participants who met the inclusion criteria were recruited in NICUs. Inclusion criteria involved parents and/or caregivers who were 18 years or older whose infant was born at 35 weeks and under and hospitalized for prematurity in the NICU for at least 10 days. Recruitment brochures were placed in the NICU parent waiting rooms and on the bulletin boards outside the NICUs (see Appendix G). Potential participants were excluded if they did not meet the inclusion criteria. Sampling for this study was purposeful.

The PI consulted with the nurse manager and nursing staff of the NICUs to determine the best times that parents were usually present and would be willing to participate. Nursing huddles are usually at 7:00p.m., and parents must leave the NICU at that time. The focus groups were scheduled around the times the nurses changed from day shift to night shift for their briefing, so it did not interfere with their visitation times with their babies in the NICU.

The PI moderated and facilitated each focus group. The discussions were tape-recorded and fully transcribed by the PI at a later date. The PI used a series of semi-structured, open-ended questions concerning the infant's health and the parent's needs in the NICU to feel confident and

enjoy their baby when they went home. Five questions were meticulously constructed from the PCI questionnaire. On a separate sheet, the parents were asked to complete demographic information consisting of the six demographic questions on the PCI. At the end of the demographic information sheet there was an open-ended question given to the parents. The open-ended question provided them an opportunity to share any other comments or suggestions to improve their confidence to care for their infant(s) at home.

Setting

The focus groups recruitment was conducted in 2 NICUs. One NICU was St. Luke's Hospital in Bethlehem, Pennsylvania, which is a 23-bed Level III unit staffed by a team of physicians, nurse practitioners, physician assistants, registered nurses, and physical therapy/speech therapy consultants. The second unit was the University of Pennsylvania's HUP NICU in Philadelphia, Pennsylvania, a 30-bed Level III unit with a six-bed transitional section of the NICU staffed by a team of physicians from the Children's Hospital of Philadelphia (CHOP), nurses, respiratory therapists, physical therapists, occupational therapists, and nutritionists, all of which specialize in infant intensive care. Both NICUs are teaching hospitals in urban areas and culturally diverse.

To generate participant interest for the focus groups, the PI reminded the nurses in the NICU of the time for the focus groups, so they could remind the interested participants to attend. The PI also left personal notes or copies of the brochure inviting and reminding parents to come to the focus groups on the baby's side table. Most focus groups were small in this study with dyads, triads, and one mini group classification as discussed by Roller and Levrakas (2015). The small groups were due to the sporadic times that families can come to the NICU. The PI attempted other times with either no parents or singletons; however, it was difficult to schedule

times for the focus groups because the situations of the baby and the family were constantly changing. Many parents did not have consistent times when they visited their babies or needed to cancel at the last minute for other family needs.

As noted in the literature, the setting and atmosphere of the actual focus groups affects the participants involved with a need to be prudently chosen. The essential requirements of the room or setting is to be comfortable, non-distracting, easy accessibility and non-intimidating. The interviewer or moderator controls for not overpowering participants and to encourage the timid to participate within their comfort level during focus groups. Smaller groups are recommended for difficult topics allowing for comprehensive insights of the participants (Krueger & Casey, 2009). Therefore, to ensure that the setting and atmosphere of the focus groups were appropriate, they were conducted in a small room encouraging a non-intimidating atmosphere.

The setting for the focus groups at St. Luke's Hospital was in a room that is not used by parents in the NICU. It was a novel area for the parents remote from the NICU, yet close enough to walk to. The room was preset and arranged by the PI with strategically placed comfortable chairs, couches, and end tables with soft lighting and without distractions or excess noise. If siblings came, the room was complete with a child-sized table and quiet toys and coloring books. The PI provided refreshments, including lunch or dinner items. An audio device was discreetly placed on the table. The families were told that the focus groups were going to be audiotaped before starting the groups.

The setting at The University of Pennsylvania Hospital was in the NICU itself at bedside. Attempting to arrange for parents in this NICU was more difficult because of the availability of the PI at this facility. It was prohibitive to bring refreshments into the NICU. The atmosphere

was quiet, but not distraction free. In this setting, it was primarily a one-on-one, face-to-face situation. However, the same probing structured format was followed as with the focus groups at St. Luke's Hospital.

Focus Groups Instrument

In qualitative research, the investigator is the instrument. For this study, the PI served as the instrument to conduct discussions in the focus groups. The questions used in the focus group were taken from the PCI Survey devised by the PI in the pilot study and approved by the dissertation committee and the IRBs of Seton Hall University, St. Luke's Hospital, and The University of Pennsylvania Hospital. Most questions were open-ended with one question having a selection of preferred choices of types of education in the NICU.

Before the involvement in the focus groups, the parents were given the Consent to Participate form (see Appendix E) to sign and also a verbal explanation of the study and the focus groups. The parents were informed before signing the permission form that the focus groups would be being audiotaped. The PI verbally presented the questions to the participants during the focus groups.

Attempts were made to avoid an excessive amount of writing to avoid losing eye contact and to develop trust of the parents in the PI's total attention to their conversations. The PI also used nonverbal cues such as sitting at the edge of a chair forward, using head nodding, and utterances such as "yes," "uh huh," and "I understand" as signs of engagement with the conversations.

The questions that were extrapolated from the PCI questionnaire to encompass all the traits or constructs were based on: stress, knowledge, confidence, and parent interaction. All focus groups were conducted by the PI and were 20-60 minutes in length. Interviews were audio

recorded and transcribed verbatim. Questions for the focus groups were semi-structured and open-ended, based upon the questions in the PCI questionnaire and were as follows (also see Appendix O):

1. Describe some stressful situations affecting your interactions with your baby in the NICU
2. What could be changed to help reduce your stress?
3. Could you have been better prepared to cope with these situations by one of the team members in the NICU? If yes, please explain how.
4. How could we best provide information about your baby's development to you?
 - a. Please rate the following as most helpful and least helpful:
 - i. Written
 - ii. Handouts
 - iii. Individual sessions at the bedside
 - iv. Group classes
 - v. Books
 - vi. DVDs
 - vii. Internet sources
 - viii. Other (please explain)
5. What else can be done in the NICU to help you feel more confident to interact with your baby at home?
6. Is there anything else you would like to add?

In an effort to gain rich data to capture the perceptions of parents of infants in the NICU in the focus groups, a qualitative approach to data acquisition was taken. Many NICU studies often

assume that the important questions relevant to the infant's health or development are related to physical and/or behavioral outcomes. With the outcomes of premature infants, it is important to also learn the needs of the parents or caregivers to develop programs to provide adequate education and interventions for better outcomes.

Why Focus Groups

While questionnaires may be able to explore certain factors of patients' experiences, they also may be unable to expose why someone holds a particular view. Due to the need to understand and learn the perceptions of the parents and obtain rich information, the research committee designated that focus groups be used to collect the data. Focus groups are especially suited to determine the perceptions of people concerning issues and services (Krueger & Casey, 2009).

It was the intention that this approach would produce insightful data with reference to the parent's perceptions of their needs in the NICU before discharge. A focus group allows a small number of people to discuss a particular topic or issue and identify themes so that the researcher may understand the complexity of the subject matter (Creswell, 2007; Portney & Watkins, 2009). An advantage to using focus groups methods is that it equalizes any discrepancies of researchers and participants. The participants become more involved in the research (Saks & Allsop, 2013).

As noted in the literature, it is important to have a group moderator who can build rapport and openness within the focus groups to share the same understanding of the culture in the NICU (Monographs of the Society for Research in Child Development, 2012). As the PI that conducted all focus groups and participated as the moderator, this researcher shared this familiarity of the NICU culture with the participants and was able provide the feeling of being forthright.

Data Collection, Coding, and Analysis

A sample size of 50 parents was found to have enough participants for saturation of information. Approximately one to six people were in each focus group for a total of 21 groups. Frequencies and percentages were utilized to develop the descriptive statistics and determine the distribution of the level of agreement of participants with the five open-ended questions and the demographic information. Huberman and Miles (1994) suggested that investigators make counts of data codes and determine how frequently codes appear in the database. Counting and reporting codes provides an indicator of frequency of occurrence (Creswell, 2013). Frequency counts are also useful for showcasing the labor and complexity of qualitative work and to generate meaning from qualitative data to document, verify, and test researcher interpretations or conclusions, and to represent target events and experiences (Sandelowski, 2001).

The focus groups were small ranging from one to six parents. This was due to the random times that the parents come to the NICU to visit their babies. However, interacting with one or two participants offered an atmosphere of a more intimate interview. Small focus groups readily facilitate the assimilation of individual accounts encouraging a natural interaction of the group and less structure. Short extracts demonstrate how participants can freely express their own individual experiences (Bradbury-Jones, Sambrook, & Irvine, 2009).

The times of the focus groups were discussed with the nurse manager to work around the schedules of the nurses and infants' schedules around the times when parents are not permitted in the NICU during the nurses' change of shift meetings. The focus group conversations were transcribed and analyzed using qualitative content and thematic analysis (Maxwell, 2013; Miles et al., 2014; Polit & Beck, 2012; Portney & Watkins, 2009).

As each focus group finished, to ensure rigor in the process, verbatim transcriptions and open coding occurred. Analysis of the focus groups began with coding of the informants conversations. Codes act a prompts to encourage deeper reflection of the parent's conversations (Miles et al., 2014). Derived from the codes were themes and connecting strategies.

The goal of coding in qualitative research is to “fracture the data” and place them into categories or themes (Maxwell, 2013). The following codes were the priority codes used to begin this investigation: interactions/perceptions stress, and confidence. These suspected areas of concerns of parents in the NICU were taken from the literature review as to what affects the interactions of parents with their infants.

Inductive coding and labeling for themes from the discussions made by parents and caregivers to the five open-ended question responses prompted the analysis. Dependability was guaranteed through the use of audio recordings and transcriptions. There were no changes in participant locations. While bracketing or suspending assumptions and beliefs is a way of allowing researchers to focus only on the gathered data, some authors question that assumptions can be put aside and believe that researchers' frames of reference always influence the interpretative process (Johnson et al., 2016). The PI bracketed any biases to ensure that trustworthiness employed reflexivity during data analysis. In this way, trustworthiness of the findings would be reflected through the words of the participants (Lincoln & Guba, 1985).

Lincoln and Guba argued that achieving credibility is one of most important elements in establishing trustworthiness (as cited in Shenton, 2004). As a form of peer review to reduce researcher bias and increase credibility and dependability, a second reviewer, blinded to the study, coded and grouped the open-ended question responses into themes (Creswell, 2007). The second reviewer is familiar with qualitative research and focus group transcriptions, thus was

comfortable in coding resultant themes. With email communication and face-to-face meetings, the PI and the second reviewer were able to reach 100 % on all codes and themes.

Based upon a high agreement, the PI believed trustworthiness of the data was established. This study then moved forward to the goal of effectively conducting a qualitative data analysis that describes the perceptions of the parents in the NICU about the information they feel they need to enjoy and feel confident interacting with their infant after the baby is released to go home. It provides rich information to address their needs while undergoing the realities of the experience with their infant.

CHAPTER IV

RESULTS

Demographics

As an essential part of the focus groups, the parents completed a demographic form. A sample of 50 parents/caregivers participated in this study. Thirty-two percent were males (16) and 68% (34) were females. The ages of parents/caregivers (see Figure 6 and Figure 7) ranged from 18 years to 50+ years. The majority of the participants (male and female) were 31-40 years old. With family centered care, it is very important to have the father's perspective as well as the mothers; however, it was more difficult to have fathers attend the focus groups or even visit their infants in the NICU for many reasons. A common cause of their absence was due to employment responsibilities.

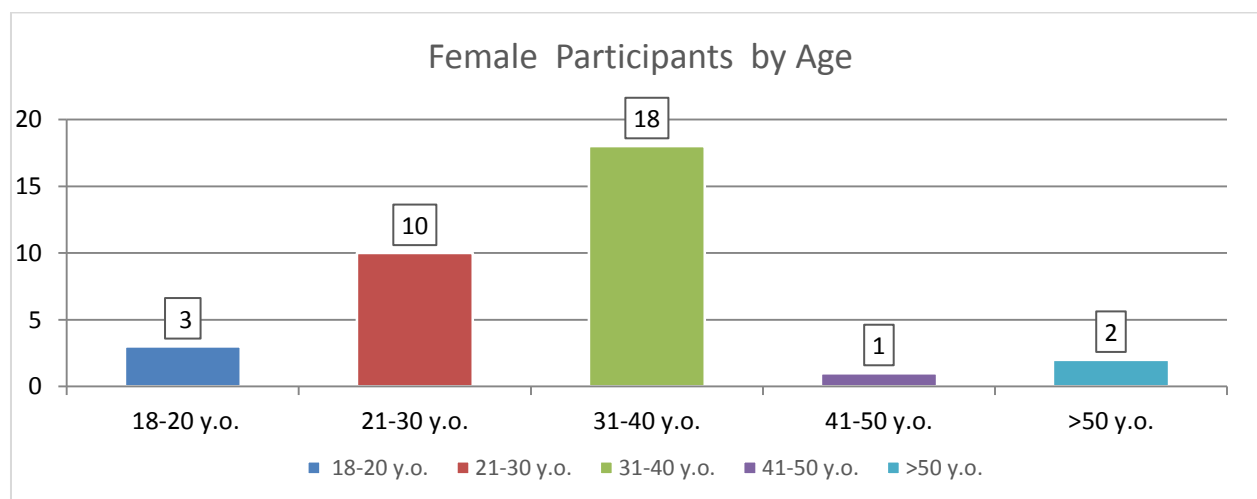


Figure 6. Female participants.

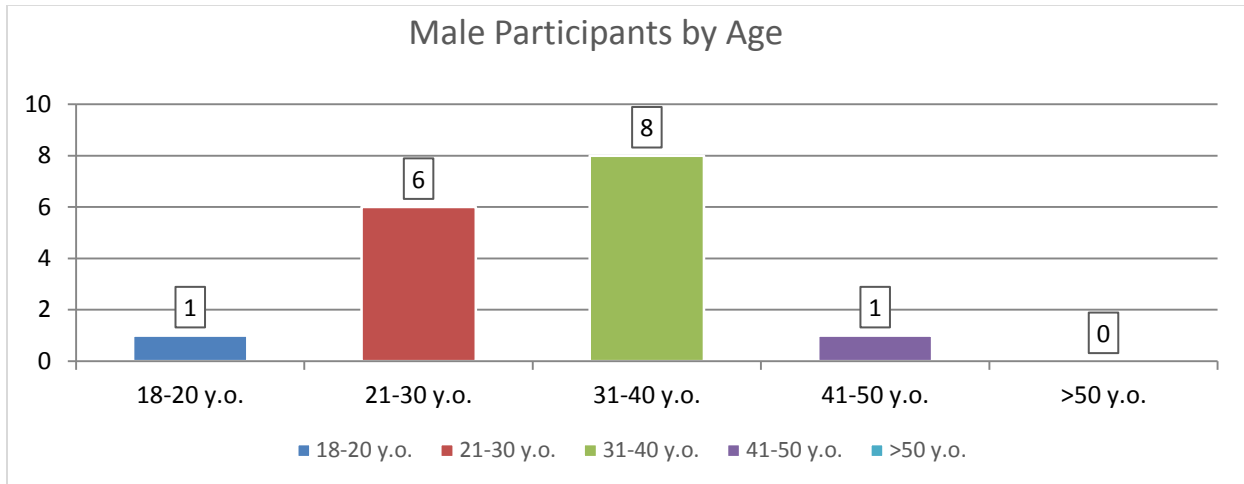


Figure 7. Male participants.

Regarding both male and female participants combined, 44% (22) were high school graduates, 38% (19) were college graduates, and 14% (7) were post-graduates as is shown in Figure 8 and Figure 9.

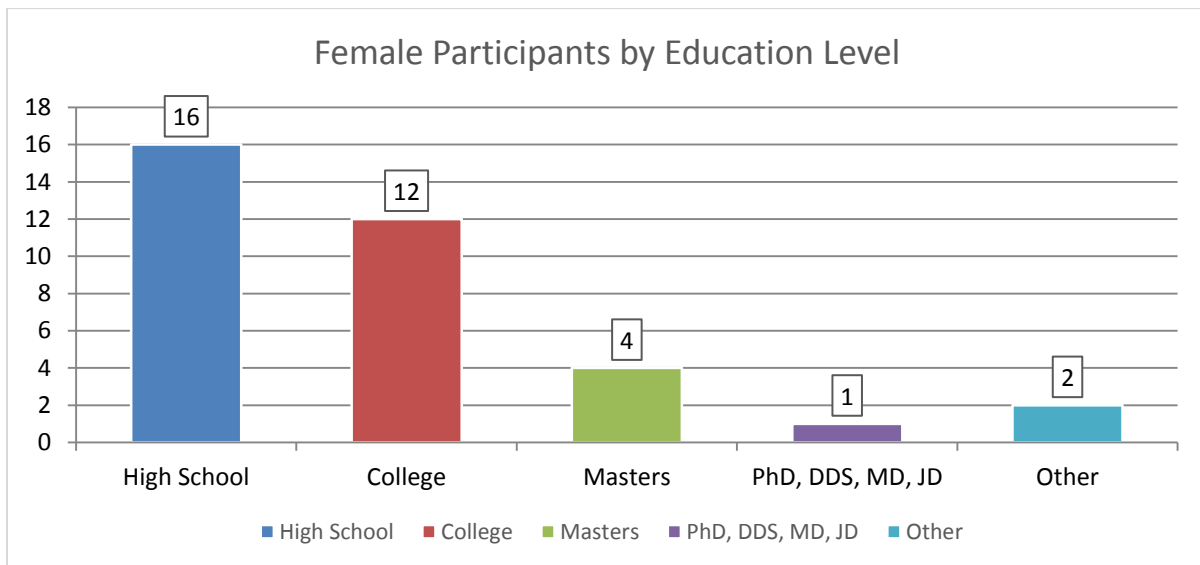


Figure 8. Education level of female participants.

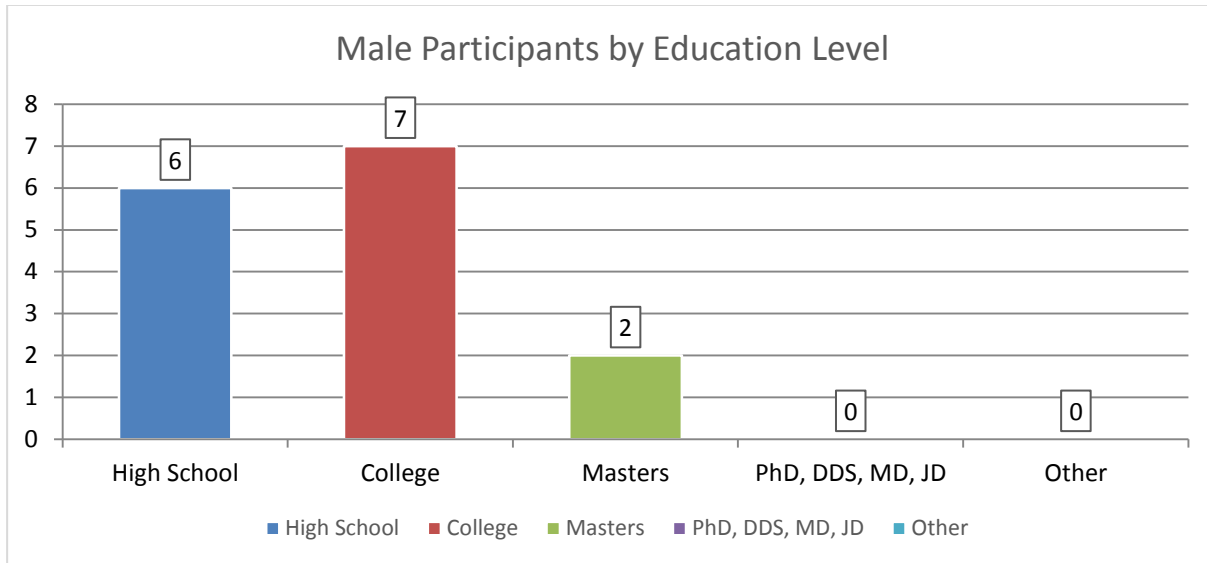


Figure 9. Education levels of male participants.

One father did not respond to the education level question. Of the female participants, 46% were high school graduates, and 56% of the male participants were college graduates.

The majority of combined participants were married (see Figure 10 and Figure 11).

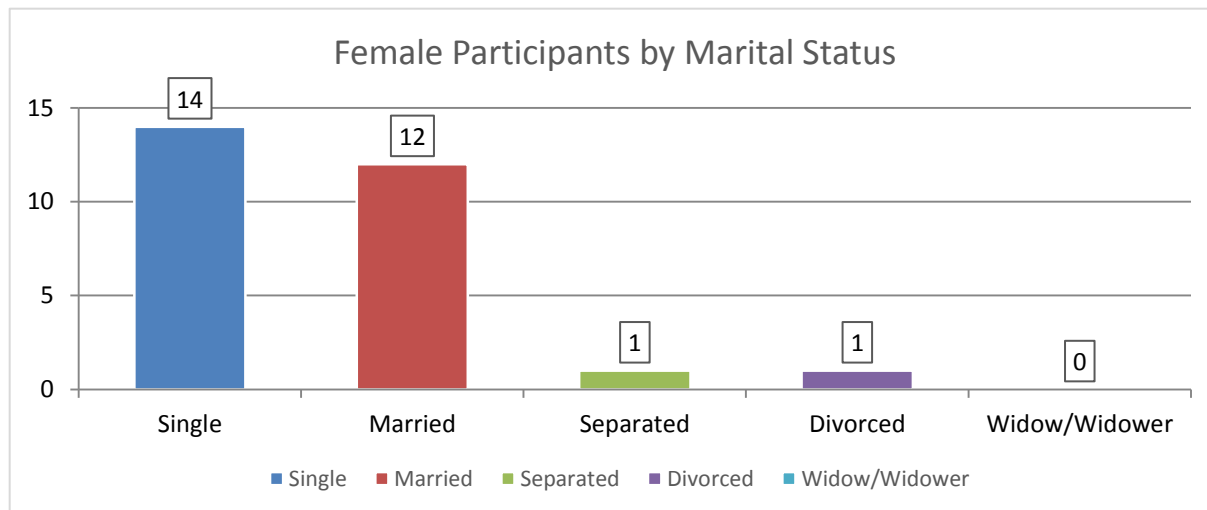


Figure 10. Marital status of female participants.

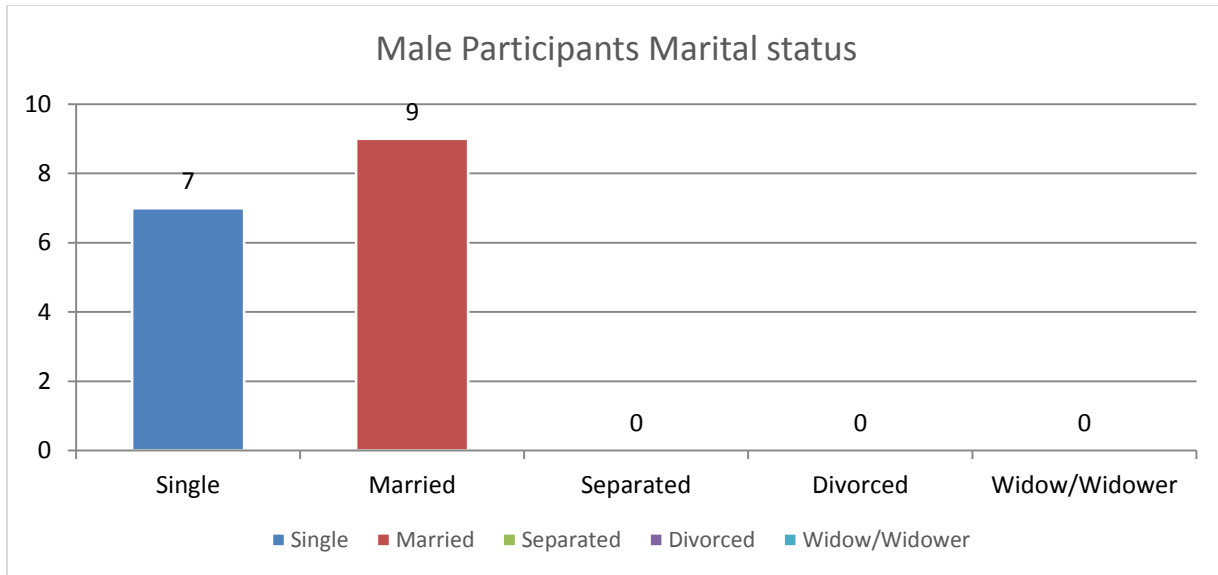


Figure 11. Marital status of male participants.

Forty-six percent females were single and 56% (9) of the males were married.

Overall, the majority of females in this study were single with only a high school education. The males were mostly college graduates and married. Demographic information did not include salaries or income. It should be noted that six females did not respond to the question concerning the marital status.

The infant's gestational ages at birth were evenly distributed among the parents/caregivers with the largest percentage 34% (17) being in the 31-33 weeks gestational birth age category then closely followed 26% (13) of parents/caregivers with infants born at 28-30 weeks gestation as shown in Figure 12.

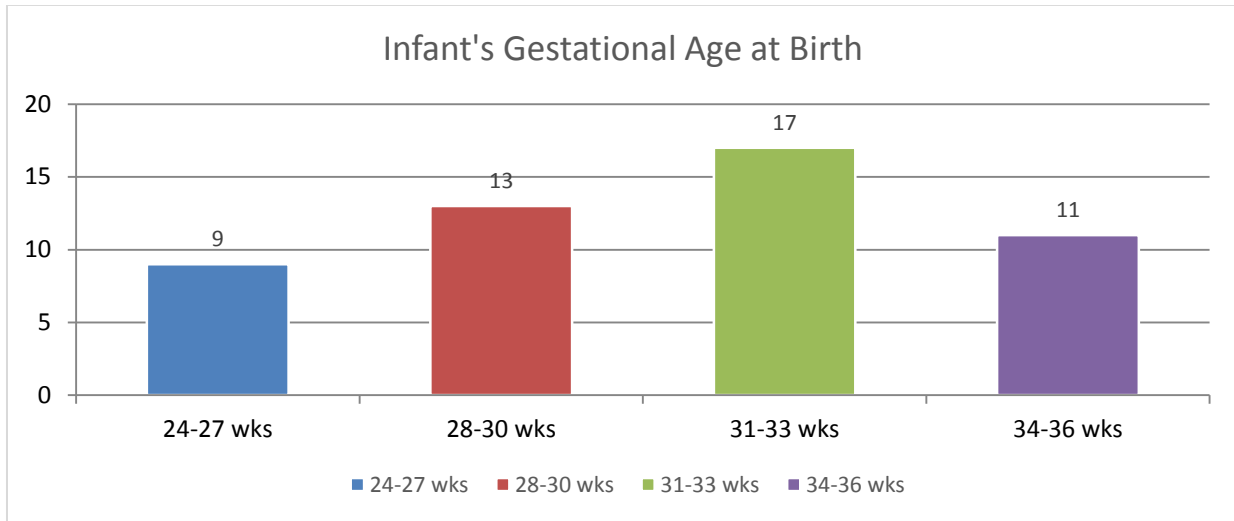


Figure 12. Gestational age at birth.

Regarding the 18% (9) of parents/caregivers of infants born between 24-27 weeks gestation, all but one had a college degree or higher, with length of stay of the infant ranging from 15 days to 104 days. The parents/caregivers of infants born at 31-33 weeks gestation provided comments regarding more physician presence in the NICU. It was interesting to note that the parents of this age level verbalized that they needed more input from the medical professionals than the micro preemies.

The parents/caregivers of infants in the 28-30 weeks gestation group ranged in age from 18 years old to 50+ years old. There were 12 infants with a length of stay ranging between 10-40 days. This group consisted of 11 mothers and 3 fathers with a variety of educational and marital status in this group. One father specifically asked for more communication with the physicians, “no matter how small or big an issue.”

The parents/caregivers of infants in the 31-33 weeks gestation group ranged in age from 21 to 50 years old. There were 50 infants with a length of stay ranging between 10-140 days.

This group consisted of 34 mothers and 16 fathers with a mixed assortment of educational and marital statuses.

The last group of parents/caregivers with infants born in the 34-36 weeks gestation group ranged from 18-40 years old. There were 11 infants with a length of stay ranging between 10-40 days. This group consisted of 16 mothers and 8 fathers with a mixed assortment of educational and marital statuses.

At the time of the focus groups, 46% (23) of parents/caregivers had infants in the NICU from 10-20 days, and 26% (13) had infants in the NICU for 21-40 days. There was a smaller percentage of parents/caregivers with infants in the NICU less than 10 days and at the extreme amount of days of 60+ in the NICU (see Figure 13).

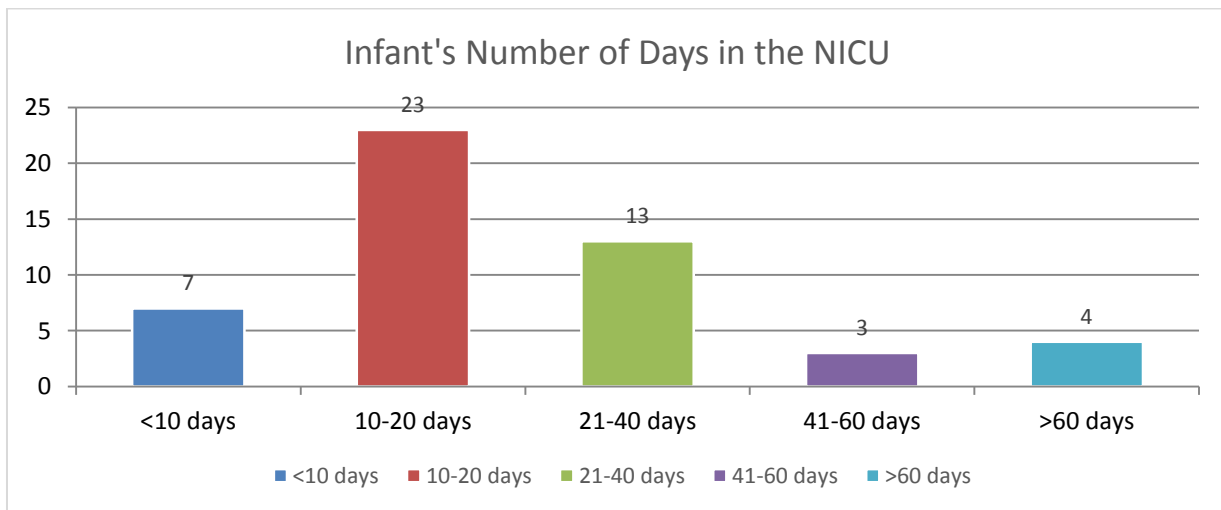


Figure 13. Number of days in the NICU.

Qualitative

Focus group question 1. The mothers and fathers were consistent regarding feelings of stress, as shown in Table 1.

Table 1

Parents' Feedback About Stress

Descriptions of Stress
“When alarms go off I feel helpless and stressful.”
“When the alarms go off I feel nervous.”
“Leaving my baby here”
“It is hard to go home.”
“I have a fear of care or lack of.”
“I’m afraid to say anything.”
“Don’t feel validated”
“I’m on edge anticipating the worst.”
“Family visiting stresses my baby. The nurses do not intervene.”
“The nurses are controlling.”
“I do not understand the tests and the results that are given.”
“The inability to make decisions about my baby”
“Not finding out information about NICU services”
“It is like a pumping room. There is no place to stay across the street for days or weeks.”
“A lack of control”
“Living 2 hours away when our baby had cardiac surgery”
“Feeling lonely”
“Unable to hold my baby”

Table 1 continued

Descriptions of Stress
“Little interaction with my baby”
“Confused by the lack of consistency of nurses”
“Leaving other children at home ... feeling guilty about their care”
“Obtaining a babysitter for other siblings”
“The doctors pushed our babies too fast. They ramped her up, took her out of quiet room to open room away from her twin brother. They took them off Cap and started full feeds all at once.”

Focus group question 2. With this question, participants offered diverse valuable recommendations concerning many areas of care in the NICU. They provided a wide range of suggestions such as communication issues with doctors and nurses could be remedied if they were asked if tests could be done on their infant before physicians order them and providing them with face-to-face daily reports if possible (see Table 2).

Table 2

Parents' Recommendations About Reducing Stress

How to Reduce Stress

“No one seems to want to help you breastfeed and I know in the beginning she couldn't, and I'm okay with supplementing with formula, but I think someone should be helping moms with encouraging breastfeeding and pumping. No one told me how to not dry up. I am deathly afraid of that!”

“There is always a different nurse. I worry with all the different people. It would be less stressful if you knew who your baby's nurse was going to be.”

“Give us information little by little.”

“When alarms go off, I feel helpless and nervous. I realize that they can't remove them, but maybe lower the tones.”

“The night nurse leave a note for me with the day nurse. This is wonderful, it allows me to do mothering.”

“I don't think people realize how hard it is and what I am going through. I would love to have someone that I could talk to that would help me get through what it is that I'm going through.”

“The nurses asked if I knew the results of a test. I did not know he had a test. The doctor and nurses need to let me know about the testing before. It makes me feel that there might be other things going on that I don't know about.”

“Not feeling validated ... Some nurses say that my baby is doing fine without explaining what is happening, that is fine.”

“Not able to hold my baby ... They need to show some things early on. I was afraid to hold my baby because I might hurt him. I might put him down the wrong way because he has wires on him.”

“Leaving other children at home ... feeling guilty, obtaining babysitting for other siblings at the hospital.”

“As a dad, the doctors always talk to “her” (pointing to the mother of the baby), but I am the Father! There needs to be better communication with the doctors instead of nurses. I want the doctor's opinion. They are running the shots as opposed to the nurses.”

Table 2 continued

How to Reduce Stress

- “There is a need for consistency of information given by the nurses. Every nurse is taught differently, but there needs to be a protocol and consistency if information.”
- “The nurses need to be unified and on the same page with whatever they do. They should always listen to the parents and take their perspective!”
- “Feeling lonely and controlled ... Nurses have a control issue and would not let me hold my baby. The charge nurse neglected me. A lot of nurses do not listen. There were also issues of them talking about me and the other mothers talking about me.”
- “If professionals would sit for even 30 minutes in the NICU as a parent and observe, they would run out like a little puppy with a tail between its legs.”
- “More privacy, especially for parents and babies who are more serious or have more health risks. Like for instance, when your doctor is giving you bad news it becomes very emotional. If it is another parent, you worry and are feeling bad for them. It is draining because of so many emotions in here.”
- “I think the hardest thing to go through is we had to leave the hospital without our baby. It is easy to come in, be strong, and smile; but as soon as I leave her, I cry. I think the hospital has cameras in their isolates, and you can access them online from home. You can watch them 24/7, and you can see that your baby is okay. That would mean a lot and take away worry when you are home and your baby is here.”
-

Focus group question 3. Many participants had difficulties with answering this question.

After responding to questions 1 and 2, they reported feeling that they already answered question 3 with the suggestions to curb stress, thus this might have led to their brevity in responding to this question. Responses to question 3 are shown in Table 3.

Table 3

Parents' Responses About How to Prepare to Cope with a Child in the NICU

Best Preparation to Cope with a Child in the NICU
“Maybe a handout of your baby’s first days in the NICU and what to expect.”
“There’s nothing there to help you cope. Sometimes you don’t know that you are going to be there. So, as far as coping, you are either strong enough to cope or you’re not!”
“I don’t think that anyone could have prepared me.”
“We did receive classes before we came into the hospital to have the baby, but maybe they should incorporate into the classes what you could expect if you have a preemie (premature birth baby) or the possibility that your baby will go into the NICU.”
“I don’t think there could have been anything ahead of time that could have prepared me for this. They could have told me everything that could happen beforehand and that would just stress me out.”
“I think we’re kind of the mindset of taking everything as it comes and learning as we go. I don’t want too much information. I want to know the what ifs, and I want to know the here and now.”

Focus group question 4. This question investigated how parents prefer to learn and have information presented to them. This is important for their preparation for home. It is imperative that parents enjoy learning in the fashion that is acceptable and best serves their learning needs. Their responses are shown in Table 4.

Table 4

Parents' Feedback on How to Best Provide Information Regarding Their Baby's Development

Best Methods of Providing Information on Baby Development	
Educational resources	Results
Individual sessions at the bedside	70%
Written Handouts	23%
Group classes	5%
Internet sources, DVDs, and pamphlets	2%
Books	0%
Other (Please explain)	0%

Focus group question 5. This question asked participants what else could be done in the NICU to help you feel more confident to interact with your baby at home. Forty out of 50 (80 %) had one or more comments to change things in the NICU. The answers were varied and specific to each participant's needs. When a cloud was performed with the words from the parent's answers, the main word that appeared was "MORE." The participants expressed a need for more instruction, more communication, and more interaction. They also offered practical ideas and thoughts about the need to learn more methods of how to handle their infant at home before they leave the NICU. Responses are shown in Figure 14.

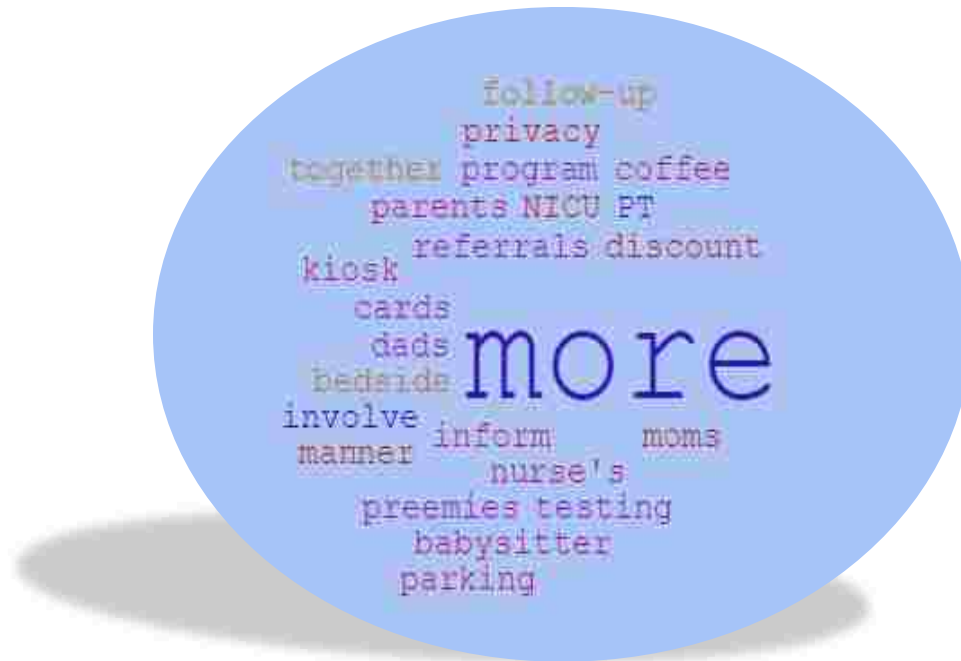


Figure 14. What else can be done in the NICU to help you feel more confident?

Focus group question 6 (on demographic sheet). This was an open-ended question, “if they have anything else they would like to add,” allowing the families and caregivers to share things that they forgot to say or were uncomfortable to express verbally when participating in the focus group. The participants expressed a need for more instruction, more communication, and more interaction. One mother wrote that she “has a 2- year old at home. “ I need to be present for more night care times to learn more about my baby’s schedule around the clock. I would like night watch more while the baby is in the hospital.” A mother as well as many other parents similarly wrote: “The nurses and doctors need to be consistent with procedures. It is confusing to parents.” Another parent wrote: “Even though rounds are a couple times a day, it would be nice to be see more of the doctor’s presence. Nurses are great, but a doctor interaction would bring more confidence after 104 days.” There were also responses describing some nurses as sweet, helpful, informative, and wonderful. More responses are shown in Table 5.

Table 5

Parrents' Feedback on Additional Ways NICU Can Help Parents Feel More Confident Interacting with Their Baby at Home

How NICU Can Help Parents Feel More Confident Interacting With Their Baby at Home

“Yes, you [the physical therapist], because you are able to interact with your baby enough and are getting enough information on how to interact with your baby, so that when you go home you want to be relaxed and comfortable taking care of my baby.”

“Some form of care for kids who can’t enter NICU so parents can care.”

“I want to do night watch before I go home. Some NICUs do not have this available. This is where I can see how I do when I get home with the baby.”

“Give instructions a week before discharge. Maybe parents should know what to expect when they get home.”

“Help the mother; and father to cope with their new stressful routines and positive and reassuring ways to complete their routines and tasks.”

“Jokingly...take the nurses home with us!”

“We are hoping that they are going to be giving us every bit of information that they can, like formula, size of diapers—even clothes—learn how to swaddle bath, and watching your exercises that I can bring home with me.”

“The babies are accustomed to the NICU, when they get home they change. It would be great to know what to expect.”

“I am here every day, and I realize that there is a lot of time that the nurses could use just 15-20 minutes to go around to parents that are out there and ask them ‘is there anything you want to be shown? Any advice you need?’”

Open coding progressing to axial coding was accomplished in questions 1, 2, and 3. The answers from the parents/caregivers are related to the coding and categorization process.

However, focus group question 4 provided information regarding how parents/caregivers want to receive information.

Axial codes from the PI when matched with the audit check were: Communication, Interaction, Stress, Coping and Prepared, Information, and NICU Prepared for Increased

Confidence to Go Home. From these codes, categories developed, which subdivided the codes. Categories to be effective were Responsive to the Purpose of this Study, Exhaustive, Mutually Exclusive, Sensitizing, and Conceptually Congruent (Merriam, 2009).

As shown in Figure 14, the horizontal columns indicate the categories derived by consensus of the audit and the PI. Communication is seen twice in this figure. It is as a code and a category under stress.

Communication	Interaction	Coping & Prepared	NICU Preparation Confidence to go home	Stress
Nurses	Nurse Inconsistencies	Never prepared	Time to hold baby	Inconsistency a) Nursing b) Procedures
Physician	Equipment	Too Early	Visits	Asking questions
Method	Nurse Style Positive	Too Late	Checklist/ Guidelines	Being heard Advocating
Positive	Nurse Style Negative	Need it early	Medical equipment preparation	Holding/Caring for baby
Negative	Nurse style	Need it ongoing		Leaving without baby
	Physician	Type of Preparation		Family don't understand
	Family	1.Tour 2.Pre birth		Lack of Information
	Other Parents	3.Hand Out 4.Face to Face		Other babies and Parents
	Preemie			Communication too little, much, early, Feeling ignored

Figure 15. Identified codes a priori.

One area that most participants agreed upon was inconsistency of communication to the families by healthcare professionals. The parents expressed that it was primarily among nurses with care and procedures for the care of the infant. Such comments as, “I questioned a nurse and felt uncomfortable because I was getting a feeling like being too picky.” Another participant

said, “Initially, the answers were up in the air with getting an answer. It often depends who takes care of your baby. There is a need for consistency.”

Validation and reliability strategies such as peer review/debriefing and eternal audit were used to ensure reliability and internal validity. There were matches of coding and themes with the PI and the peer reviewer. There was consistency of reasoning and coding with the various focus groups. The plentiful information that the participants provided enables readers to decide how the information obtained is compared to the reality of the situation (Merriam, 2001).

Triangulation is another method to ensure validity. The literature reported about communication difficulties, stress of parents, and lack of confidence of parents with infants in the NICU. Along with the participants’ verbal expressions through the interviews and the PI’s personal observation of the NICU, seeing what the parents verbalized formed the triangulation, which is another way to reaffirm the information is valid.

Data linked to question 4 presented that 70% of the participants rated individual sessions at the bedside as the preferred method of educating and learning (as was shown in Table 6). They indicated that the timing of the education is very important. Some remarks by participants included:

Just the timing of when they start to actually show you things makes a huge difference.

Instead of showing everybody towards the end when they are getting ready to take their child home, you should show things in the first week. It makes it so much simpler and makes the parent feel more comfortable.

Another participant remarked, “It would be better if they gave us information little by little.”

Additionally, another participant said, “It might be easier one on one because other people may have questions that you don’t have [if in a group session].”

Twenty three percent of the participants indicated that their first choice of how to receive information while their infant is in the NICU is handouts. However, some participants expressed that information on the handouts is not helpful. One said, “It is canned, and not all about my baby.” Another participant said, “It is a one size fits all concept! Handouts are less helpful because they would be generalized about care, not individually about my baby’s care.”

Five percent of participants perceived group classes to be effective, and 2% liked videos, pamphlets, and the Internet for educational information. Most commented that the Internet could not be trusted and found videos to be “worthless.”

At the end of focus group question 6 asked: Is there anything else you would like to say? This gave the participants another opportunity to reflect. This final question also served as a closure to our researcher/participant affiliation with the focus group. Several participants used this as a time to add thoughts that they wanted to be known. Some used this last question to compliment the NICU while others used it to give negative reports of incidents or changes they want to see happen. The essence of the comments from participants to this question stressed how they want more information, more interaction with their infant, more consistencies, and have additional needs they want to see met. The key word to the answers to this question was “more.”

In descriptive research, one investigates the experience or phenomena of the participants’ experience. Through the focus groups, the participants in this study identified areas where they need “more” assistance from NICU personnel. In qualitative analysis, the focus is to find the emergent pieces of information. Through inductive analysis the emergent themes develop. The following figures describe the inductive reasoning (themes) discovered in this study.



Figure 16. Theme 1 and Theme 5: Roles and Responsibilities, and Consistency of Care.

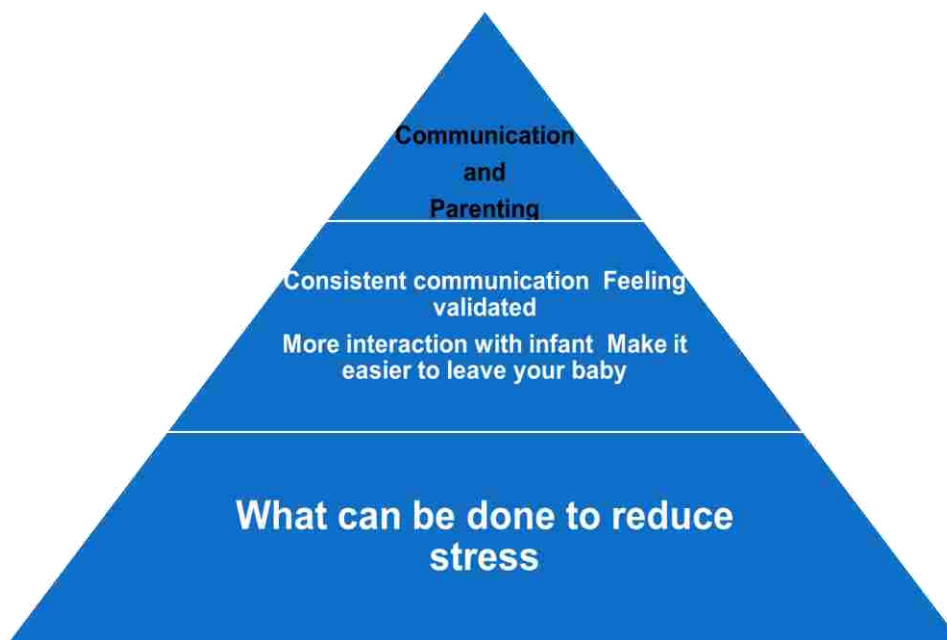


Figure 17. Theme 2, Theme 6, and Theme 7: Communication and Parenting, Interaction with Infant, and Be Heard.



Figure 18. Theme 3: Self-Help.

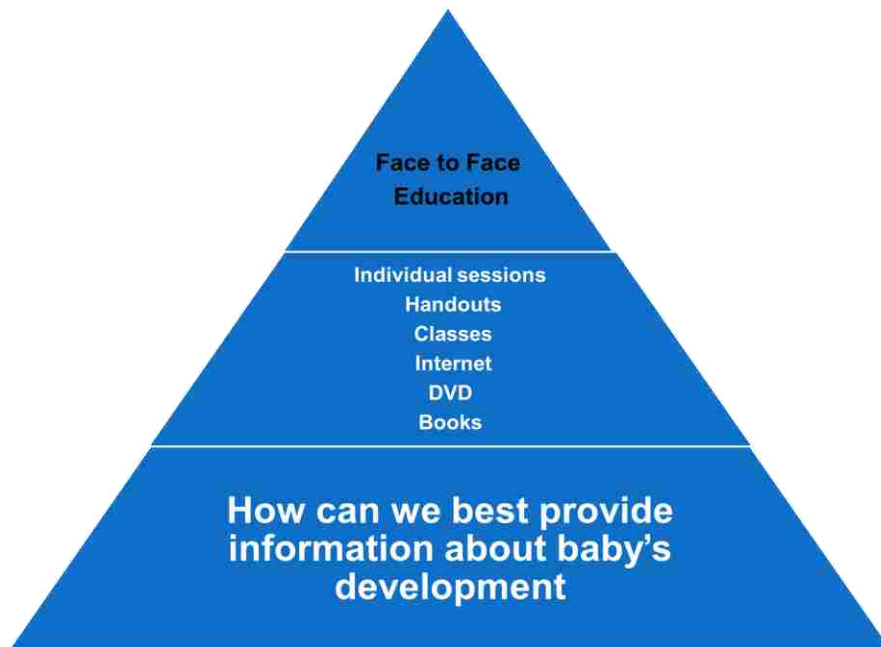


Figure 19. Theme 4. Face-to-Face Education.

An accepted analytical method is thematic analysis from the coding categories by identifying important phrases, patterns and themes, commonalities and differences, explaining consistencies, and relating any consistencies to a formalized body of knowledge (Neale, 2016). The themes were the basis and cornerstone of this study. These themes are fully described along with their implications to address the needs of the parents/caregivers of infants in the NICU in the next chapter. The following seven themes evolved from this study:

1. Roles and Responsibilities
2. Communication and Parenting
3. Self-Help
4. Face-to-Face Education
5. Consistency of Care
6. Interaction with Infant
7. Be Heard

CHAPTER V

DISCUSSION

From the candid remarks of parents, consistent communication, more one on one interaction with professionals, and more interaction with their infants are the findings as the suggested ingredients to produce confident parents from the NICU. Parents would be less anxious allowing them to enjoy their baby and help to progress them developmentally.

Findings Related to the Literature

Parents are an integral part of the care of an infant in the NICU. Family centered care is the standard of care in most NICUs as noted in the literature (Als, 1982; Browne, 2011; Lawhon, 2003; Treyvaud et al., 2009; Vanderveen et al., 2009). Parents and their interaction with their infant are affected by the NICU environment (including physical space, equipment etc. or people such as the medical personnel and staff) as well as the parent's/caregiver's personal mental state during their stay in the NICU. They seek the support and information to develop confidence. Relationships between parents of preterm infants and NICU personnel are influenced by several factors. It is imperative that this relationship is understood because it influences the infant's overall development as shown in Figure 19 (Davis, et al., 2003b).

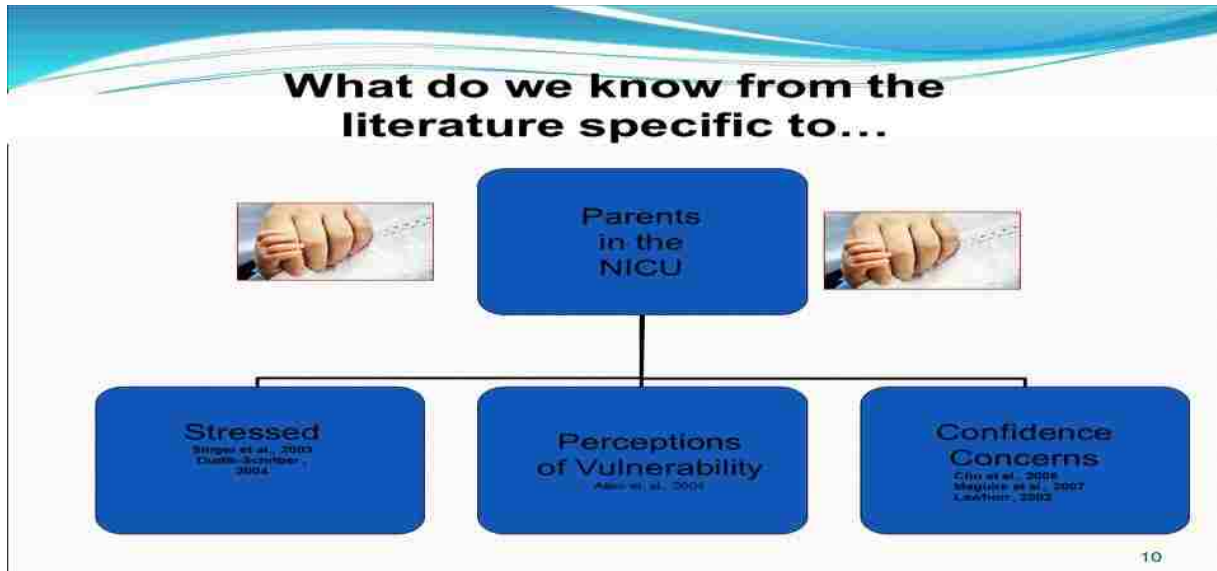


Figure 20. Factors about parents with infants in the NICU from literature

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In the literature, it was noted that NIDCAP is a form of developmental care in a NICU based on the synactive theory built upon years of animal studies concerning the serial development of sensory, cognitive, and motor functions in the fetus (Als 1982, 1986; Nelson & Bedford, 2016). According to Lawhon (2003), utilizing the NIDCAP philosophy, the family is vital to the infant's development within the family centered care approach. Family centered care provides an individualized care plan and adaptation to the environment for effective interaction with the premature infant in the NICU. The ultimate goal in the NICU is to foster family-friendly goals specially designed to promote the least stressful environment for each parent-infant dyad.

During the focus groups, the participants expressed displeasure at not always being considered an active team member. They reported being stressed by medical professionals as

indicated by comments such as, “Nurses appeared annoyed when I asked questions.” “The health professionals forget that it is people they are dealing with and lack compassion.”

Als et al. (2003) indicated that developmental care through investigating the NIDCAP program showed improved motor development and weight gain and may alter brain function and structure, thus causing a decrease in infant stress levels. It is known that prematurity has an effect on the dyadic quality of mother-infant interaction, and that the mothers of preterm infants are described as being “more controlling, intrusive, and active in their interactions with their infant” (Forcada-Guex et al., 2011, p. 24).

The participants in this study openly discussed how many emotional situations, communication issues, loneliness, and a lack of interaction with their baby produces stress during their stay in the NICU. Their comments poignantly indicated that the most prominent reasons for stress stemmed from conflicting communication of professionals with the parents, consistency of communication of nurses and doctors and staff with parents, the mother and father’s need to be a parent to their infant, and the fear of asking professionals questions because they feared what care would be given to their infant. Due to the communication difficulties of professionals with each other and with parents, the subsequent state of mind of parents such as feelings of loneliness, rejection, confusion, and decreased confidence are persistent as noted by the descriptions disclosed by the participants.

Parents’ feelings of premature infants in the United States mirror the feelings of the parents in Sweden as stated by Lindberg and Öhrling (2008):

Feeling support from and having the opportunity to talk to the staff results in less worry.

Being received by the staff with kindness is of great importance, and by receiving support from them, mothers feel that the infant is well taken care of. Mothers described it as

important to receive information specific to their experience and related to their unique situations, which they didn't always have. (p. 466)

Mother-infant interactions improve the development of infants and corresponding responses to stimulation. Parents of premature infants require support in developing effective interactions with their infants (White-Traut et al., 2013). The needs of the parents, as found in this study, if not addressed, could negatively affect the optimal development of the infant.

In an attempt to investigate the supports available to parents in the NICU that would foster interactions, Ward (2001) performed a descriptive study using the NICU Family Needs Inventory to identify the perceived needs of parents of premature infants. Ward (2001) suggested that there is a need to inform parents of the infant's treatment plan and procedures, answer parent's questions honestly, actively listen to parent's fears and expectations, and assist parents in understanding infant responses to hospitalization. The participant parents in the focus groups of this study expressed these same concerns on the medical level as well as educational level from all NICU personnel. They expressed fear, anxiety, distrust, feelings not validated, poor interpersonal relationships, and loneliness.

The medical team in the NICU has the responsibility to impart the knowledge needed and to instruct parents on how to effectively interact with their infant through programming to increase infant responsiveness and developmental growth (Ravn et al., 2011). In a randomized control trial, Ravn found that the "developmental prognosis among preterm infants is influenced by the quality of early mother-infant interactions" (p.221). The author concluded that effective interventions might increase mother-infant interaction and produce additional maternal sensitivity and a caregiving atmosphere for the premature infant. Listening to our parents, we know that they want to understand their infant's needs and communication as well as have more

interaction. The participant parents in this study expressed their need to be heard. There is a need to impart these feelings to the NICU medical team and to effectively work with families to attain optimal outcomes of the parent and the infant.

Themes

Theme 1: Roles and responsibilities. When an infant is admitted to a NICU, parents are told when and how to hold and respond to their infant. As indicated in the focus groups, they feel they do not know their role or responsibilities in this setting. In a study by Gibbs et al., (2016), parents expressed that they are unable to experience the anticipated parent events that are dreamed of during pregnancy such as having the baby and going home with a healthy baby.

Theme 2: Communication and parenting. In the NICU, communication is very important to parents. During the focus groups in this study, participants expressed that they want more communication with the healthcare professionals. They reported receiving mixed messages from professionals on the same topic or question, which causes great stress. When participants described how there are many different people caring for their infant, they would ask the professionals a question and receive multiple non-related answers. They asserted developing a lack faith in which professional was correct and had the accurate information. This greatly affects their interaction with their infant by increasing their stress and anxiety. With these negative emotions, participants disclosed having difficulty enjoying interactions with their infant. When asked what could be changed to decrease the stress, 50% reported that consistent communication by health care professionals is needed. Some examples of participants' actual statements were, question: What could be changed to help reduce your stress? Answer: "I don't think people realize how hard it is and what I am going through. I would love to have someone that I could talk to that would help me get through what it is that I'm going through." Another

comment was, “There is always a different nurse. I worry with all the different people. It would be less stressful if you knew who your baby’s nurse was going to be.”

Weiss, Goldlust, and Vauche (2010) investigated parents’ satisfactions with communication regarding healthcare providers in a NICU. The authors found that communication styles differ among parents. The communication needs of parents change over their time in the NICU. Weiss et al. also reported that communication needs change with a baby’s acuity of illness. We know that the parents want consistent communication, but this may be affected by styles and understanding. According to the author, parents’ satisfaction can increase with better communication. With better parent-professional satisfaction with communication, the parents may be less stressed, thus improving their interactions with their infant and in turn improving infant outcomes of development.

Theme 3: Self-help. As one prepares for big events, the preparation involves gathering supplies, reading, asking questions, and/or mentally thinking through preparing in their minds how the event will proceed. When speaking with the participants in the focus groups, they were asked the question: How could you have been prepared better for the NICU? As described in the literature by Cooper et al. (2007) mothers feel more confident and less stressed when they have an opportunity to talk with a specialist before delivery about what to expect of a premature infant. However, from the responses in the focus groups in this study, 90% (45 out of 50) reported that no one could help them cope. Each participant repeatedly gave variations of the same answer. The answer was almost unanimously stated, “Nothing could prepare me for the NICU!” This short, yet powerful sentence describes parents’ lack of confidence and despondences in this setting despite their educational background and/or marital relationship situation. However, a few parents remarked: “It seems like such a traumatic experience to be

thrown into the NICU experience that you don't know what it all entails." It is a nebulous atmosphere that cannot be forewarned effectively in the eyes of the parents.

Each parent experiences the NICU with individual responses and expectations; however, the overall goal of parents is to go home with their baby. Preparing a parent for the NICU could be superficially done as suggested by some participants. They recommended that during the prenatal parent class, there could be a segment that briefly discusses the NICU as a potential part of the birthing journey in the event of an unforeseen event. If they knew that could happen and have a basic idea for the reasoning why an infant might go to a NICU, it may help them cope better with this situation.

Theme 4: Face-to-face education. "Knowledge is power" (Sir Francis Bacon). This quote resounds with insightful advice for educating parents/caregivers in the NICU. The focus groups provided the participants in this study with a forum to articulate their needs. The PI heard their anxieties, helplessness, fears, lack of confidence, and other emotions and behaviors. These behaviors and emotions evoking negative factors allude to having a lack of power stemming from an insufficient knowledge base to effectively participate in the NICU.

Knowledge and education are key components within all realms of the participants' experiences in the NICU in addition to the questions posed in the focus groups. Each stage of their journey seemed to require a knowledge base of information. When parents/caregivers were asked the preferred method of learning about what to do and what not do in the NICU, they expressed wanting individual needs addressed with face-to-face interventions for optimal learning. The majority of the participants selected one-on-one education at the bedside. They also reported wanting the education to be individualized their needs and their infant's needs. Participants disclosed that with education groups of parents/caregivers in classes, they do not

receive specific information applicable to their family's particular needs. Some reported they did not interact as well because they were not "group" people.

Before discharge, collaborating with all team members in the NICU to educate the parents is vital for the infant's developmental outcomes and the parent's compliance with instructions. The aim of collaborating with all team members in the NICU is to work together as a team for the well being of the infant and families (Ohlinger et al., 2003). Much of the research involving parent education and discharge planning in the NICU typically revolves around nurses and physicians doing the primary education without the involvement of other disciplines (Gravem et al., 2009; Melnyk et al. & Fairbanks, 2008; Sneath, 2008). However, collaboration and team efforts are highly encouraged when working with families in the NICU and pediatrics (Brown Ohlinger, Rusk, Delmore, & Ittman, 2003). When collaborating, the role of the parent/caregiver is the most important team member (Goldstein, 2012). Upon discharge, the parent is the primary person caring for the infant.

Physical therapists are movement specialists and knowledgeable of developmental milestones. Physical therapists have the skills to evaluate infants and determine any atypical developmental or movement aberrations (Palisano, Orlin, & Schreiber, 2017). They are experienced with parent education and careful team collaboration with other team members such as occupational therapists and speech therapists (Campbell, 2012; Dusing, Van Drew, & Brown, 2012; Goldstein, 2013; Palisano et al., 2017). There are programs available that maybe given one-on-one. The NICU Care Path is a structured tool developed by pediatric physical therapist Suzanne Campbell. It is based on family centered care. It includes (a) recognizing infant cues, (b) social and sensory stimulation, (c) feeding, and (d) accessing community supports upon discharge. Activities are based upon the infant's age and abilities (Goldstein, 2013). Through a

program such as the NICU Care Path, parents receive the one-on-one education that they perceive to be as the optimal method of learning.

Working with the parents before discharge to learn how to move and play with their infant will allow the parents/caregivers to enjoy their infant. The PI, enlightened by the comments of the participants in this study, perceives that graded and sequential progression of imparting information concerning the development of the infant throughout their NICU journey is more conducive to learning. Working with the parents consistently and face-to-face until discharge is what the parents identified as a need. This would be set up as opposed to squeezing in training 1-2 days before discharge. This will prepare parents to decrease stress of handling and moving their infant. Therapists may select a specific method based on the individual needs of the infant, family, and culture of the NICU for optimal outcomes (Goldstein, 2013). By educating the parents, we can empower them to be the parents that they have desired to be someday.

Theme 5: Consistency of care. As the conversations of the participants evolved, there were several occasions that a paradoxical statement developed in the focus groups discussions. There was a significant and essential paradox with this data. The self-contradictory statements were embedded in conversations. One mother reported an incident regarding her boyfriend's mother who came to visit and kept disturbing the baby. The mother of the infant asked her boyfriend's mother stop and leave the infant alone; however, the boyfriend's mother continued to put her hand on the infant thereby setting off the infant's monitor. Although the mother wanted more freedom with her infant and interactions, nurses appeared to restrict during her visits with her infant. The mother said, "I did not want anybody other than me and him [boyfriend]. I don't want anybody touching him [the infant]."

Contending with incidents like this causes a mother to be stressed. In response to this incident, this mother remarked paradoxically,

I blame the nurses though ... It makes it easier on you, because if not they [family and friends] start saying, 'you are spoiling them.' And the more that people mess with him ... and the more he gets mad, the longer he's going to spit everything up, which means the longer it is going to take for him to come home.

Another mother in this focus group agreed and gave her thoughts concerning this as well. The paradox is that the interaction of the nurses is needed when visitors are there to keep the baby calm, yet the mother knows her baby and wants to have some control of the care of her infant.

Another example of a paradoxical situation is the mother that expressed her comfort with certain nurses and not others. She remarked,

One of the things that I think that would make it better is that there are certain nurses I feel 100 times more comfortable leaving the baby with than others, and I don't think there is a good outlet to express that you feel more comfortable with certain nurses over others.

Another mother said,

We are their advocates. At first, I was so scared to talk, to move. I have been here for a month. Now I have a whole bunch of things I know that I do not like. It is different for me now.

The parents appeared to develop mixed feelings. They are happy to have the nurses, but expressed how harsh they can be and their lack of empathy. They also want the nurses to be in strict control over their visitors, yet have compassion for them, the parents, and help them with their developing parenting role.

Theme 6: Interaction with the infant. The sensitive feeling of parenting is taken from parents in the NICU. One mother sadly said, “I do not feel like a mother here.” She indicated that is due to lack of interaction with her infant. She stated, “I am told when I can touch my infant, feed my infant, and change my infant.” With these statements, one becomes concerned about the emotional health of the mother and providing for her needs. This is not the parenting that this mother envisioned during her pregnancy. With this lack of mothering abilities and skills reinforced, behaviors such as depression and anxiety may become problematic. Thus, these negative maternal behaviors affect the interaction of the parent-infant dyad (Melnyk et al, 2008).

The sense of bonding is very important to parents. Mothers who have had previous children expressed this burning need for interaction. As one mother discussed, “I don’t get much interaction with them. There is no bonding right now, and that is hard. I’ve had 3 kids, so I know how important that bonding time is and that is SAD to me.” After another question was posed to this same mother, she continued to speak about the lack of interaction. From this ongoing conversation, it appeared to weigh heavily on her mind. She continued, “It would be ideal to hold them right now, but I know it is not practical right now, and I understand that because it is not what is best for them right now.” This demonstrates the strength of the need of parents to hold and interact with their infant. With kangaroo care, the research indicates its positive effects on the health of parent and infant (Flacking, Thomson, & Axelin., 2016).

At times, it appeared that there were a variety of feelings emerging from the participants. Mothers expressed that they feel that the nurses act more like mothers than they do. One mother voiced, “My one twin has an attitude. He loves (nurse’s name). She just talks and he smiles. It is so weird. I’m your mother, not her (with emphasis)!” With this powerful statement, it is obvious that the mother crying out to be her infant’s mother, not a stranger. Paradoxically, this mother

said of another nurse with her other twin, “He has his favorite nurse and another one whom he does not like. He stresses out!! I want to say ‘go away ... go away’ (emphatically)!”

Another parent said, “Nurses have a control issue and wouldn’t let me hold him.” A powerful statement that a parent communicated was, “I think the hardest thing to go through is when you have to leave the hospital without your baby. It is easy to come in and be strong and smile but as soon as I leave here, I cry.” Another said, “I feel like you really don’t get enough contact with your baby or time to see your baby.”

These statements dramatically tell the medical community in the NICU that the lack of interaction with their infants imposes emotional stressors on these parents. As clinicians, we need to address these needs to promote positive interaction of parent and infant for optimal outcomes of this dyad.

To instill confidence with the parents, they, as the primary caretakers, should have positive parenting feelings instilled in them. Interaction is the key to decreasing these ill feelings of helplessness and a non-parental feeling. Early intervention of decreasing the negative feelings to prevent anxiety, depression, and other behavioral problems should be encouraged and implemented. Interactions and touch are important stress relievers for parents (Melnik et al., 2008; Melnik et al., 2006; Melnik et al., 2002).

Theme 7: Be heard. How we communicate to others affects relationships of couples, friends, colleagues, classmates, teammates, and anyone we interact with. There is evidence that parents who receive useful information are more satisfied parenting their infant with their care in the NICU (Cooper et al., 2007; Weiss et al., 2010). Therefore, staff members must understand parents’ information needs and effectively communicate using terminology that is easy to understand (Bialoskurski, Cox, & Wiggins, 2002; De Rouck & Leys, 2009). This is the area that

highlights the findings in this study. The parents voiced many concerns about various communication concerns. Thus, communication is an essential ingredient for caregivers of infants as well as the professionals working with families in a NICU.

The parents in this study conveyed their feelings about communication across many interpersonal levels such medical professionals to parents, parents to baby, baby to parent, and parent to parent. They indicated that with poor communication, their stress level increases. Participants also expressed the perception of a lack of validation of their feelings and not being able to be an actively involved parent to their infant.

Jones, Woodhouse, and Rowe (2007) reported that parents and physicians differ with their opinions and preferences regarding communication. They described that physicians obtain medical information and parents seek to be heard and understood. Less is known about communication of other medical professionals and families. The parents in this study emphasized how communication in the NICU is poorly orchestrated. They perceived that their opinions are not valued and have no one to go to express any disdain or concerns. One father said, “The shift changes. There is no information given to me. The doctors always talk to her (gesturing to his female partner) but I am the father! (Emphatically) I need to know also!” Another participant stated,

It would be interesting if there were a way to comment on the nurse’s bedside manner without necessarily insulting them. Every once in a while, there is a nurse that has terrible bedside manner or a nurse that you didn’t click with. It would be nice to be able to communicate a desire to have a nurse that you do work well with and feel comfortable with.

These parents are imploring and silently screaming: Please hear me!

As emphasized by Weis, Zoffman, and Egerod (2013), parents' value having deeper levels of communication that are two-way and involve informal and formal discussions asking them questions concerning personal issues. The importance of the interpersonal relational forms of communication cannot be undervalued. We need to understand and know the emotional impact that parents endure in the NICU.

Previous research has highlighted and equated the importance of communication in medical situations to patient satisfaction with care. For example, Van Riper (2001) showed that family centered approaches, where communication-based criteria are valued, improve parent satisfaction in NICU. Health professionals prioritize clinical or technical criteria. The results of this study emphasize the importance of communication to parents that provides clear information.

Communication does not seem to be a need exclusive to parents in the United States. Wang, He, and Shu (2016) expressed that they discovered using a study-specific questionnaire and a Chinese version of the Critical Care Family Need Inventory that parents report that medical personnel in the NICU should listen to parents' thoughts, worries, and beliefs. Parents want medical personnel to provide accurate and honest information about the premature infant's medical condition, care, and expected outcomes. The authors reported that mothers experience more stress and fathers experience extreme highs and lows during the birth, NICU hospitalization, and post discharge coping by returning to work with feelings of despair and helplessness. Fathers and mothers experience different emotional needs during the NICU stay. However, Wang et al. also demonstrated that both parents have the same communication needs of honesty and assuring them that their infant was receiving optimal care. These result reflects

the studies in the United States of parent's perceived needs as well as in this study (Jones et al., 2007; Van Riper, 2001; Weis et al., 2013).

In this study, participants reported enjoying and look forward to receiving communication from the physical therapist that works in the NICU. There were notes from the physical therapist in the communication book at the infant's bedside that relayed information of how their infant performed for the therapist that day. As one father stated,

I like the physical therapy notes in the binder. I would like the doctors to write a note also. The nurses are not coming over to me. I work 12 hours and come here. The communication book would be so helpful for me. In the communication binder here ... Use it so there is some method of daily leads of what's happening. I do this at work from day-to-day, why not here?

Some participants remarked that they wish more people in the NICU would provide information in this book. The book provides the parents with some feelings of participation with their infant's care and demonstrates that their parental role is important to the infant's overall well-being and development.

Consistency

An area of concern in the NICU is consistency of communication. According to The Free Dictionary by Farlex (2017), *consistency* is an agreement or accordance with facts, form, or characteristics previously shown or stated; agreement or harmony between parts of something complex; compatibility. This definition highlights the distinct issue that parents present, which is there is a lack of consistency with answers given to them.

Lack of consistency of information to participants with infants in the NICU was extensively expressed throughout the focus groups. Participants expressed their individual

anxiety with conflicts of information concerning their infant when presented to them by various medical personnel. One mother reported that when she came to the NICU, “I would have liked the nurse to teach me the steps of what to do and what not to do.” Another mother in that same focus group replied to her, “I think it depends on the nurse, because my nurse actually did tell me what everything was for, and I think some are more knowledgeable than others.” Another mother indicated communication inconsistencies with the following statement:

Parents need to feel that questions and concerns are welcome. This does not always happen with different staff. It is hard to be on the same page with you ... your husband and 65 nurses! We did not want to cause waves, and we would end up fidgety. Even my friend was fidgety with her nurse due to nurses not agreeing.

This lack of consistency causes undue stress to parents. They become distrusting, which changes the relationships and interactions with the medical personnel and ultimately with the infant.

In a study by Russel et al. (2014), the authors concluded that 10 of the 39 participants in their study indicated that medical personnel in the NICU gave them conflicting information and advice. It is understandable that people may differ or have differing opinions; however, this is something that the professionals should discuss before announcing to the family. This causes parents/caregivers to question what they are doing with their infant, thus causing stress to supervene. As another mother in a group expressed:

The nurses do not check things like the placement of the NG tubes. This is important because the babies are fed 4 times in the shift. He has reflux. This stressed me. Doctors said one thing, they the nurses, said another. I had to watch *everything* (emphasized) that happens to our baby to avoid *bad* (emphasized) mistakes. In this NICU, there are stressful things. Well, some nurses ignore you. They walk right past me and not acknowledge me. I would like to converse. I wanted to talk to them about his [infant’s] circadian schedule and rhythm. It is uncomfortable for me to ask for re tapping of NG. Sometimes they [nurses] are in the way. Every nurse is taught different ways. There needs to be some protocol. For instance, concerning the colostrum, I questioned a nurse and felt uncomfortable because I was getting a feeling like being picky more. Initially, the

answers were up in the air without getting an answer. It often depends who takes care of your baby. There is a need for consistency. I felt there was some unnecessary increases oxygen by nurses, for example, going from 2.5 to 4 liters. Mothers do not like the jumping around, and no one seems to know why. There is confusion of how high to put the oxygen. They make changes and no one told me. It concerns me because I know that increased oxygen causes blindness.

Another parent, a father, remarked: “The nurses sometimes let us wrap and bundle the baby.

Others do not! It will be better, when they [the twins] are not here and home with me!”

Due to these inconsistencies of communication, parents develop mistrust, a lack confidence, and become suspicious of their infant’s care. One mother said,

I think the nurses need to communicate more things with the parents. I just found out today that my child has a heart murmur, and they have been monitoring it, but no one has told me, or his father. The nurse said to me that they were going to do a test on Monday. And I said “a test for what?” And she was surprised that I didn’t know. Nobody mentioned anything until today, doctors or nurses. It makes me wonder if there is something else going on with him that I don’t know about.

In this particular focus group, two participants discussed the positive and negative feelings and outcomes of having communication inconsistencies. Participant 1 said,

You asked earlier about what could be done to make parents less stressed, and one of the things that I think that would make it better is that there are certain nurses I feel 100 times more comfortable leaving the baby with than others. I don’t think there is a good outlet to express that you feel more comfortable with certain nurses over others. And lately, it seems like every shift there has been a different nurse, and that makes a lot of stress for the parents, worrying how the baby is doing at night. In a direct response to this, participant 2 stated,

My son had some trouble earlier in the week. He had one nurse that was consistently with him and she noticed that he didn't seem right and she notified the doctor who ran blood tests and they came back positive that he had a urinary tract infection. Now, if that nurse wasn't consistently with him to notice the change, it may not have been noticed right away. There is less stress on the parents when you know your baby has the same nurse. Listening to the perceptions of the participants in this study concerning inconsistencies helps to understand parents' fears, anxieties, mistrust, anger, and belittling feelings that they experience day-to-day when their infant is in the NICU. For some, it is months of these negative feelings. As a professional caring for the welfare of the infant and concerned for the optimal development of functional skills and behaviors, one becomes concerned how the parent-infant interaction is evolving with the amount of negative tensions that the parents endure each day.

Limitations

Qualitative studies are always descriptive and exploratory. It is the beginning of a research journey of a particular topic. This study is considered as exploratory in nature, providing information as a stepping-stone toward further investigations of the perceived needs of parents with infants in the NICU to enjoy and feel confident with their baby when he or she is released and sent home. Due to the design of this study, its findings cannot be generalized.

The Parent Child Interaction questionnaire (PCI) that was developed in the pilot study for this study consisted of 39 questions using a Likert scale and five open-ended questions. Despite the richness of the information from the focus groups, using the statistical analysis information from the PCI questionnaire of the perceptions of the parent's needs would provide more quantitative objectivity to this study.

Another limitation of this study includes that it was conducted in only two Level III NICUs in Pennsylvania, which are not generalizable to other such institutions.

Additionally, it would be advantageous to include a larger sample size of participants and use multiple centers across the United States. However, in qualitative studies, 50 participants is a large population, but still not large enough to generalize the results. Having a larger sample of participants across multiple centers in different sections of the USA would provide diversity of cultures as opposed to only families in NICUs from only southeastern Pennsylvania.

In addition to the peer reviewer who collaborated to attain trustworthiness, it would be interesting to have a parent of an infant who was recently discharged from the NICU also review the interviews to determine themes.

The focus groups were usually one to four people. Although the participants appeared to enjoy the intimacy of the small session, possibly larger groups may have enhanced the conversations.

The sampling in this study relied on the parents who were available during the times designated for the focus groups. With more accessible scheduled time slots for the focus groups, more parents may have been able to attend and provide richer discussions and offer more diversity of opinions.

The information obtained from the participants in this study was collected as a generic group. The PI did not specifically isolate the responses to the person's age, sex, or education. Analyzing the information with a specific demographic area, for example delineating the responses by all fathers, all mothers, those with a certain education or specific gestational age group, may possibly provide more in-depth data to understand the perspectives of specific

groups. Additional information such as if participants are first time parents and their socioeconomic resources may also provide more defining information.

Most of the literature relevant to this study area revolves around nursing and physicians. Possibly, the questions for the focus groups could have included some queries investigating the involvement of the parents with specific medical personnel such as physical therapists, occupational therapists, social workers, psychologists, and speech therapists as providers of knowledge in the NICU to explore if they could help fulfill the needs of the parents.

Methodological Reflection

The methodological process was two-fold. Due to a lack of a published survey to explore the needs of what parents of preterm infants feel they need prior to discharge from the NICU led first to a pilot study to generate a questionnaire. Once validity and reliability were established, this valuable tool became available for professionals in the NICU. Since there was a valid and reliable tool, it was acceptable to use the open-ended questions from the questionnaire for the focus groups (see Appendix K).

During the focus groups, information rich conversations about areas of concern with the participant parents emerged. Creswell (2013) likened qualitative research to “a fabric woven with many textures, blends, and colors to the worldly perspectives of individuals woven to hold together and formulate the fabric of qualitative research” (p. 42). Qualitative research is being utilized more often in medical research because its uses have been fully investigated and improved.

Due to the methodology selected for this study, the PI determined that the participants be allotted the opportunity to be candid without recourse. They expressed a desire to convey their concerns to “someone,” but were afraid it would negatively affect the care of their infant. When

the PI originally began this study, it was determined that the PCI questionnaire with Likert style questions and some open-ended questions would be used. However, due to unforeseen circumstances, the design of the study required adjusting. Thus, focus groups became the design of choice. Using this method provided a wealth of information from the participants that may not have been captured in a questionnaire.

The participants were grateful for the opportunity to speak about their needs without judgment. Some enjoyed the experience so much that they asked if they could come again. This in itself points out a need for parents to have the chance to speak to a medical representative one-on-one and simultaneously feel safe to express their feelings. This type of opportunity may help to decrease anxiety and increase their comfort level during their infants NICU journey.

Using qualitative methods in this study ensured practical and valuable information to develop programs, which instills confidence. Fortunately, the small focus groups and the one-on-one attention allowed a comfortable atmosphere for individual participation as opposed to large group participation. With any group, there is the possibility that group dynamics may affect perceptions influencing the unit of analysis of an individual's thoughts (Polit & Beck, 2012). Similarities in participants' stories also make it clear that the perceptions of parents of their needs individually are different but through analysis share basic themes.

There were 50 participants involved with this study. The hospitals were St. Luke's Hospital Network, Bethlehem, Pa. and the University of Pennsylvania Hospital, Philadelphia, Pa. Consequently, this limited the information available and therefore lacks the ability to generalize to the general population.

CHAPTER VI

CONCLUSION

This study intended to explore the perceptions of parents with infants currently in an NICU, specifically to inquire about what they feel they need before their infant is discharged. It was important to learn about their experiences in the NICU, which would enable them to feel confident and enjoy their infant at home.

The findings of this study provide valuable information that can be used for staff development and skills training. Medical personnel in NICUs operate in a challenging environment with the demands of attending to the infants and providing family-centered care. The findings from this study can be used to help the medical team in NICUs to prioritize the communication and educational needs of mothers and fathers.

Guralnick's (2001) developmental systems model provides a framework for infants and children in the community entering the early-intervention programs. Many of the underlying domains are similarly representative of the needs of children and parents preparing to exit the medical model in a NICU to go home and to begin utilizing community services. According to the author, this theoretical model guides the early intervention program based on a multi-component interactive system. A significant aspect in this model is that families are the primary influences on the outcomes of children. A quote from the National Research Council and Institute of Medicine (2000) is very appropriate when describing the NICU parent/caregiver dyad:

Young children establish and can benefit greatly from a variety of close relationships.

Yet those adults who are most consistently available and committed to the child's well-

being play a special role in promoting competence and adaptation that cannot be replaced by individuals who are present less consistently or whose emotional commitment is not unconditional. (p. 389)

Guralnick's model could be likened to the process of parents in the NICU in many ways. As we learned from the participants' candid remarks, they want to be parents to their infants and valued by being heard. The model for early intervention would be a type of protocol that could be implemented with some adaptations for a medical facility. In Guralnick's model, the parent and infant are the center with all the supports of staff and community surrounding them. With a proposed NICU parent model to collaborate with the medical model, it would function like a funnel. The medical personnel would be flowing useful and important knowledge and information into the parents with good communication and knowledge so that parents' confidence would increase and they would feel valued. Thus, the parent/caregiver and infant interaction and infant outcomes would improve (see Figure 20).

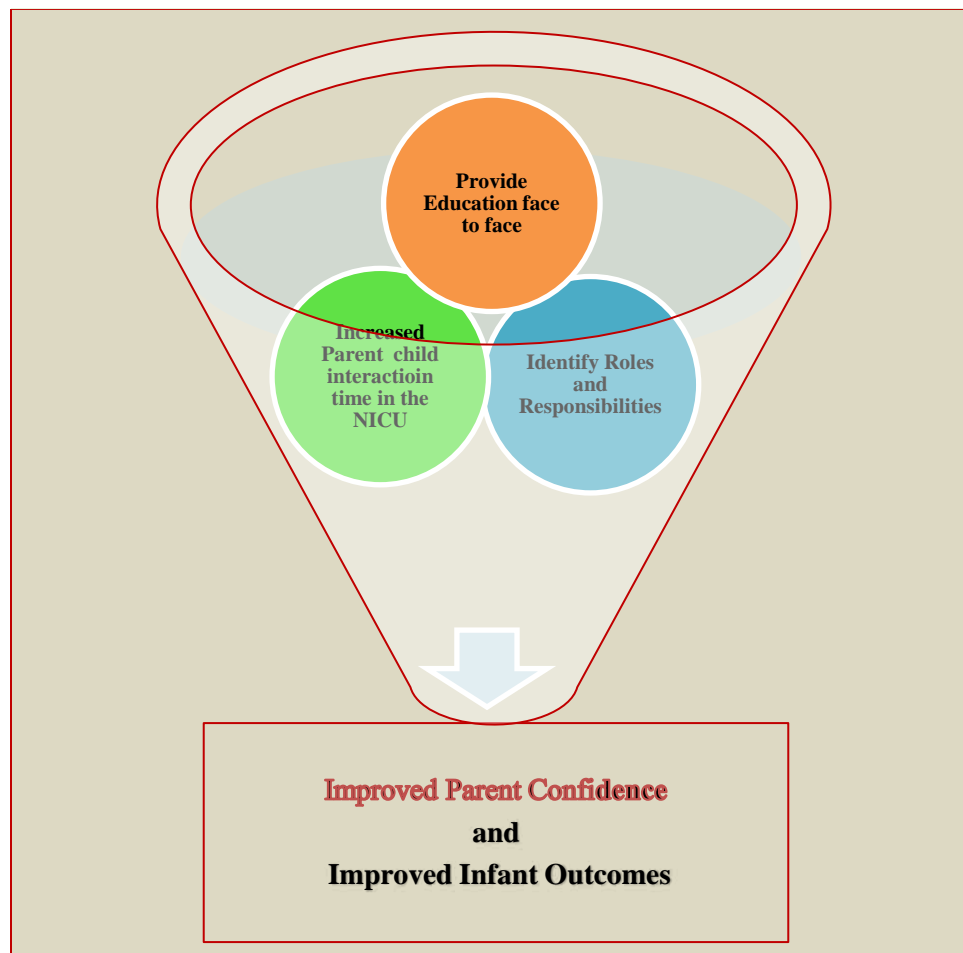


Figure 21. Proposed parent NICU model. © 2017 Maureen A. Rinehimer

In the NICU, services have stipulations regarding a medical model, whereas the early intervention model is based on an educational model, which is family centered. However, if a model for the NICU could focus on the need for increased knowledge of parents including effective communication with medical professionals and support family centered care, it would seem that making the adaptations would be feasible.

Trends with NICUs are to provide family-centered care. The March of Dimes is a big proponent of family-centered programs (Cooper et al, 2007). Ideally, using a model that would

allow for the medical needs that an intensive care unit demands and also allow for more parent/caregiver interaction with medical staff and their infant would help to improve better outcomes. .

In order for a NICU parent model to work, healthcare professional in NICUs must listen to what parents need. Parents have different educational levels and preferred methods of learning. From this study, the parents prefer individualized teaching sessions at the bedside to identify the specific needs of their parent-infant dyad. They do not perceive learning in groups to be effective. They reiterated that they want “their” infant’s needs met, which possibly cannot be accomplished in a group setting.

An NICU parent model would include individual education programs, clearly identifying parent roles and responsibilities, and enabling more parent interaction with their infants. The interventions are based on the needs of the parents/families to provide the child with the optimal support for better outcomes. This type of program could give families the ability to be parents to their child, yet receive support as needed. It would be beneficial for the administrators in the NICU to consider adopting some of these principles for better infant outcomes, improved parent satisfaction, decreased hospitalization, and more knowledgeable parents to promote developmental care for their infant.

Another area to investigate is consistency of communication. As a theme that developed in the focus groups, participants in this study expressed their stress, frustrations, and distrust due to inconsistent communication by the medical personnel. Total team building and inter professional communication programs would provide a consistent language and information sharing for the families. Weis et al.(2013), by performing a three-step intervention in NICU, revealed that launching effective communication with the parents and providing information about their infants and the required care can result in increased satisfaction. Analyzing healthcare

quality is usually evaluated using medical outcomes, including neonatal readmission and patient and family satisfaction. Weis et al. also discovered from other studies that information could lead to parental confusion; therefore, it can decrease confidence in health care systems, increase anxiety, and eventually decrease parental satisfaction. In this study, the non-consistent information caused confusion as well as stress and distrust in parents.

The Weis et al. (2013) study of 110 first time mothers discovered that a guided family-centered care program provides intervention to promote the discovery of the parents' individual preferences and concerns for more focused communication of parents and nurses and the effect on maternal participation and satisfaction. However, as the parents imparted to the PI in the focus groups, communication is not exclusively with nurses, but all medical personnel.

Increased parental participation in the NICU correlates with decreases of re-hospitalizations (Erdeve et al., 2008; Hutchinson, 2012). The parents are anxious to take their infants home. However, if the knowledge, confidence and communication of medical personnel to the families are lacking before discharge, the potential of re-hospitalization can occur. Thus, this could possibly cause destruction of any confidence the parents developed and increase levels of stress.

As clinicians, we need to listen to our parents/caregivers and embrace positive contacts of parent/caregiver with an infant for the best possible outcomes of parent and infant interaction and ultimately infant developmental outcomes and parent satisfaction for overall improved healthcare outcomes. The following powerful, yet simple sentence serves as a take home message, which was aptly stated by a parent in one of the focus groups: "When I hold my baby, I feel more confident to take him home."

Future Research

Continued research using the PCI tool to screen parents of their needs to reinforce parent-infant interaction will provide not only qualitative information but also some quantitative answers for the parent-infant dyad. Also, it would be useful to study the timing of when certain information is applicable and when it is “too much too early,” as a participant in this study reported.

Further research is needed to delineate the parents’ needs to specific groups of parents. For instance, information for parents with infants born 24-29 weeks, parents of infants born 30-34 weeks, and parents of late preterm infants. Each group of parents may present with varying needs. It is important to investigate how and when a team of professionals including physicians, nurse practitioners, physician assistants, nurses, physical therapists, occupational therapists, speech therapists, respiratory therapists, psychologists, and social workers are collaborating to provide an educational program utilizing the expertise of these specialists for individualized information to educate parents prior to leaving the NICU in an organized, time specific manner.

Despite research indicating that there are programs to encourage communication and teaching, parents still report that these areas are not being addressed in the NICU. Future research may need to focus on why existing programs are not being utilized and how to remedy the lack of programming available to parents. Additionally, research concerning other medical professionals becoming more actively involved in educating and interacting with parents such as physical therapists, occupational therapists, speech therapists and psychologists. Investigations are needed to understand their roles as parent educators in the NICU and their effect on the infant’s outcomes.

The participants in this study reported that there is nothing to prepare them for the NICU. It is essential to investigate how to serve parents in the early days of the NICU or prenatally to have a slight exposure to the idea if they went into a NICU to allay their fears.

Investigating and screening for parents who may benefit from counseling sessions requires research. Evidence suggests that parents of premature infants hospitalized in the NICU wish to understand the technical aspects of care and have the opportunity to discuss their experiences and emotions with staff members (Bialoskurski et al., 2002; De Rouck & Leys, 2009). Participants in the focus groups in this study wanted to return to these focus groups because they enjoyed having someone listen to them. This may be an indicator of a need for counseling

Parents' perceptions can offer a path in preparing educational materials, which prepare the parent for the NICU experience and the subsequent discharge of their infant. Sneath (2009) asserted there is "a further need for more research into parent perceptions of their preparedness for their infant's discharge" (p. 245).

As one thinks about the role of parents in a NICU and what influence they have on an infant, there is a need to focus on their reasons for stress and lack of confidence by understanding the lack of knowledge, and the poor communication and its timing to develop working programs for the best delivery of services by medical personnel in the NICU for the parents/caregivers to achieve optimal outcomes of the infant. The statement by Rose Kennedy supports the idea that parents affect the lives of their infants. As Rose Kennedy said,

When you hold your baby in your arms for the first time and you think of all the things you can say and do to influence him, it is a tremendous responsibility. What you do with

him can influence not only him, but everyone he meets and not for a day, a month or a year but for time and eternity.”

As clinicians, we have the responsibility to support the parents to positively affect their infant into eternity.

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APPENDIX A

IRB Letter of Approval, 2013



July 25, 2013

Maureen Rinehimer
P.O. Box 305
Pocono Pines, PA 18350

Dear Ms. Rinehimer,

The Seton Hall University Institutional Review Board has reviewed the information you have submitted addressing the concerns for your proposal entitled "Consultant in Neonatal Intensive Care Units and Outpatient Pediatric Physical Therapist". Your research protocol is hereby accepted as revised and is categorized as exempt.

Please note that, where applicable, subjects must sign and must be given a copy of the Seton Hall University current stamped Letter of Solicitation or Consent Form before the subjects' participation. All data, as well as the investigator's copies of the signed Consent Forms, must be retained by the principal investigator for a period of at least three years following the termination of the project.

Should you wish to make changes to the IRB approved procedures, the following materials must be submitted for IRB review and be approved by the IRB prior to being instituted:

- Description of proposed revisions;
- *If applicable*, any new or revised materials, such as recruitment fliers, letters to subjects, or consent documents; and
- *If applicable*, updated letters of approval from cooperating institutions and IRBs.

At the present time, there is no need for further action on your part with the IRB.

In harmony with federal regulations, none of the investigators or research staff involved in the study took part in the final decision.

Sincerely,

Mary F. Ruzicka, Ph.D.
Professor
Director, Institutional Review Board

cc: Dr. Genevieve Pinto Zipp

Office of Institutional Review Board
Presidents Hall • 400 South Orange Avenue • South Orange, New Jersey 07079 • Tel: 973.313.6314 • Fax: 973.275.2361 • www.shu.edu

A HOME FOR THE MIND, THE HEART AND THE SPIRIT

APPENDIX B

Request for Approval

**REQUEST FOR APPROVAL OF RESEARCH, DEMONSTRATION OR
RELATED ACTIVITIES INVOLVING HUMAN SUBJECTS**

All material must be typed.

PROJECT TITLE: Factors that Contribute to Parent - Child Interactions of Pre Term Infants in Neonatal Intensive Care Units


CERTIFICATION STATEMENT:

In making this application, I(we) certify that I(we) have read and understand the University's policies and procedures governing research, development, and related activities involving human subjects. I (we) shall comply with the letter and spirit of those policies. I(we) further acknowledge my(our) obligation to (1) obtain written approval of significant deviations from the originally-approved protocol BEFORE making those deviations, and (2) report immediately all adverse effects of the study on the subjects to the Director of the Institutional Review Board, Seton Hall University, South Orange, NJ 07079.

Maureen Rinehimer 5-14, 2013  5/14/2013
RESEARCHER(S) OR PROJECT DIRECTOR(S) DATE

**Please print or type out names of all researchers below signature.
Use separate sheet of paper, if necessary.**

My signature indicates that I have reviewed the attached materials and consider them to meet IRB standards.

Genevieve Pinto Zipp PT, EdD 5-14-2013  5/14/2013
RESEARCHER'S ADVISOR OR DEPARTMENTAL SUPERVISOR DATE

Please print or type out name below signature

The request for approval submitted by the above researcher(s) was considered by the IRB for Research Involving Human Subjects Research at the in June 2013 meeting.

The application was approved not approved by the Committee. Special conditions were were not set by the IRB. (Any special conditions are described on the reverse side.)

Mary J. Ruszicka, M.D. 7/25/13
DIRECTOR, SETON HALL UNIVERSITY INSTITUTIONAL REVIEW BOARD FOR HUMAN SUBJECTS RESEARCH DATE

APPENDIX C

IRB Letter of Approval 2014



May 21, 2014

Maureen Rinehimer
P.O. Box 305
Pocono Pines, PA 18350

Dear Ms. Rinehimer,

The Seton Hall University Institutional Review Board has reviewed the information you have submitted addressing the concerns for your proposal entitled "Factors that Contribute to Parent - Child Interactions of Pre Term Infants in Neonatal Intensive Care Units". Your research protocol is hereby approved as revised through expedited review. The IRB reserves the right to recall the proposal at any time for full review.

Enclosed for your records are the signed Request for Approval form, the stamped Recruitment Flyer and original Consent Form. Make copies only of these stamped forms.

The Institutional Review Board approval of your research is valid for a one-year period from the date of this letter. During this time, any changes to the research protocol must be reviewed and approved by the IRB prior to their implementation.

According to federal regulations, continuing review of already approved research is mandated to take place at least 12 months after this initial approval. You will receive communication from the IRB Office for this several months before the anniversary date of your initial approval.

Thank you for your cooperation.

In harmony with federal regulations, none of the investigators or research staff involved in the study took part in the final decision.

Sincerely,

Mary F. Ruzicka, Ph.D.
Professor
Director, Institutional Review Board

cc: Dr. Genevieve Pinto Zipp

Office of Institutional Review Board

Presidents Hall • 400 South Orange Avenue • South Orange, New Jersey 07079 • Tel: 973.313.6314 • Fax: 973.275.2361 • www.shu.edu

A HOME FOR THE MIND. THE HEART AND THE SPIRIT

APPENDIX D

Request for Approval of Research 2014

**REQUEST FOR APPROVAL OF RESEARCH, DEMONSTRATION OR
RELATED ACTIVITIES INVOLVING HUMAN SUBJECTS**

All material must be typed.

PROJECT TITLE:

Factors that contribute to Parent – Child Interactions of Pre – Term Infants in Neonatal Intensive Care Units

CERTIFICATION STATEMENT:

In making this application, I(we) certify that I(we) have read and understand the University's policies and procedures governing research, development, and related activities involving human subjects. I (we) shall comply with the letter and spirit of those policies. I(we) further acknowledge my(our) obligation to (1) obtain written approval of significant deviations from the originally-approved protocol BEFORE making those deviations, and (2) report immediately all adverse effects of the study on the subjects to the Director of the Institutional Review Board, Seton Hall University, South Orange, NJ 07079.

Maureen Rinehimer 2-11-2014

Maureen Rinehimer 2-11-14

RESEARCHER(S) OR PROJECT DIRECTOR(S)

DATE

**Please print or type out names of all researchers below signature.
Use separate sheet of paper, if necessary.**

My signature indicates that I have reviewed the attached materials and consider them to meet IRB standards.

Genevieve Pinto Zipp 2-11-2014

Genevieve Pinto Zipp 2-11-14

RESEARCHER'S ADVISOR OR DEPARTMENTAL SUPERVISOR

DATE

Please print or type out name below signature

The request for approval submitted by the above researcher(s) was considered by the IRB for Research Involving Human Subjects Research at the March 2014 meeting.

The application was approved not approved by the Committee. Special conditions were were not set by the IRB. (Any special conditions are described on the reverse side.)

Mary J. Ruzicki, M.D.
DIRECTOR,
SETON HALL UNIVERSITY INSTITUTIONAL
REVIEW BOARD FOR HUMAN SUBJECTS RESEARCH

5/21/14
DATE

Seton Hall University
3/2005

APPENDIX E

Letter of Solicitation 2 pages



Seton Hall University
400 South Orange Avenue, Street
South Orange, New Jersey 07079

Seton Hall University
Institutional Review Board

MAY 21 2014

Approval Date

RESEARCH PARTICIPATION FORM

Date _____

Researcher's Affiliation:

The primary investigator, Maureen Rinehimer is a physical therapist at St. Luke's Hospital Bethlehem, Pa in the Neonatal Intensive Care Unit (NICU) and also a PhD student at Seton Hall University. Maureen is the Primary Investigator of this PhD research project with the guidance of my advisor Genevieve Zipp PT, PhD, and 2 other members of her committee Terrance Cahill EdD, FACHE and Raju Parasher PT, EdD from Seton Hall University South Orange, New Jersey.

Expiration Date
MAY 21 2015

Purpose:

This research explores what parents who have infants in the NICU perceive they need to go home to enjoy and interact with their baby.

Procedures:

Having been in the NICU for greater than a week parents sometimes experience many feelings of what you and your baby (ies) need. As an infant moves toward the discharge, parents may have feelings of what was taught and what still needs to be addressed or you to be confident caring and interacting with his/her infant at home. A Parent Child Interaction Survey with questions concerning the needs of parents in the NICU was developed by the primary investigator. Using some of the questions from this survey, the investigator will be exploring these needs through focus groups with parents.

Description of the focus group:

This focus group could be defined as a group of interacting parents having a common interest of premature infants, brought together by Maureen acting as a moderator, who uses the group and its interaction as a way to gain information about a specific ideas to understand what parents feel they need to confidently interact with their infant at home. If possible, both parents are encouraged to attend. However, if only one is able to attend that is acceptable.

At the beginning of the focus group the primary investigator will ask the parents to fill out a demographics sheet asking for information such as: parent's age, schooling, how long the baby has been in the NICU, the gestational age of the baby at birth, marital status, and if male/female.

The focus group will be audio taped so that Maureen may transcribe the information accurately. The tapes and the transcriptions will be safely kept in my locked office. At the end of the study the tapes and the transcriptions will be destroyed.

Instrument:

Questions will be taken from The Parent Child Interaction Survey (PCI) to gather information from parents of what they feel helps them to better interact with his/her infant.

Voluntary Nature of Research:

As a parent of an infant who has an infant in the NICU, one or both parents are being invited to participate in this research. Maureen would like to learn about parent's experiences as a parent preparing to take a baby home.

Participation in this focus group is completely voluntary and anyone may refuse to participate at any time with no penalty or change of an infant's care.

Anonymity:

There are no risks to the infants or parents in this study. Participation does not impact the treatment of a baby. None of the information linked to any specific parents or names disclosed outside of the room. The information taken from the study will not have any name(s) attached to the ideas or suggestions to ensure anonymity.

Confidentiality:

During this survey, parents will be asked some questions about your past experiences and your ideas about what you learned in the NICU, if and how it helped and what the staff in the NICU can do to make it better. The transcriptions and the audiotapes will not be shared. They will be locked in primary investigator's office. At the end of the study they will be destroyed.

Records:

Dr. Zipp, the research committee and Maureen will have access to the transcriptions and kept confidential. There may also be an attempt to try to publish the results of the study. Any of your statements that we use will be credited to parents if they choose to have his/her name on some of the quotes said in the focus group, unless the parents decide to use a false name. If you would like a copy of the study, please provide me with your address and a copy of the results will be sent in the future,

Risks:

There are no risks to either the baby or parents with this research study. If parents choose not to participate the baby's care continues as usual. If the parents feel that they need to speak to social services this can be arranged for a meeting with them.

Contact Information: please call Maureen Rinehimer (570) 954 2189 or email her at maureen.rinehimer@shu.edu or call Genevieve Zipp at (975) 275 - 2457.

If there are questions about your rights as a participant in this study, please contact Institutional Review Board Administrator, Mary F. Ruzicka, Ph.D. (973) 313-6314 irb@shu.edu

If you have any immediate questions, you may ask the nurse clinical coordinator of the NICU, Dawn Hosier RN(484) 526 - 4434.

Parents must be 18 or over to be eligible to participate in this study.

By attending the focus group parents are indicating that they consent to participate in the study.

Thank you for your participation in this study. All input from every parent is very important.

Good luck and Enjoy your baby (ies)!

Signature and date _____

Seton Hall University
Institutional Review Board

MAY 21 2015

Approval Date

Expiration Date

MAY 21 2015

APPENDIX F

IRB Approval Letter 2015



April 21, 2015

Maureen Rinehimer
P. O. Box 305
Pocono Pines, PA 18350

Dear Ms. Rinehimer,

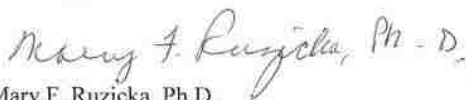
The Seton Hall University Institutional Review Board has reviewed your Continuing Review application for your research proposal entitled "Factors that Contribute to Parent - Child Interactions of Pre Term Infants in Neonatal Intensive Care Units."

You are hereby granted another 12-month approval, effective **May 21, 2015**. Your new stamped Consent Form and Recruitment Flyer are enclosed.

If any changes are desired in this protocol, they must be submitted to the IRB for approval before implementation.

Thank you for your cooperation.

Sincerely,


Mary F. Ruzicka, Ph.D.
Professor
Director, Institutional Review Board

cc: Dr. Genevieve Pinto Zipp

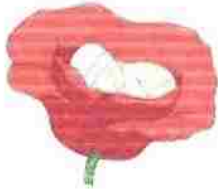
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A HOME FOR THE MIND, THE HEART AND THE SPIRIT

APPENDIX G

Parent Brochure

INVITATION
PARENTS..... YOUR ASSISTANCE IS NEED



WHO: ONE OR BOTH PARENTS OF INFANTS IN THE NICU WHO WERE BORN AT 24-36 weeks

WHAT: To give YOUR IDEAS and SUGGESTIONS of what YOU feel is needed to take your baby home with confidence and to enjoy your baby (s). Everything is confidential!
Refreshments will be provided.

WHY: The information will be used in a research study to fulfill the requirements of our NICU physical therapist Maureen Rinehimer's PhD studies at Seton Hall University, South Orange, NJ.
The information will help future parents and infants in NICUs. It will Help To Clarify What Parents Perceive That They Need To Promote Positive Parent / Child Interactions Of Preterm Infants In The NICU.

WHEN: Tuesday and Friday Evenings at 7 PM

WHERE: As you leave the NICU, turn right ...Go to the end of the hall in the last room on the right.

If you are interested in helping Maureen, please tear off the bottom. Write with your name and date when you will attend. Place it in the box at the sink at the exit or give it to your nurse.

.....
Name(s) _____
Tues _____ Friday _____ (Put date)
Either call or text my cell (570) 954 2189 or e mail Maureen at rineshim@slhn.org
Thank YOU! Maureen Rinehimer

Seton Hall University
Institutional Review Board

MAY 21 2014

Approval Date

Expiration Date

MAY 21 2015

Seton Hall University
5/2013

APPENDIX H

IRB Letter of Approval 2016



OFFICE OF INSTITUTIONAL
REVIEW BOARD

SETON HALL UNIVERSITY

April 11, 2016

Maureen Rinehimer
P. O. Box 305
Pocono Pines, PA 18350

Dear Ms. Rinehimer,

The Seton Hall University Institutional Review Board has reviewed your Continuing Review application for your research proposal entitled "Factors that Contribute to Parent - Child Interactions of Pre Term Infants in Neonatal Intensive Care Units."

You are hereby granted another 12-month approval, effective May 21, 2016 for data analysis only.

If any changes are desired in this protocol, they must be submitted to the IRB for approval before implementation.

Thank you for your cooperation.

Sincerely,

Mary F. Ruzicka, Ph.D.
Professor
Director, Institutional Review Board

cc: Dr. Genevieve Pinto Zipp

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A HOME FOR THE MIND, THE HEART AND THE SPIRIT

APPENDIX I

Pilot Procedures

Principal Investigator Created Tool

The PCI Scale based on the four constructs: knowledge, stress, confidence, and parent child interaction was developed to be used with parents who have been in the NICU for at least 10 days. The process began with a plan using the Inclusion Criteria of 10 (but 9 actual participants completed) Parents of infants who were 33 weeks and under (gestational age) at the time of birth and who were treated in the NICU for at least 1 week. There were 10 (8 actual participants completed) Health Care Professionals who hold a license in their professional area (PT, RN, OT, SLP) and who have knowledge of research design. The professionals and parents must be 18 years or older.

Participant Recruitment

Recruitment brochures for the Pilot Study (See Appendix F) were placed on a Neonatal site to enlist professionals as well as in the NICU at St Luke's. Brochures were placed at the bedside of parents of infants born 32 weeks or younger who were currently in the NICU for at least 10 days. Ten professionals and ten parents agreed to participate.

After IRB approval for the Focus Groups, recruitment letters were placed at the bedsides of infants who qualified. Brochures were placed in the family waiting room and on the Bulletin board at the NCIU.

Instrument Development: Delphi Technique

Assessing Validity

To determine content validity is a subjective process (Portney & Watkins, 2009). The approach chosen for this pilot study was to calculate the average percentage of items that the experts agreed upon. A value of .90 is a standard of excellent content validity. (Polit and Beck, 2012).

This was a two-phase project (See Appendix H 1). Initially, the PI developed 45 questions which were mailed to the 10 professionals and 10 parents with a letter of explanation of the Delphi Technique. With each question, the experts were asked 1. Is the question appropriate for the survey to be answered Yes or No. If no, please explain why. 2. Is this question in the proper sequence? Yes or No If no, please explain why. Phase 1 consisted of these participants reviewing and editing the questions. Eight parents and nine professionals responded. The PI worked with their suggestions and resubmitted the revised questions. As a result the questions were placed under 5 categories of interest. This completed round one. The revised questionnaire was then mailed for Round 2 with corrections to the professionals and parents made with questions to be reevaluated designated with a grey answer box with a stamped return envelope enclosed for return. Questions that did not reach 80 % consensus by 4 parents and 7 professionals.

A similar process was repeated for one more round until 80% agreement occurred between the professionals and the parents to obtain content validity. Along with the two questions requiring revision from round 2 was the request to either mail back or email any corrections within two weeks. If a response was not received within the set time they were informed that their lack of responses would be then be assumed by the PI to mean that they were in agreement and thus no further changes would be required. The final consensus for content validity was 95.14%. Thus with this agreement it was a valid tool.

Reliability Assessment of the Tool

Phase two was to assess Internal Consistency. A letter of introduction with the PCI Survey was mailed to parents of infants who had been in the NICU. In this letter the PI explained the purpose of this phase was to measure homogeneity of items on a trait. A survey link utilizing the Seton Hall Asset link with the PCI questionnaire on it was available for various NICU facilities to answer. Professionals throughout the United States completing the survey using the Asset Survey System through Seton Hall University. From the data Internal Consistency & Item Reliability Assessment of questions under the 4 constructs was achieved. The data measured items based on the constructs of confidence, knowledge, parent child interaction, and stress to form a single survey that is reliable (Litwin, 1995).

Questionnaire Results

As a result a valid and reliable tool became the product of this pilot study. 80% consensus was achieved based on appropriateness, clarity and sequence. The parents and professionals had 100% agreement with appropriateness and sequence. Also, professionals and parents had 90% agreement with clarity. The total percentage of agreement was 94.14%.As indicated by Polit and Beck, 2011, the PCI questionnaire therefore possesses excellent content validity with an average score over .90.

Reliability of the PCI: Recommending Practices Reliability.

Item Reliability was established through the Cronbach's Alpha of each area See Figure #
Cronbach alpha measures internal consistency. It is useful for dichotomous questions or with greater than two answers (Portney and Watkins, 2008). There were 60 people who attempted to

take the survey, but only 22 completed the survey. Some of the parents indicated that they had difficulty with the Asset site.see (See Appendix H 2)

The final valid and reliable questionnaire contained a total of 43 questions (See Appendix H 4).

The survey was distributed by the traits .the first trait, stress has 8 questions using a Likert scale for 6 of the questions and three open ended. The second trait was knowledge which had 16 questions of which 14 utilized the Likert scale, 2 dichotomous questions , 1 open ended question, and one ordinal scale 1-7 least to most. The third trait, Confidence had 6 questions. with 4 Likert scale questions,1 dichotomous question and 1 open ended question. The fourth trait was parent child interaction which contained 5 Likert scale questions. The fifth are contained 6 demographic questions. The final question after the demographics was a broad open ended question. For this study all the experts participated on line through the Seton Hall University Asset survey site. The survey may be taken on line or hand written as preferred by the parents or caregiver.

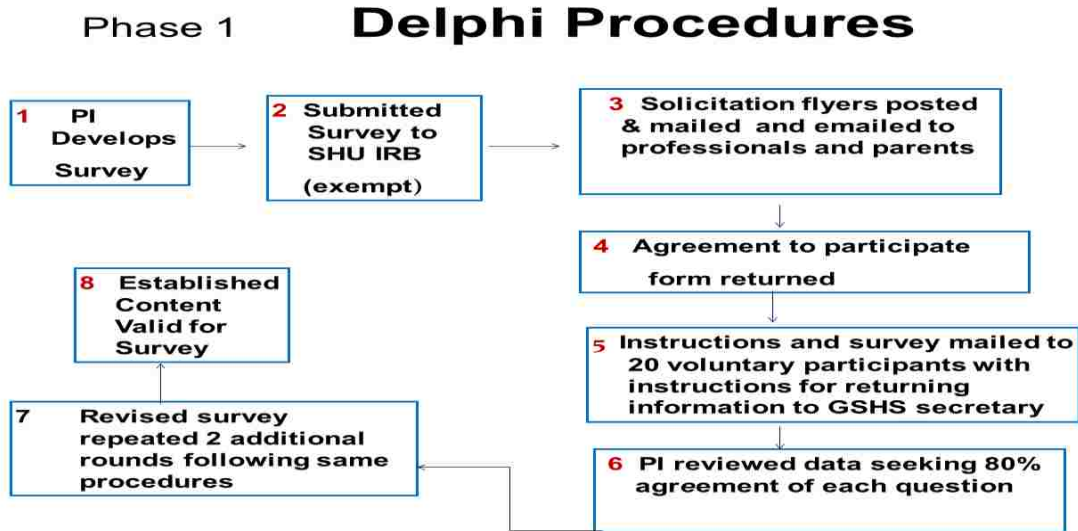
Transitional care and interventions for the mother /infant dyad which begins at the time the infant enters the NICU, and continues until when the infant is discharged to home is needed. Comprehensive parent education and effective interaction including knowledge of infant's behavioral cues, knowledge of when to interact with an infant and characteristics of the infants' states, recognizing cognitive and communication development and understanding of infants' sensory cues as well as encouraging typical developmental gross motor skills is needed in the NICU for effective parent infant outcomes at home.

Therefore, there is a need to investigate what parents perceive as needed to care for their infant while the infant is in the NICU at various points of time prior to discharge, during discharge and when at home. The purpose of this proposed project is to investigate the needs of parents of

infants in the NICU: 1. Ease of care for their infant, 2. Parent confidence and 3. Learn to enjoy interacting with their infant, and 4. Assist their infant's overall development in anticipation of their transition from NICU to home to facilitate parent / infant relationships.

APPENDIX J

Flow Chart of Pilot Study



APPENDIX K

Reliability of PCI

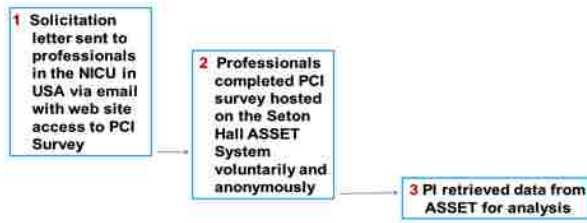
Table **PCI Reliability Data**

Traits	Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	# of Items
Knowledge	.798	.815	38
Stress	.646	.719	7
Confidence	.708	.786	13
Parent Child Interaction	.710	.746	5

APPENDIX L

Internal Consistency and Item Reliability of PCI

Phase 2: **Internal Consistency & Item Reliability Assessment**



APPENDIX M

Parent Child Interaction Questionnaire

Parent Child Interaction Survey (PCI)

This survey explores how you perceive your interactions with your child in the neonatal intensive care unit (NICU). Participation in this study is voluntary and does not place any risks on your child's care.

A. Stress					
	<i>Strongly Agree</i>	<i>Agree</i>	<i>Neutral</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
<i>1. I become stressed when I see and hear the monitors in the NICU</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>2. I feel stressed seeing the bright lights on in the NICU most of the day and night.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>3. I feel stressed or anxious when I play with my baby in the NICU.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>4. I feel stressed when my baby likes to be with the staff as much or more than with me.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>5. I feel stressed not having alone time with my baby in the NICU.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>6. I feel stressed when I am not with my baby.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7(A). Describe some stressful situations affecting your interactions with your baby in the NICU.					
<div style="border: 1px solid black; height: 60px; width: 100%;"></div>					
7(B). What could be changed to help reduce your stress?					
<div style="border: 1px solid black; height: 60px; width: 100%;"></div>					
8 Could you have been better prepared to cope with these situations by one of the team members in the NICU? If 'Yes', please explain how.					
<div style="border: 1px solid black; height: 60px; width: 100%;"></div>					

B. Knowledge					
	<i>Strongly Agree</i>	<i>Agree</i>	<i>Neutral</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
<i>9. I understand the information that health care professionals give me about my baby's health.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>10. The NICU staff taught me how to hold my baby.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>11. I know the signs when my baby is stressed.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I learned how to recognize the signs of stress in my baby from: (Please check all that apply).					
	<i>Strongly Agree</i>	<i>Agree</i>	<i>Neutral</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
<i>Nurses</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Nurse Practitioners/Physician Assistants</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Physical Therapists</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Occupational Therapists</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Speech Therapists</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Physicians</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<i>Strongly Agree</i>	<i>Agree</i>	<i>Neutral</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
<i>13. The NICU staff taught me how to calm my baby.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>14. The NICU staff taught me how to play with my baby</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>15. The NICU staff taught me how to position (place) my baby in the isolette, crib or bassinette.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>16. The NICU staff taught me how to take my baby out of the isolette, crib, or bassinette.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>17. The NICU staff prepared me to interact with my baby.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>18. The NICU staff taught me how to feed my baby?</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

B. Knowledge (continued)

19. I received written information which helped me understand how to interact with my baby

	Yes	No	Not part of the NICU team
Nurses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nurse Practitioners/Physician Assistants	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical Therapists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational Therapists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speech Therapists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physicians	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

20. I received verbal information which helped me understand how to interact with my baby from:

	Yes	No	Not part of the NICU team
Nurses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nurse Practitioners/Physician Assistants	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physical Therapists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Occupational Therapists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Speech Therapists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Physicians	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
21. Given the information I received from NICU staff I feel comfortable interacting with my infant at home.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. I believe I need additional information from NICU staff in order to feel comfortable interacting with my infant at home.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

B. Knowledge (continued)

23. How could we best provide information about your baby's development to you? Please Rate the following 1 to 7 (1 being least useful and 7 most useful).

	1	2	3	4	5	6
<i>Written handouts</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Individual sessions at the bedside</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Group classes</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Internet sources</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Books</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>DVD's</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>Other</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you answered 'Other' to the previous question (number 23) please explain.

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Neutral</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
<i>24. While my baby is in the NICU, I would attend formal parent training classes to learn ways in which to interact with my baby.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. Please suggest how we can better teach you to interact with your baby in the NICU (s).

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Neutral</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
<i>26. I understand that I play an important role in the development of my child.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C. Confidence					
	<i>Strongly Agree</i>	<i>Agree</i>	<i>Neutral</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
<i>27. I am afraid to touch my baby because I may hurt or upset the baby.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>28. In the NICU as my baby becomes stronger and healthier I feel more confident involving my child in play.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. While in the NICU I gained confidence in interacting with my baby from..... Please check the appropriate box for each category					
	<i>Yes</i>	<i>No</i>	<i>Professional not present on the NICU Team</i>		
<i>Nurses</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
<i>Nurse Practitioners/Physician Assistants</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
<i>Physical Therapists</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
<i>Occupational Therapists</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
<i>Speech Therapists</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
<i>Physicians</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>		
30. I am confident in my understanding of what my baby should be able to do in the following areas of development: Please check the appropriate box for each developmental category 1-5.					
	<i>Strongly Agree</i>	<i>Agree</i>	<i>Neutral</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
<i>1. Gross Motor Development (rolling, sitting, etc.)</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>2. Fine Motor Development (Using hands to play)</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>3. Speech Development (making sounds & hearing)</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>4. Cognition Development (toy play & following directions)</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>5. Sensory Development (being able to accept and enjoy textures, sounds and sights)</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

C. Confidence (continued)

31. What else can be done in the NICU to help you feel more confident to interact with your baby at home

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Neutral</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
<i>32. Overall, I am confident handling and caring for my infant at home.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

D. Parent/Child Interaction

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Neutral</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
<i>33. When I see how small my baby is, or any unusual features with my baby and all the equipment around my baby, it affects how I interact with my baby.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>34. When I see all the equipment around my baby, it affects how I interact with my baby.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>35. I am comfortable playing with my baby in the NICU</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>36. When I come to visit my baby in the NICU, I am given the opportunity to relax and enjoy my baby.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>37. I believe that my interactions with my baby and me are important</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

E. Demographics:							
		<i>13-20 years</i>	<i>21-30 years</i>	<i>31-40 years</i>	<i>41-50 years</i>	<i>Older than 50 years</i>	
<i>What is your age?</i>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	<i>Elementary School</i>	<i>High School</i>	<i>Associates Degree</i>	<i>Bachelors Degree</i>	<i>Masters Degree</i>	<i>Doctoral Degree</i>	
<i>40. What is your highest education / degree?</i>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	<i>Single, Never Married</i>	<i>Married</i>	<i>Separated</i>	<i>Divorced</i>	<i>Widowed</i>		
<i>41. Please select the description of your marital status?</i>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
E. Demographics (continued)							
		<i>23-26 wks</i>	<i>27-29 wks</i>	<i>30-32 wks</i>	<i>32-34 wks</i>	<i>35-37 wks</i>	<i>38 wks</i>
<i>42. Please select the age of your baby at birth.</i>		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43. How many days has your baby been in the NICU?							
<input type="text"/>							
44. Please share in the space below any other comments or suggestions.							
<input type="text"/>							
<p>Thank you for taking the time to complete this survey. The information you provided will help to improve the care and support provided to the infants and parents in the NICU.</p> <p>Maureen Rinehimer PT, MS, MHS</p>							

APPENDIX N

Demographic questions of the Focus Groups

Demographics:

Please answer all the questions.

Please check your age

1. 18-20 years 21-30 years 31-40 years 41-50 years older than 50 years

2. Are you Male Female?

3. What is your highest education?

Elementary School High School College Masters PhD, MD, DDS Other

4. What is your marital status?

Single Married Separated Divorced Widow / Widower

5. How old was your infant at birth? _____

6. How many days has your infant been in the NICU? _____

7. Please share with me any other comments or suggestions to improve the things that you feel are needed to improve your confidence to care for your infant ?

APPENDIX O

Questions Utilized in the Focus Groups

Questions for the Focus Groups

1. Describe some Stressful situations affecting your interactions with your baby in the NICU.
2. What could be changed to help reduce your stress?
3. Could you have been better prepared to cope with these situations by one of the team members in the NIC? If 'Yes', please explain how.
4. How could we best provide information about your baby's development to you? Please rate the following 1 to 7 (1 being the least useful and 7 most useful)

Written Hand Outs

Individual sessions at the bedside

Group classes

Internet sources

Books

DVDs

Other

If you answered 'Other' to the previous question please explain.

5. What else can be done I the NICU to help you feel more confident to interact with your baby at home?