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Family-Centered and Developmentally Supportive Care in the Neonatal Intensive Care Unit

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A capstone project submitted in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree from the University of Indianapolis, School of Occupational Therapy.

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A Capstone Project Entitled

Family-Centered and Developmentally Supportive Care in the Neonatal Intensive Care Unit

Submitted to the School of Occupational Therapy at University of Indianapolis in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree.

By

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Abstract

While the intensive environment of the NICU can act as a barrier to parents fulfilling the parental occupation, evidence demonstrates that family-centered, developmentally supportive care leads to more successful outcomes for premature newborns and their families. A needs assessment at a Level III NICU in Indiana revealed the need to provide more thorough parent education to assist parents with fulfilling their role in the NICU. As a Doctoral Capstone Experience (DCE), the occupational therapy student developed and implemented a program to promote parent education and participation, supporting healthy infant-parent bonding in the NICU. The program included the creation of a NICU Binder and the presentation of Parent Education Courses to provide thorough education regarding principles of developmental care. The results of the post-session parent survey, a measure of parent satisfaction, indicated a positive outcome with a score of 4.5083/5.0. The post-program NICU staff survey, a measure of overall program satisfaction, indicated a positive outcome with a score of 4.725/5.0. The DCE also led to a more collaborative relationship between therapy and nursing in the NICU. The site will sustain the family-centered care program as NICU therapists continue the parent education sessions and add topics as deemed appropriate.

Family-Centered and Developmentally Supportive Care in the Neonatal Intensive Care Unit

Introduction

Premature infants are likely the most vulnerable patients a healthcare provider can encounter (Westrup, 2015). Nearly 500,000 infants are born at less than 37 weeks' gestational age or with low birth weight (less than 2500 grams) in the United States (Altimier & Phillips, 2016). Of these 500,000 infants, 10-15% are placed in the Neonatal Intensive Care Unit (NICU) due to their complex medical status. However, these infants, even those born as early as 23 weeks' gestational age, have a greater chance of survival as a result of medical advancements that have occurred over the past 30 years (Altimier & Phillips, 2013). While survival rates are higher, premature infants still have a greater risk for medical and developmental impairments that can cause poor overall outcomes, and result in disability (Altimier & Phillips, 2013; Altimier & Phillips, 2016).

There are many factors to consider when caring for premature infants in the NICU. In more recent years, healthcare providers and researchers have determined that family-centered neurodevelopmental supportive care, or neuroprotective family-centered developmental care, results in more successful outcomes for premature newborns and their families (Altimier & Phillips, 2013; Altimier & Phillips, 2016; Westrup, 2015). Neuroprotective developmental care involves providing interventions that support and protect the infants' vulnerable, still-developing neurological and sensory systems (Altimier & Phillips, 2013; Altimier & Phillips, 2016). Family-centered care ensures that healthcare providers in the NICU approach care holistically by considering the needs of the parents and siblings in addition to the needs of the infant (Westrup, 2015).

Since family-centered, developmentally supportive care is evidenced as best practice, these principles were used to expand best practice at a Level III NICU at a hospital in Indiana. Through collaboration between therapy services and NICU nursing, a family-centered, developmentally supportive program consisting of parent education and support was implemented.

Literature Review

Effects of Premature Birth on Neurodevelopment

The majority of fetal neurodevelopment occurs during the third trimester of pregnancy (Altimier & Phillips, 2013). Therefore, when an infant is born prematurely, their neurologic system has not fully developed, and the infant is at higher risk for having neurodevelopmental problems. These infants often demonstrate impaired motor, sensory, cognitive, and behavioral development. Later in life, these initial impairments can lead to motor delays, cognitive deficits, learning disabilities, behavioral disorders, and poor emotional regulation (Altimier & Phillips, 2013; Altimier & Phillips, 2016).

Sensory development and its effects. Neurosensory development is an integral part of an infant's overall neurological development. The sensory system is meant to develop the following order: tactile, vestibular, olfactory, gustatory, auditory, and visual senses. Ideally, this process should not be tampered with as this can result in "behavioral, cognitive, and functional deficits" (Altimier & Phillips, 2013, p. 11). These deficits can occur because neurobehavioral development is closely intertwined with neurosensory development. When an infant experiences a sensory event, the brain is signaled to have a behavioral response. As such, sensory development is imperative to the development of behavioral and emotional self-regulation, cognition, and overall function. The underdeveloped sensory system of the premature infant does

not allow the infant to appropriately understand, tolerate, or behaviorally regulate the sensations that they experience (Altimier & Phillips, 2013).

A mother's womb is a protective environment that provides positive sensory experiences for the fetus. When an infant enters the world prematurely, he or she is removed from the protective environment of the womb without being fully prepared for the sensory experiences of the extra-uterine environment. Therefore, extra-uterine sensory experiences can be negative for the infant, and result in developmental problems due to how these experiences modify typical neurodevelopment (Altimier & Phillips, 2013).

The NICU Setting and Neurodevelopmental Care

By its nature as an intensive care unit, and in comparison to the environment of the womb, the NICU may provide negative extra-uterine sensory experiences. In order to create a more positive environment for infants in the NICU, Altimier & Phillips (2013) have developed The Neonatal Integrative Developmental Care Model which includes seven core measures for neuroprotective family-centered developmental care: (a) healing environment, (b) partnering with families, (c) positioning and handling, (d) safeguarding sleep, (e) minimizing stress and pain, (f) protecting skin, and (g) optimizing nutrition (Altimier & Phillips, 2013, p. 10).

These seven measures combine to create a positive environment for the infant. In order to facilitate a healing environment, ideally each infant should have a single room to reduce stress factors for the infant and family, as well as to control infection. Furthermore, all sensations should be strictly monitored in the NICU. Temperature, touch, proprioception/vestibular, smell, taste, sound, and visual stimuli are all carefully controlled to ensure the infant receives the correct type and amount of sensory stimulation. Incubators or radiant warmers are used to help the infant with his/her thermoregulation. In addition, the NICU should be a quiet environment,

with limited lighting and scents. When positioning, holding, or handling an infant, staff should use gentle touch and slow movements. Infants should ideally be positioned in flexion with hands to mouth to promote the natural posture he or she would be experiencing in the womb.

Furthermore, body containment should be used to mimic the enclosed feeling of the womb as it helps to decrease stress and increase self-soothing. The NICU environment should promote and protect sleep cycles as the most neurodevelopment occurs during sleep, especially during rapid eye movement (REM) sleep (Allen, 2012; Calciolari & Montirosso, 2011; Graven, 2006).

Therefore, infants should not be awakened for handling, care, or therapy during their REM sleep as this can disturb their development. Premature neonates also have very delicate and thin skin. Soaps and other products that are sensitive and gentle on skin should be used at all times. The use of adhesives should be avoided whenever possible, but if necessary, should be applied and removed gently. In terms of feeding, breast milk should be used whenever possible due to its many benefits for the infant's health and development, and feeding schedules should occur based on each infant's feeding cues (Boucher, Brazal, Graham-Certosini, Carnaghan-Sherrard, & Feely, 2011; Cosimano & Sandhurts, 2011; Gartner, Morton, Lawrence, Naylor, O'Hare, Schanler, & Eidelman, 2005). Using these measures will help to reduce the amount of stress and pain each infant experiences (Altimier & Phillips, 2013; Altimier & Phillips, 2016).

Another example of developmentally supportive care is the Newborn Individualized Developmental Care and Assessment Program (NIDCAP). This program was originally developed by Dr. Heidelise Als, a Clinical and Developmental Psychologist from Harvard Medical School and Boston Children's Hospital. The aim of the program is to structure the NICU environment to allow for the best outcomes for each infant. The program includes observation and analysis of five subsystems of behavior: "autonomic, motor, state regulation or

state organization, attentional/interactional, and self-regulatory systems” (Westrup, 2007, p. 445). The NIDCAP certified staff creates the infant’s developmental goals, care plan, and environment based upon these observations and analyses of the infant’s behavioral cues. NIDCAP has been shown to reduce length of stay, improve behavior, and improve electroencephalogram (EEG) and magnetic resonance imaging (MRI) results (Buehler, 2014). Westrup reported on a study by Tyebkhan, Peters, McPherson, and Henderson (2004), which found that very low birth weight (VLBW) infants who have had NIDCAP intervention have shorter hospital stays (Westrup, 2007, p. 446). Westrup also reported the results of Als, et al. (2004), which demonstrated “beneficial structural changes in the NIDCAP infants compared with a control group in tissue distributions as well as in microstructural development of the white matter” (Westrup, 2007, p. 446). The NIDCAP Federation describes the program as a cultural shift that results in better outcomes (Buehler, 2014).

The principles of developmentally supportive care that both Altimier and Phillips (2013, 2016) and Westrup (2007) have described represent best practice. Therefore, these principles were used when implementing the family-centered, developmentally supportive care program at the Level III NICU at an Indiana hospital. While many of these principles were already being used at this NICU, it was critical to ensure that these principles carry over into any new program.

Family-Centered Care

The Neonatal Integrative Developmental Care Model (Altimier & Phillips, 2013; Altimier & Phillips, 2016) and NIDCAP (Westrup, 2007) are both developmentally supportive and family-centered programs. Both models recognize the importance of family-centered care in the NICU setting. For example, Core Measure 2 of Altimier and Phillips’ Seven Neuroprotective Measures is partnering with families (Altimier & Phillips, 2013; Altimier & Phillips, 2016).

Westrup (2007) also explained that the role of the family is integral to developmental care. When an infant is born prematurely and requires admission to the NICU, the infant's family experiences a crisis. Parents are often unfamiliar with the NICU and they may be intimidated by the intensive environment. Furthermore, the separation of the infant from the parents can negatively affect the formation of the parent-infant attachment, thereby affecting the parents' ability to effectively understand and interact with their child (Altimier & Phillips, 2013; Westrup, 2015). If parents are not involved in their infant's healing, development, and care in the NICU, both the infant and the parents are likely to experience negative outcomes (Altimier & Phillips, 2013).

The goal of a family-centered approach to care in the NICU is to address the needs of parents and promote the involvement of the family in the healing, development, and care of the infant (Altimier & Phillips, 2013; Westrup, 2015). Several studies have shown that family-centered care programs have developmental benefits to the infant, encourage a positive parent-infant relationship, and support the needs of the parents and family, resulting in better outcomes for the infant, the parents, and the family as a whole (Bracht, O'Leary, Lee, & O'Brien, 2013; Dudek-Shriber, 2004; Goldstein, 2013; MeInyk et al., 2006; O'Brien et al., 2013; Pineda, Bender, Hall, Shabosky, Annecca, & Smith, 2018; Welch et al, 2012; Westrup, 2007; Westrup, 2015).

Many studies have focused on education and participation of caregivers. For example, MeInyk et al. (2006) developed the Creating Opportunities for Parent Empowerment (COPE) program, which implemented family-centered care through an educational-behavioral intervention and consisted of audiotaped educational sessions and participation in behavioral activities. COPE was shown to significantly reduce stress, depression, and anxiety in mothers.

When the program was tested through a randomized, controlled trial, infants of parents enrolled in COPE had a shorter length of NICU stay by 3.8 days, and a shorter length of hospital stay by 3.9 days in comparison to the control group. Furthermore, sample-blind observers of parents enrolled in COPE reported mothers and fathers had more positive interactions with their infants than parents did in the control group.

Welch et al. (2012) also published a randomized-controlled study regarding a family-centered care program called Family Nurture Intervention (FNI). The study used early interventions to address the infant-mother relationship, the emotional well-being of the mother, and the development of the premature infant (Welch et al, 2012). One hundred and thirty families participated in FNI, while 130 families received standard care as the control group. The intervention was based upon “Calming Activities.” For example, mothers participated in odor exchange, firm sustained touch, vocal soothing, and eye contact while the infant remained in the incubator. Once the infant was out of the incubator, the “Calming Cycle” consisted of holding and feeding. Another aspect of FNI was the implementation of family sessions that helped the mother engage, bond with, and care for her infant. The results of the study demonstrated that FNI increases activities and behaviors that improve infant development, the emotional well-being of the mother, and the infant-mother attachment relationship. The researchers concluded that their study provides evidence for using “early and extensive mother-infant interactions, within the constraints of the NICU” (Welch et al, 2012, p. 14). As such, this study supports the use of holistic family-centered care in the NICU for the benefit of both the infant and the family.

Providing education for knowledge and skill, and allowing for participation in infant care are important and empowering methods of family-centered care. Another method is that of addressing the psychosocial health of parents and families in the NICU. For example, Morgan

and Rimmer (2011) implemented the Family and Baby Project, a “needs-led, non-judgmental service that could respond to individual cases” (p. 156). Support workers in the Arrowe Park Hospital NICU provided two sessions a week that were specific to the needs of each family. Support workers completed intensive training that consisted of “full neonatal induction and bereavement training” (Morgan & Rimmer, 2011, p. 156). The researchers conducted a post-discharge questionnaire to the 60 parents who had participated in the program. One hundred percent of parents were highly satisfied with the support program (Morgan & Rimmer, 2011). Purdy, Craig, and Zeanah (2015) completed a review of literature to provide recommendations for how multiple disciplines can work together to provide the best care for parents and their psychosocial needs. The authors found the need for emotional support, parenting education, medical follow-up, home visit services, and interprofessional practice to support parents in the NICU. This supports the need for interdisciplinary work to address “the continuum of parent-infant needs” (Purdy, Craig, & Zeanah, 2015, p. S27).

In order to achieve better outcomes for both infants and parents, Bracht, O’Leary, Lee, and O’Brien (2013) developed Family-Integrated Care, a program that addressed both the education and psychosocial/emotional support that parents need in the NICU. The researchers reported that a weekly parent education series for NICU parents was already occurring at the hospital. To expand family-centered care, the researchers enrolled mothers in groups of four or five and implemented daily educational sessions five days per week. The mothers in the program also acted as primary caregivers to their infants for at least eight hours per day and participated in medical rounds. A unique feature of this study was the inclusion of “veteran parent mentors.” These mentors were parents who had previously had an infant in the NICU. They provided parents with peer support and helped teach the educational sessions on “coping, discharge

planning, and breastfeeding” (Bracht, O’Leary, Lee, & O’Brien, 2013, p. 122). The researchers evaluated the program through qualitative feedback from the participants at discharge. The results demonstrated, “mothers were provided with the tools to parent their infants in the NICU, recognize their own strengths, increase their problem-solving strategies, and emotionally prepare them to take their infant home” (Bracht, O’Leary, Lee, O’Brien, 2013, p. 115). Thus, the program was deemed successful and has since been adapted to provide the best possible parental education and support.

Therapists’ Roles in Family-Centered Care

The previously mentioned studies were primarily conducted by physicians and nurses. As the program I implemented consists of collaboration between therapists and nurses, the question was, “What is the role of the therapist?” In 2014, Goldstein, a physical therapist, published a systematic review of the literature regarding therapy’s role in family support and education in the NICU. Goldstein focused on the role of therapists as parent educators and categorized her findings into four main themes: (a) family context, (b) education assessment, (c) methods for teaching, and (d) topics for teaching. Family context referred to different stressors that affect families in the NICU. Goldstein found that the NICU Discharge Path can be used as an educational assessment to understand the family. By using this tool, therapists can more effectively partner with the family and empower parents. Goldstein concluded that therapists should focus on teaching parents about physical contact/handling, reading cues, anticipatory guidance/adjusting age for prematurity, equipment/positioning recommendations, and postural control. Furthermore, therapists should recognize parents as adult learners and adjust their teaching strategies based on parent preferences and benefits. She concluded that therapists need to use evidence-based strategies to focus on evidence-based topics during teaching sessions with

parents. According to Goldstein, a therapist's goal should be to provide family-centered care by providing parents with the knowledge and skills that will allow them to most positively affect their infant's development.

Recently, Pineda, an occupational therapist, partnered with a group of physicians and therapists to address the issue of parental presence in the NICU (Pineda, Bender, Hall, Shabosky, Annecca, and Smith, 2018). How can one implement family-centered care if parents are not present? Pineda and colleagues conducted their study at St. Louis Children's Hospital in a Level III-IV NICU. The researchers collected parent participation information from documentation in electronic medical records. Their key findings were that parents were present in the NICU four days per week on average, and held their infants an average of two to three days per week while their infants were in the NICU. Participation in the NICU was more common for Caucasian mothers who were married, employed, or older, and had a supportive family, fewer children, or were actively producing breastmilk. Furthermore, parent participation occurred more for infants who were more medically stable and required fewer medical interventions. The infants who were held more by their parents benefitted with better short-term outcomes. If parents participated in skin-to-skin care, their infants had better short-term and long-term developmental outcomes. As such, both infant medical factors and family sociodemographic factors affected whether or not parents were present, how much they were present, and how much they actively participated in their infant's care (Pineda, Bender, Hall, Shabosky, Annecca, & Smith, 2018).

While Goldstein (2014), and Pineda et al (2018) provided evidence for therapy's role in family-centered care, Gibbs, Boshoff, and Lane (2010) demonstrated that occupational therapists have a unique role in family-centered care in the NICU. In their article, the authors explained that occupational therapy has had a growing role in providing services to premature infants and

their families. In fact, occupational therapists have a unique perspective since we understand parenting as an occupational role. The intensive environment of the NICU can act as a barrier to parents fulfilling that parental occupation (Gibbs, Boshoff, & Lane, 2010). As such, the authors explained that one can use the Person-Environment-Occupation (PEO) Model to understand parents and their occupational role. The PEO Model is useful for understanding parenting in the NICU as it allows one to analyze and understand the complex interactions that occur between a person, their environment, and their occupations (Gibbs, Boshoff, & Lane, 2010). For example, the interaction between the person and the occupation is altered due to the infant's fragile medical condition. Parents may feel disconnected from their child as they have less physical contact, they may be frightened, and they may doubt their abilities to care for their child. Furthermore, the interactions between the person and the environment in the NICU may be affected by the geographical location of the hospital, or the communication between parents and medical staff. The geographical location of the facility may affect the parents' ability to present in their child's life while the interactions between parents and medical staff may have an effect on the parents' roles. The environment also affects the occupation since there are physical barriers due to medical equipment such as incubators and ventilators that impact the parents' ability to care for their infant (Gibbs, Boshoff, & Lane, 2010). Since the PEO model allows one to understand these interactions in depth, the model will be used as the lens to understand parents and their needs when developing and implementing a family-centered, developmentally supported care program in the NICU.

Literature Review Summary

As evidenced by physicians, nurses, and therapists alike, family-centered care in the NICU results in more positive outcomes for parents and their infants (Bracht, O'Leary, Lee, &

O'Brien, 2013; Dudek-Shriber, 2004; Goldstein, 2013; MeInyk et al., 2006; O'Brien et al., 2013; Pineda, Bender, Hall, Shabosky, Annecca, & Smith, 2018; Welch et al, 2012; Westrup, 2007; Westrup, 2015). Specifically, family-centered care in the NICU helps reduce stress, promote parental attachment and bonding, improve infant self-regulation, sensory development, and neurodevelopment, and reduce length of stay and costs for families and hospitals (Altimier & Phillips, 2013; Westrup, 2015). However, the NICU often acts as a barrier to parenting (Gibbs, Boshoff, & Lane, 2010). Thus, to improve outcomes for infants and their families, healthcare providers in the NICU should use an interdisciplinary approach to encourage parent participation, as well as educate, empower, and support parents through family-centered care.

Screening and Evaluation

In the first four weeks of the doctoral capstone experience, a needs assessment was conducted to provide evidence of any gaps or un-addressed issues related to family-centered practice in the NICU. The needs assessment was an essential component of the experience as it helped to narrow the focus of the project to be site-specific and client-centered. Through the lens of the Person-Environment-Occupation model, the NICU environment and experience alters the infant-parent relationship, as well as the ability for the parent to fulfill this occupational role. The findings of the needs assessment helped determine the needs of the parents in the NICU and how best to address these needs to provide them more opportunity to fulfill their role as parent, thereby providing holistic, family-centered care. As such, the needs assessment informed the development and implementation of the family-centered care program (Bonnell & Smith, 2018).

Site Profile and Context

The site at which the program was implemented was a Level III NICU at a hospital in Indiana. According to the American Academy of Pediatrics, a Level III NICU provides care to

infants who are born at less than 32 weeks' gestation, weigh less than 1500 grams, or have critical medical or surgical needs, regardless of age or weight (American Academy of Pediatrics, 2012). In addition, a Level III NICU has "continuously available personnel (neonatologists, neonatal nurses, respiratory therapists) and equipment to provide life support for as long as necessary" (American Academy of Pediatrics, 2012, p. 593).

The Level III NICU at which the doctoral capstone took place has been cited as the leading NICU in this area of the state since the 1970s (Franciscan Health, 2018). The current facility has 14 private suites, each of which can be expanded to accommodate for multiple births if necessary. In addition, the unit is specifically designed to be a healing environment for infants and their families. For example, the site has sound-dampening doors, adjustable lighting, and individual thermostats in each suite. A neonatologist and nursing staff is present within the unit 24 hours per day, seven days per week. Occupational therapists, physical therapists, respiratory therapists, and specialty nurses and physicians are called to the unit when necessary.

While the staff at the site does not specifically report utilizing family-centered care, they have adopted practices that could be classified as family-centered care. Parents receive special access badges that allow them 24-hour access to the NICU. The unit also has a family resource center that serves as an area for parent and family retreat. The quiet room is available for parents to rest, and there is a shower in the family resource center for parents who would prefer to not leave the hospital.

Evaluation Methods

Clinical observations and qualitative surveys were utilized to complete a needs assessment. Due to Institutional Review Board regulations at the site, personal interviews were not allowed to be completed as part of the needs assessment. Clinical observations were made

during visits to the NICU. A survey for parents and a survey for nurses were drafted and sent to the therapy supervisors and the NICU director for approval. Upon approval, surveys and accompanying boxes were placed in the NICU. Parent surveys were placed in the family resource center, while nursing surveys were placed in the staff break room. The unit secretary was made aware of the survey placements. Few surveys were returned initially. To remedy this, surveys were individually distributed to nurses and parents. Four nursing surveys were returned, and two parent surveys were returned. Refer to Appendix A and B for surveys.

Evaluation Results

Clinical observations of parent education and participation were made during the first four weeks of the doctoral capstone experience. It was observed that fewer parents were present in the NICU during the morning hours. Parents tended to visit in the late afternoon and evening hours. Parental presence in the NICU was specific to each family; some parents were rarely present in the unit, while others were present daily. When parents were present, nurses were encouraged to involve the parents in infant care. For example, if parents were present during care times, nurses assisted them with feedings, diaper changes, and baths. Lactation consultants were called in as needed. Nurses also supported infant/parent attachment by encouraging holding and skin-to-skin care whenever possible.

Physical and occupational therapists and speech language pathologists were also involved in parent education and participation. Observations were made of therapists briefly educating parents on topics such as positioning, infant massage, and feeding. However, education was typically brief and occurred when parents' attention was divided. Oftentimes, therapists were unable to provide parent education because parents were not present during therapy sessions. Therapists were typically in the NICU during the morning, hours which were characterized by

less parental presence. Based on thorough clinical observations, a need at this site was for more complete and consistent parent education on topics related to infant development, as well as more parent participation in these activities while their infant is in the NICU.

On the two parent surveys that were returned, one parent stated interest in interpreting infant behavior and wanted more information about the developmental follow-up clinic. Another parent was interested in all educational topics listed: (a) positioning and handling, (b) skin-to-skin care, (c) interpreting infant behavior, (d) developmental milestones, (e) equipment, and (f) feeding. This parent was also interested in a parent group and the developmental follow-up clinic.

Four nursing surveys were returned. All surveys indicated that parents needed knowledge about interpreting infant behavior, a parent group, and referral to the developmental clinic. Less frequently circled items included positioning and handling (3), developmental milestones (2), mental health resources (2), skin-to-skin care (1), equipment (1), and feeding (1). Nurses also commented that there was a need to educate parents on “how to touch a sick baby” as well as a need to help parents understand when they can begin holding and handling their baby based on the infant’s medical concerns and complexities.

Problems Related to Occupational Performance

When parents have an infant in the NICU, the typical infant/parent attachment process is altered (Goldstein, 2013). As such, parents’ occupational performance is affected. Furthermore, it can be difficult for parents to fulfill their occupational role as a parent (Gibbs, Boshoff, & Lane, 2010). Dudek-Shriber (2004) reported that the most stressful part of parents having an infant in the NICU was the change in their parental role and relationship with the infant. Depending on the medical status of their infant, parents may not be able to toilet, feed, bathe,

hold, or comfort their child. As such, parents are unsure of what their role is with their infant when they are in the NICU (Dudek-Shriber, 2004). The results of the doctoral capstone needs assessment demonstrated that parents in the NICU need more education and support. It has been found that providing education and support is empowering for parents (Goldstein, 2013). By meeting these needs, the NICU staff can support the creation of a positive parent-infant relationship, thereby helping parents to fulfill their occupational role.

Family-Centered Care in Other Settings

Family-centered care has been studied and implemented in other settings by many disciplines. For example, in their 2018 study, Coats et al explored family-centered care in the Pediatric Intensive Care Unit (PICU), Cardiac Intensive Care Unit, and the Neonatal Intensive Care Unit. The authors explained that family-centered care supports family involvement and decreases stress by “improving communication, helping manage stress and coping, and decreasing conflicts” (Coats et al, 2018, p. 52). The authors focused on the role of nursing in family-centered care and studied nurses’ perspectives of benefits and challenges to implementing family-centered care in various intensive care settings. In the study, family-centered care was implemented through changes in the physical environment, facility policy, and clinical interaction. Changes in the physical environment included transitioning to individual private rooms. Policy changes included 24-hour unit access for families. The results of the study demonstrated benefits for families, but also challenges for nurses as a result of changing how care was delivered. The study by Coats et al. (2018) informed the assessment and implementation of a family-centered care program for the doctoral capstone experience. In addition, the authors demonstrated a need to consider benefits for families as well as challenges for healthcare professionals when implementing family-centered care in any setting.

Family-centered care has also been studied and implemented in early intervention settings. Stoffel, Rhein, Khetani, Barnekow, James, and Schefkind (2017) discussed the importance of family engagement in early intervention. Stoffel and colleagues explained that partnering with families in early intervention is essential for quality care as it supports and encourages families to “teach, nurture, and advocate for their children” (Stoffel, et al., 2017). The authors reported that occupational therapy practitioners can partner with families when providing care, as well as when evaluating outcomes of therapy from the family’s perspective. This study also informed the doctoral capstone experience as it highlighted the importance of evaluating a family’s satisfaction and perspective of care and outcomes. This study supported the need to include a family/parent exit survey in the evaluation of the doctoral capstone program.

A 2017 article by Lardinois, Gosselin, McCarty, Ollendick, and Covington also demonstrated the importance of family-centered care in pediatric care settings. The authors focused on physical therapy clinical education models in the pediatric setting, and the need to include “family-centered care for all patient/client and family interactions” (Lardinois, Gosselin, McCarty, Ollendick, & Covington, 2017, p. 131). The study examined communication, collaboration, and reflection for physical therapy students in the pediatric setting. The need for family-centered care as an Essential Core Competency emerged from the study. This study and the previously mentioned studies provided support and evidence for family-centered care implementation in various settings by various disciplines including occupational therapy, physical therapy, and nursing.

These studies demonstrate the need for family-centered care across the continuum of care. According to the Centers for Disease Control and Prevention (CDC), low birthweight, premature birth, multiple births, and infections during pregnancy increase the risk for many

developmental disabilities (CDC, 2017). NICU infants are often admitted due to one or more of the conditions described by the CDC. Therefore, NICU infants as a population are at higher risk for developmental disabilities, and are more likely to receive services such as early intervention and/or outpatient pediatric therapy after discharge from the NICU. If family-centered care begins in the NICU setting, parents may learn to advocate for themselves and their children early on, thus improving outcomes for their children and their family as a whole.

Implementation

The process of planning the family-centered program began through collaboration between the occupational therapy student and two therapy supervisors who had previous experience working in the hospital's NICU. The program idea developed from the intersection of the supervisors' knowledge and expertise of the facility, and the student's vision to promote family-centered care. After reviewing the surveys that were completed during the needs assessment, the student and supervisors developed specific interventions to be implemented.

To address the needs related to family-centered care in the NICU, two interventions were implemented at the Indiana hospital Level III NICU during the DCE. The first was a NICU Binder that consisted of information to support parent understanding and involvement in the NICU. The binder included information about developmental care, understanding infant behavior, skin-to-skin contact, positioning and handling, protecting sleep, and developmental milestones. It also provided a list of additional resources to support parents. For example, information was provided about social work, mental health, the developmental follow-up clinic, early intervention, and outpatient therapy. Furthermore, certificates acknowledging the infant's and their parents' progress in the NICU were included throughout the binder to provide a more interactive intervention. The NICU Binder was not yet published by the Public Relations

department at the conclusion of the DCE. Upon publication by the site, each family will receive a binder upon their child's admission to the NICU. Nursing will introduce the binder to parents and therapy will use and reference the binder with the parents and encourage parents to ask any questions.

The second intervention was a series of parent education courses. Four courses occurred in the series. The courses were held on March 16, March 30, April 13, and April 25, 2018. The first two courses were held at 6:00 pm. The last two courses were held at 5:30 pm. The first course covered the topic of Positioning and Handling, and was taught by the occupational therapy student. The second course was Infant Massage, taught by the facility Massage Therapist. The occupational therapy student was present to assist the Massage Therapist in any way necessary. The last two courses were taught by the occupational therapy student: Interpreting Infant Behavior and Practicing Skin-to-Skin Care, and Developmental Milestones. Powerpoint presentations were used during each course. The Powerpoint presentations were printed as handouts for the attendees.

In order to begin the series of courses, approval was needed from several groups. The program was first presented to the therapy management team. Upon receiving feedback and approval from the therapy management team, the program was then presented to the NICU director. Once the NICU director had the opportunity to make suggestions and gave approval, the occupational therapy student presented an in-service to the NICU nurses regarding the family-centered care program to support positive collaboration and inter-professional practice. The course series began on March 16, 2018 and occurred on a bi-weekly basis.

Leadership Skills

Leadership skills were essential to the implementation phase of the DCE. Leadership skills that were utilized include flexibility, communication, perseverance, and advocacy. Flexibility and communication were necessary for the DCE as many different groups of people were involved in the process. Flexibility was required to adjust schedules and plans to ensure all groups involved had the opportunity to provide feedback and to ensure all parties were in agreement. Clear communication was important when describing the DCE project to others. For example, the occupational therapy student needed to communicate the purpose and goals of the project to the project supervisors, the NICU nurses, the NICU director, and the social worker to ensure everyone understood. This was a new experience for the student and the facility; therefore, it required significant flexibility and communication on the parts of all involved.

Perseverance and advocacy were also important to the DCE. Perseverance was a key skill to be utilized throughout the experience, especially when there were barriers in the process. For example, per facility policies, interviews were not allowed to be completed as part of the needs assessment. Therefore, perseverance was required to create a different process through which to complete the needs assessment. Perseverance continued to be used throughout the DCE to achieve the goals of the project. Advocacy was also necessary, especially when presenting the project to the NICU director and nurses. It was essential to advocate for family-centered care in the NICU and the role of occupational therapy in this setting and approach to care. The site utilized aspects of family-centered care, but there were still adjustments and changes that could be made to improve practice. Furthermore, therapy is not a constant presence in the NICU at this site; therefore, advocacy for occupational therapy's distinct value and role was significant to the success of the project.

Staff Development

To promote staff development, the DCE project was presented to the NICU nursing staff in the form of an in-service. The evidence and research supporting the project were briefly presented, as well as an overview of the project to be implemented. This promoted family-centered care, as well as interprofessional, collaborative practice between nursing and therapy. The NICU binder and parent education PowerPoints were sent to the NICU therapists to ensure they were aware of what was implemented.

Outcomes and Discontinuation

Outcomes

When evaluating the efficacy of a program, it is necessary to use an outcome measure to quantify the results. In the case of this DCE, the occupational therapy student created a survey for parents to complete after each parent education course attended (see Appendix C). The purpose of the survey was to serve as a measure of efficacy, utility, and satisfaction for the parent education courses. The survey was a five-point Likert scale with options ranging from “Strongly Disagree” (1) to “Strongly Agree” (5).

A mother and father couple attended the first parent education meeting entitled “Positioning and Handling” on March 16, 2018. Following this first meeting, the average score of the survey was 4.8 out of five, demonstrating an overall positive experience. The attendees answered “Strongly Agree” (5) for questions one through seven, as well as question nine. They answered “Excellent” (5) for question 10. Both attendees answered “Neutral” (3) for question eight, “The class gave me an opportunity to connect with other NICU parents.”

One parent couple attended “Infant Massage,” the second course in the four-course parent education series, on March 30, 2018. One attendee reported “Strongly Agree” (5) for questions two through seven, “Agree” (4) for questions one and eight, and “Neutral” (3) for question nine.

This attendee gave the course an overall rating of “Excellent.” (5) The second attendee reported “Agree” (4) for questions one through six, as well as question nine. The second attendee answered “Strongly Agree” (5) for question seven, and “Neutral” (3) for question eight. This attendee rated the class as “Good” (4) overall. A question about the day and time of the course was added to the survey prior to the second course to capture information regarding scheduling for continuous quality improvement. Both attendees answered “yes” to this question, “Was this a good day/time for you?” The average score of the post-course survey was 4.3 out of five, demonstrating overall satisfaction with the course.

Three individuals from one family, a mother, father, and grandmother, attended the third parent education meeting about skin-to-skin care and infant behavior cues on April 13, 2018. One individual recorded “Strongly Agree” (5) for questions one, two, five, and six. This individual recorded “Agree” (4) for questions three, four, seven, and nine, and rated the class as “Excellent” (5) overall. The other two attendees answered “Agree” (4) for questions one through seven, and question nine. They both gave the course an overall rating of “Good” (4). All attendees answered “Neutral” (3) or non-applicable for question eight. The average score of the post-session survey was 4.067 out of five, demonstrating an overall positive rating for the course.

Two of the three attendees at the third meeting replied to the question regarding day and time. They both reported that the day and time worked well for them. It should be noted that the third meeting occurred on a Friday evening at 5:30 pm, while the previous two meetings occurred on Friday evenings at 6:00 pm. The time was changed on a trial basis to determine if a change in time made a difference for attendance. While three individuals attended this session, all three individuals were from the same family. This was consistent with attendance from the

first two sessions in which one family attended each session. Therefore, the change in time did not seem to affect attendance.

Three individuals from one family, a mother, father, and grandfather, attended the fourth parent education session, “Developmental Milestones.” The average score of the post-session survey for the fourth session was 4.867 out of five. Two attendees recorded “Strongly Agree” (5) to questions one through nine, and gave the session and overall rating of “Excellent” (5). The third attendee recorded “Agree” for questions one and nine, “Strongly Agree” for questions two through seven, “Neutral” for question eight, and also gave the session an overall rating of “Excellent.” It should be noted that the course was held on a Wednesday at 5:30 pm. The day was changed on a trial basis to determine if a change in day made a difference for attendance. The time was determined as a result of a discussion with nursing. Nurses reported 5:30 pm to be a more appropriate time due to care times beginning at 6:00 pm. All attendees agreed that the session was held at a good day and time. The change in the day of the week did not seem to make a difference for attendance. One family attended the last session, demonstrating consistency in the attendance of one family at a time throughout the session series. There were no repeat attendees. During the first and third courses, NICU census was greater than six infants. During the second and fourth courses, NICU census was six infants or less. The post-session parent surveys demonstrated an overall positive experience for each session (see Figure 1 for results). The average score across all sessions was 4.5083 out of five. Thus, the parent education sessions resulted in positive outcomes for parents.

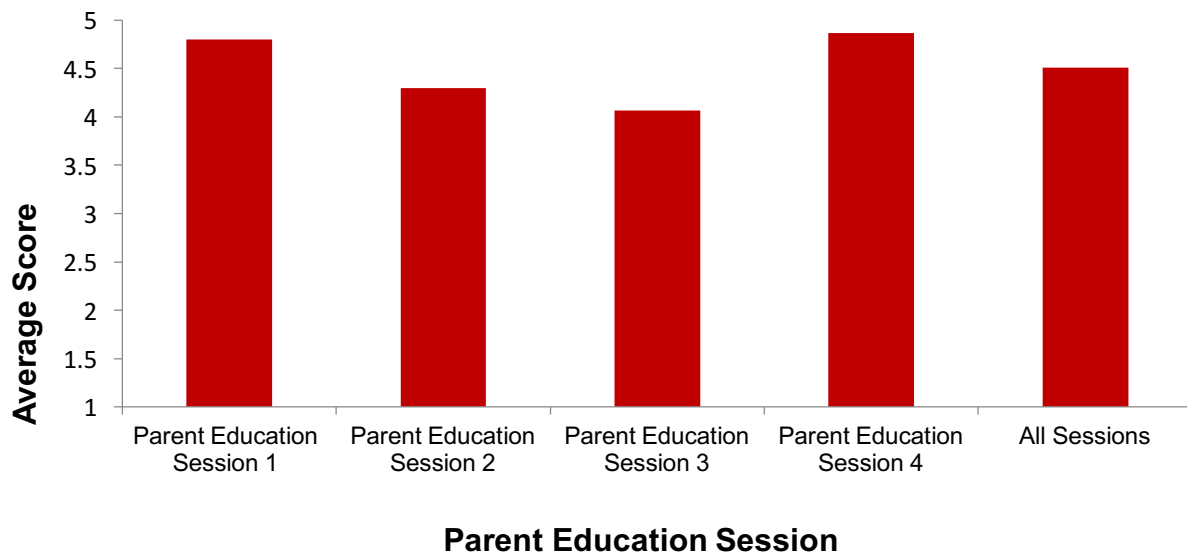


Figure 1. Post-session parent survey results. This figure illustrates average survey scores for each parent education session and the average score for all sessions combined.

A post-program survey was also distributed to NICU nursing and therapy staff in order to evaluate the overall effect of the program on the NICU (see Appendix D). Similar to the post-session parent survey, the post-program staff survey was a five-point Likert scale with options ranging from “Strongly Disagree” (1) to “Strongly Agree” (5). There were also three open-ended questions. Two of these questions asked for suggestions for topics and methods of presentation for the parent education series. The third question asked for any overall comments, suggestions, or concerns. Eight staff members returned completed surveys. Not all respondents answered the open-ended questions. The respondents who did answer the open-ended questions stated suggestions for including feeding as one of the parent education topics, creating videos that could be viewed in parent rooms, and providing specific training on the topic areas for the nurses. The Likert scale survey responses were analyzed by question (see Figure 2 for results).

The average score for questions one through five were 4.875, 4.625, 4.5, 4.75, and 4.875, respectively. The average score for all survey responses was 4.725 out of five. These results demonstrated an overall positive outcome for the family-centered, developmentally supportive care program that was established at the Level III NICU in Indiana.

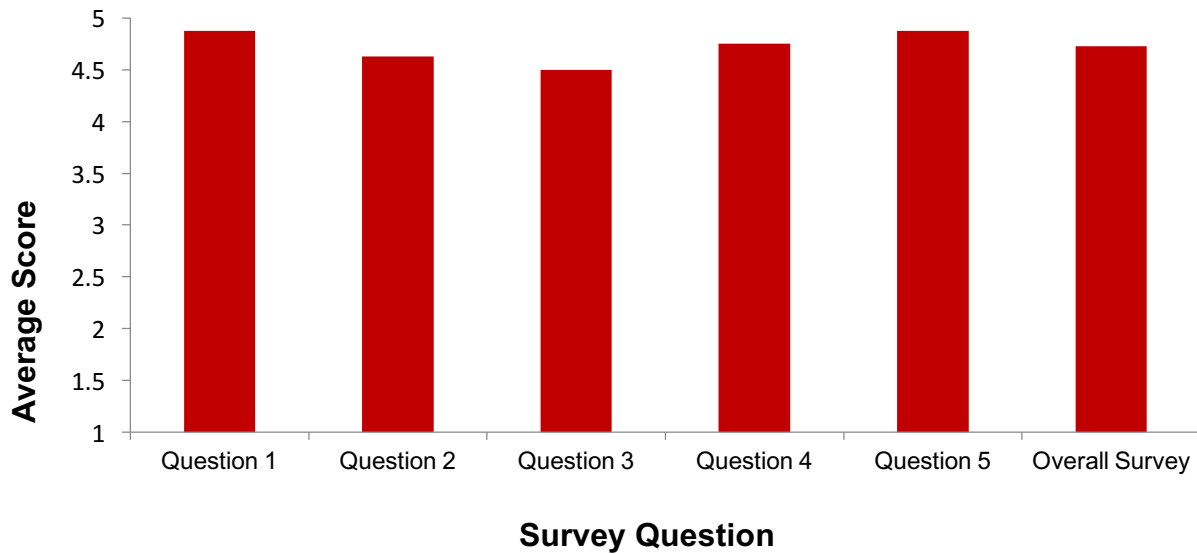


Figure 2. Post-program staff survey results. This figure illustrates the average score for each post-program staff survey question and the average score for all survey responses.

The efficacy of the NICU Binder was unable to be determined, as the Binder was not finalized and distributed by the conclusion of the DCE. However, the fourth question on the Post-Program Staff Survey was, “The NICU Binder will be useful to parents, nurses, and the unit as a whole.” The average response to this question was 4.75 out of five, demonstrating a positive response to future implementation of the NICU Binder. Once the site officially implements the Binder, it would be beneficial to utilize parent and nursing surveys to determine the efficacy, utility, and satisfaction of the Binder.

Discontinuation

Sustainability and discontinuation are significant aspects of program planning (Bonnell & Smith, 2018). As such, specific actions were taken to ensure sustainability of the projects that were implemented during the DCE. First, while the post-session parent survey was utilized as an outcome measure, it also served as a measure for continuous quality improvement. As part of a new program, it was imperative that the site had a method to measure the efficacy, utility, and satisfaction of the parent education meetings. The site will continue to utilize the post-session parent survey as a continuous quality improvement measure. The site will modify the survey as needed as the program continues to grow.

To ensure sustainability of the parent education meetings, physical, occupational, speech, and massage therapists will rotationally teach the parent education courses after the completion of the DCE. A schedule for the parent education meetings was created for the duration of 2018. The meetings will continue to be held biweekly throughout the year. The therapists will be responsible for signing themselves up to teach the courses based on their availability. The courses will continue as part of a four-course series: Positioning and Handling, Infant Massage, Behavior Cues and Skin-to-Skin Care, and Developmental Milestones.

Following edits by the Public Relations department, the NICU Binder will be published and distributed to each NICU family upon admission to the unit. The NICU nurses will introduce the binder to parents upon arrival to the unit. NICU therapists and nurses will refer to and utilize the binder when providing individual parent education at bedside. NICU milestone certificates will be kept in a file cabinet on the unit. When an infant reaches a special milestone on the unit, the healthcare provider that witnesses the milestone will fill out the certificate and add it to the parents' NICU Binder. This will be done in an effort to ensure the binder is an interactive and useful material.

At the conclusion of the DCE, the occupational therapy student met with the NICU Director to discuss the results and sustainability of the program. The meeting focused on fostering future opportunities for collaboration between therapy and nursing in the NICU. As a result of this meeting, it was determined that a NICU therapist will attend the weekly interdisciplinary care conferences on Thursday mornings. Furthermore, the NICU therapists will be encouraged to utilize the white boards in infant's rooms to communicate with nursing more consistently. These measures will help to sustain the collaborative relationship that was established during the DCE. In the near future, the NICU therapists and nurses plan to utilize the Infant Positioning Assessment Tool (IPAT) to assess infant positioning, and collaborate on creating a protocol for cue-based feeding on the unit.

Since family-centered care has been shown to be best practice in the NICU, the project created during the DCE responds to society's needs by helping the site expand its practice in the area of family-centered care. Family-centered care programs have developmental benefits to the infant, encourage a positive parent-infant relationship, and support the needs of the parents and family, resulting in better outcomes for the infant, the parents, and the family as a whole (Bracht, O'Leary, Lee, & O'Brien, 2013; Dudek-Shriber, 2004; Goldstein, 2013; MeInyk et al., 2006; O'Brien et al., 2013; Pineda, Bender, Hall, Shabosky, Annecca, & Smith, 2018; Welch et al, 2012; Westrup, 2007; Westrup, 2015). The family-centered care program that was established provided education and support to parents to help foster healthy infant development and the parent-infant bond.

Overall Learning

The 16-week Doctoral Capstone Experience ultimately resulted in the development of family-centered programs for the Level III NICU in an Indiana hospital. In order to develop

these programs, the student completed research of peer-reviewed journals and educational materials to gain knowledge regarding developmental, family-centered care in the Neonatal Intensive Care Unit. The student spent many hours shadowing therapists, nurses, and social workers in the NICU, as well as attending unit rounds, to attain neonatal clinical skills and knowledge, and to understand the procedural and cultural aspects of the unit.

Throughout the DCE, professional communication was critical to accomplishing the student's goals. In order to implement new programs in the NICU, it was essential to build rapport and trust with the neonatal nurses, doctors, and therapists. A large portion of the experience involved building this rapport in order to promote buy-in and interdisciplinary collaboration. The student utilized professional written and verbal communication to establish this rapport.

Interprofessional collaboration was a key component of the experience. Neonatal occupational therapists, physical therapists, and speech language pathologists were consulted throughout the creation of the materials, as well as the implementation of the program. When drafting the program materials, including the NICU Binder and the parent education presentations, the student asked for the assistance and advice of the NICU therapists. Therapists from each discipline provided constructive feedback that was utilized to edit and revise the materials as needed. The advice and suggestions from the therapists helped to ensure the documents presented developmentally appropriate information, and were clinically accurate, easily understood, and generally well-received.

Upon approval of the program materials from the neonatal therapists and the student's site mentors, the student presented the program materials to the NICU Director, charge nurses, nurses, and Medical Director. Throughout the multiple meetings and presentations with various

members of the NICU team, the student learned how to professionally and effectively communicate with the NICU staff in a respectful and productive manner. In order to establish an interdisciplinary, cooperative environment, the student sought the NICU staff's comments, questions, concerns, and advice regarding the materials and the program implementation. The NICU staff's suggestions were constructive and helpful in developing the program. All suggestions or concerns were thoroughly discussed, considered, and employed with the guidance of the site mentors.

Due to their continuous presence on the unit, neonatal nurses were the primary points of contact in the NICU. Therefore, it was critical that neonatal nurses were supportive and willing to participate in any new programming or initiatives in the NICU. Fortunately, the occupational therapy student was able to create positive, professional relationships with the neonatal nurses, and therefore gained their support and assistance with implementing the family-centered care program. As such, the DCE allowed the student to assist the site in creating more opportunities for communication and partnership between the NICU therapists and nurses.

When presenting the parent education courses, the student applied therapeutic use of self to create a supportive, open, and non-judgmental environment for parents. It was essential to build rapport with the parents as clients during the courses. The courses were presented using non-medical terminology, anecdotal examples, and professional, yet personable, communication to ensure the courses were accessible and understandable for each parent.

The doctoral capstone experience fostered the student's development of communication, leadership, and interdisciplinary skills. By utilizing professional communication and leadership, as well as mutual respect and understanding for every member of the NICU community, the student was effective in creating positive relationships that were fundamental to the successful

implementation of the program. Overall, the student established positive professional relationships with members of the NICU community, made an encouraging impact on the NICU's practice and culture, and established a well-received program that will be sustained into the future.

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Appendix A

Parent Needs Assessment Survey

My name is Doron, and I am an Occupational Therapy student from University of Indianapolis. I am completing my Doctoral Capstone Experience here at Franciscan, and I am focusing on the NICU. I have done quite a bit of research about what healthcare professionals can do to support parents in the NICU. I would love to know what you think you might benefit from.

Please circle any of the following topics you would like more information on:

1. Positioning and Handling
2. Skin-to-Skin Care
3. Interpreting your infant's behavior
4. Developmental Milestones
5. Equipment
6. Feeding

Please circle any of the following you would be interested in:

1. Parent Group
2. Developmental Follow-Up Clinic
3. Mental Health Resources

Do you have any other questions, comments, or concerns?

Appendix B

Nursing Needs Assessment Survey

My name is Doron, and I am an Occupational Therapy student from University of Indianapolis. I am completing my Doctoral Capstone Experience here at Franciscan, and I am focusing on Family-Centered Care in the NICU. I have done quite a bit of research about what healthcare professionals can do to support parents and families in the NICU. I would love to know what you think parents might benefit from, and any other concerns/comments you might have.

Please circle any of the following topics you think parents may need more information on:

1. Positioning and Handling
2. Skin-to-Skin Care
3. Interpreting infant behavior
4. Developmental Milestones
5. Equipment
6. Feeding

Please circle any of the following you think parents may benefit from:

1. Parent Group
2. Developmental Follow-Up Clinic
3. Mental Health Resources

Do you have any other questions, comments, or concerns?

Appendix C

Post-Session Parent Survey

1. The information helped me understand my baby and his/her development.

Strongly Disagree Disagree Neutral Agree Strongly Agree

2. The class encouraged me to be involved with my baby's care whenever possible.

Strongly Disagree Disagree Neutral Agree Strongly Agree

3. The information will help me when I take my baby home.

Strongly Disagree Disagree Neutral Agree Strongly Agree

4. The information was easy to understand.

Strongly Disagree Disagree Neutral Agree Strongly Agree

5. The instructor was prepared and organized.

Strongly Disagree Disagree Neutral Agree Strongly Agree

6. It was important to the instructor that I understood the information.

Strongly Disagree Disagree Neutral Agree Strongly Agree

7. The instructor was friendly and answered my questions well.

Strongly Disagree Disagree Neutral Agree Strongly Agree

8. The class gave me an opportunity to connect with other NICU parents.

Strongly Disagree Disagree Neutral Agree Strongly Agree

9. The class gave me more confidence when caring for my baby.

Strongly Disagree Disagree Neutral Agree Strongly Agree

10. Overall, I would rate the class as:

Poor Fair Average Good Excellent

11. Was this a good day/time for you? If not, what would be a better day/time?

12. Please place any other comments, questions, concerns below. Thank you for coming!

Appendix D

Post-Program Staff Survey

1. The topics presented in the parent education meetings were relevant to infant care in the NICU.

Strongly Disagree Disagree Neutral Agree Strongly Agree

2. The parent education meetings were effective at providing thorough parent education.

Strongly Disagree Disagree Neutral Agree Strongly Agree

3. The parent education meetings benefitted the parents, infants, and the unit as a whole.

Strongly Disagree Disagree Neutral Agree Strongly Agree

4. The NICU binder will be useful to parents, nurses, and the unit as a whole.

Strongly Disagree Disagree Neutral Agree Strongly Agree

5. The family-centered care program was beneficial to providing best care in the NICU.

Strongly Disagree Disagree Neutral Agree Strongly Agree

6. Are there any other topics you would include in the parent education meetings?

7. Are there other ways you would like the information to be presented?

8. Any other comments/questions/concerns? Thank you!