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## Creating Confident and Connected Families: A Program to Improve Parental Self-Efficacy in the Neonatal Intensive Care Unit

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Creating Confident and Connected Families: A Program to Improve  
Parental Self-Efficacy in the Neonatal Intensive Care Unit

Capstone Project

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Post-Professional Doctor of Occupational Therapy (Dr.OT.) Program

Submitted April 30, 2019

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to Elise Bloch, Ed.D, OT/L

For the Doctor of Occupational Therapy (Dr.OT) degree

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### **Abstract**

Infants in the Neonatal Intensive Care Unit (NICU) require life sustaining intervention for weeks to months after birth. This intervention is remarkably stressful for both the infant, who is ill-equipped to handle life outside the womb, and for the parents who are filled with fear and stress due to the illness of their son or daughter. The experience of hospitalization can lead to stress, shame, anxiety, and even post-traumatic stress disorder for families of NICU infants. Knowledge about the unique stressors, challenges, and needs for support of preterm infants has proven helpful to boost confidence and feelings of wellbeing within the NICU family population. This capstone paper discusses a program designed in the NICU to improve the education, knowledge, confidence, and self-efficacy of parents in the NICU. Details of program design, implementation, results, and implications for the future will be presented.

*Key Words:* neonate, newborn, NICU, stress, post-traumatic stress disorder, shame, parenting, occupational performance, program, self-care, education, kangaroo care, positioning, Kawa Model, infant communication.

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## **Chapter One**

### **Introduction**

The preterm infant is not equipped to perform many occupations as he or she was designed to remain inside the womb and have many life-sustaining functions performed for him or her at this age. However, when born early, the occupational expectations increase substantially for the infant as he or she is expected to digest, breathe, and function with the help of machines instead of the womb and placenta (Philbin, Lickliter, & Graven, 2000). Maintaining internal homeostasis, vital sign stability, and state regulation are prerequisites for occupational performance for infants. The inherent abilities of the infant, based on their gestational age and developmental progression, must be considered prior to the expectation of occupational performance (Humphry & Wakeford, 2006; Philbin et al., 2000). While the womb was quiet, dark, comfortable, and predictable, life in the NICU cannot be described in the same manner. Rather a cacophony of sound greets the infant whose immature neurological system is ill-prepared to deal with these new stressors (Pineda, Guth, Herring, Reynolds, Oberle, & Smith, 2017). Likewise, the NICU environment is a challenge to parents, who are alarmed by the intensity of care required for their infant (Chinchilla, 2012).

Although necessary and lifesaving, the presence of medical monitors, lines, tubes, and equipment can create a physical barrier to interaction with the infant and affect the occupational performance of both infant and parent (Gibbs, Boshoff, & Lane 2010). Parents expect to be able to hold, comfort, feed, and touch their infants immediately, and oftentimes the occupations of parenting are restricted or delayed in the NICU environment (Whitcomb, 2012). Furthermore, the occupation of parenting is restricted by hospital staff at times due to the complexity of the infant's needs. The presence of certain life-sustaining lines such as arterial lines, endotracheal

tubes, or intravenous lines limit the ability of the infant to be moved safely. Although the risks associated with movement with such lines are explained to parents, there is still a loss reported in the delay of expected interaction with one's infant according to one NICU mom now active on the Family Advisory Council (Sara Henney, personal communication, October 8, 2018). Optimal growth and development occurs within nurturing relationships and the experiences in early infancy affect development throughout the lifespan (Weatherston, Ribaud, & Glovak, 2002).

Parents expect that the transition into parenting will occur naturally (Yaman & Altay, 2015). The typical parental expectations of diaper changes, midnight feedings, and rocking an infant to sleep are disrupted when birth occurs before it was expected (Gibbs, Boshoff, & Stanley, 2016). The birth of a preterm infant is unexpected, and creates trauma and stress within the family system. This stress can affect a parent's ability to interact with and parent his or her child (Gibbs et al., 2016). Parents consistently report the feeling of being out of control in the neonatal intensive care unit (Price & Miner, 2009 a) and this can affect their ability to care for their child (Pizur-Barnekow & Erickson, 2011). The skills of the infant are dependent upon the skills of the parent, which are disrupted by anxiety, stress, and their experience in the NICU (Alkozei, McMahon, & Lahav, 2014).

A central goal of infant-based occupational therapy is to promote co-occupations, attachment, and relationship between infant and parent (Whitcomb, 2012). When developmental skills or experiences are disrupted, there is a need for occupational therapy intervention. The challenges placed on the infant and the family during a NICU stay are significant and in need of intervention to promote typical development. The latest occupation-based research in the NICU addresses attachment needs by studying family-centered care and co-occupations despite the difficulties and distractions inherent in the environment (Whitcomb, 2012).

Preterm births present stressors and delays in skill progression for both the infants and their parents. Infants, whose bodies and brains are immature and ill-equipped for life outside the womb are challenged. Parents of preterm infants are likewise challenged and stressed as their ability to comfort their infant and provide the expected occupations of parent are delayed. This paper will present the current state of families in the NICU at a large central Florida hospital, the problem, present a program designed to address the current issues and improve the self-efficacy of families in the NICU. Subsequently the program evaluation feedback will be discussed along with recommendations for future practice, research investigation and education. To best serve these families, more must be known about their experience of hospitalization.

### **Demographics of the Broader NICU Community**

Approximately 10% of all births in the United States require a NICU admission (Weis, Zoffmann, Greisen, & Egerod, 2013). Persons from all ethnicities and socioeconomic statuses are represented in NICU admissions in the United States as well as at the hospital where this program was instituted in Orlando, Florida. Orlando boasts a population of 2.5 million people with an average growth of 138 residents a day, according to recent research (Brinkmann, 2016).

Other helpful demographic data about the city of Orlando include: the average household income in Orlando was \$47,507, or \$26,829 per capita income, in 2015 dollars (Quick Facts: Florida, n.d.). Nearly 15% of the community live below the poverty line (Quick Facts: Florida, n.d.). Therefore, a sizable minority of Orlando residents have financial strain on a regular basis, which can affect their health care options.

While Orlando is most famous for its world-class attractions and tourist destinations, including Walt Disney World and Universal Studios, it is also known for having a thriving health care industry with four children's hospitals. Therefore, healthcare is in great demand in the area

as well. The hospital where this program was implemented has over 200 pediatric beds, 102 NICU beds, and regularly operates at or near bed capacity.

**Community within a Community.** Oftentimes a community is defined by geographic terms, proximity, or demographic characteristics. However, the community of individuals with shared experiences is also a uniting factor warranting community development (Minkler, 2012). One source defines communities as, “units of patterned social interactions or symbolic units of collective identity” (Minkler, 2012, p. 40). Communities can be found in persons with shared experiences, community programming begins by starting where people are, including in hospital units (Minkler, 2012). Since most families with hospitalized infants spend several months in the hospital, they have time to develop relationships with staff and other families and to become a community within the broader community.

The parents of preterm infants in the NICU constitute a community with shared experiences, unique needs, and a sense of cohesion. Efforts to improve the experience of hospitalization for families are currently being addressed by the administrators at this hospital. This capstone project is unique in that it defines the parents of preterm infants as a community and undertakes program development to serve the specific needs of this community. There are a variety of stakeholders in this capstone project including: currently admitted families, discharged families, the Family Advisory Council, rehabilitation administration, hospital administration, and fellow bedside staff members. Stakeholder interviews and a needs assessment determined the best course of action to address the needs of this underserved community within a community

### **The Need: The Traumatic Experience of the NICU for Families**

Currently there are over one hundred hospitalized infants at the large central Florida hospital where this program was designed and implemented. These infants need support to eat, breathe,

grow, and thrive, which the expert staff at the hospital provides each day. There is much research about the importance of trauma-informed care for infants in this situation (Coughlin, 2014).

However, their parents' experience is also traumatic and they need support to act and feel like parents, to take on new roles and routines, and to cope with the loss of normalcy that comes with having a hospitalized child. Parents voice feelings of emotional imbalance due to the complexity of their child's needs and they often feel ill-prepared to care for their children after discharge (Latva, Lehtonen, Salmelin, & Tamminen, 2004). Parents often show symptoms of depression and post-traumatic stress disorder (PTSD) from their experience in the NICU (Clotney & Dillard, 2013). These symptoms often last well beyond the duration of hospitalization, even up to seven years post discharge (Treyvaud, Lee, Doyle, & Anderson, 2014).

### **Parental PTSD in the NICU**

The NICU can be an overwhelming place to exist and parent and families often display maladaptive behaviors or diagnoses after their experience of their child's hospitalization due to the complexity of the hospital environment (Cohn & Lew, 2015). Post-traumatic stress disorder is one diagnosis heavily researched in the parents of preterm infants. PTSD can be defined as "a feeling of extreme anxiety that is brought about by fearful and threatening experiences in which the individual experiences a lack of control" (Clotney & Dillard, 2013, p. 23). The prevalence of PTSD with this population has been shown in a variety of studies in the United States and abroad (Horsch et al., 2016; Yaman & Altay, 2014). Davidson et al. (2017) estimated that one quarter to one half of parents with children admitted to intensive care units (ICU) experience psychological distress including acute stress disorder, PTSD, and depression. Therefore, considering the experience and possible trauma of the parent is crucial in this population and setting.



### **Occupational Injustice**

Occupational justice is a theoretical concept which describes times when occupations are restricted for a constellation of reasons. Initially the term occupational justice was used in vocational research outside of the occupational therapy body of research to describe jobs which were not meaningful (Hammel & Beagan, 2016). Researchers and theorists, Ann Wilcock and Elizabeth Townsend, were the first to apply this concept to occupational therapy and have worked to expand the concept and apply it to a client's participation in meaningful, self-directed occupations for the promotion of health and well-being (Wilcock & Townsend, 2000).

Occupational injustice can affect the infant, whose typical occupations are altered based on a new and challenging environment, and the parent whose expected occupations of parenting run into barriers due to the fragility of their infant, restrictive hospital policies, and the presence of life-sustaining lines. One method to increase occupational justice is to educate families on the needs of their infants, as well as their own occupational needs, through means appropriate for adult learners.

### **Parental Education Needs**

Infancy is a crucial time for the creation of healthy habits and bonds between infant and parent. Poor health in a child during the prenatal and early childhood period has been shown to cascade into significant health concerns within a few years (Braungart-Rieker, Burke Lefever, Planalp, & Moore, 2016). However, the converse is also true, that healthy habits beget health and wellbeing. Education and awareness is heavily correlated with healthy outcomes (Braungart-Rieker et al., 2016).

Decreased patient or parental knowledge is associated with poorer outcomes and increased health care utilization costs (Craig et al., 2015). Therefore, improving education,

awareness, and health literacy are specific goals of healthcare entities and health promotion.

“Health literacy describes specific literacy skills needed to obtain, understand and use information to make decisions and take actions that will have an impact on health status” (Muscat et al., 2017, p. 1393). All patients need education about their health and needs and in the case of NICU infants, their families need education to support their child’s growth and development. Family-centered parent education programs address the needs of families to improve the health of both infant and parent, promote healthy behaviors, reduce stress, improve knowledge, increase self-efficacy, and promote healthy parent-child relationships and bonding (Gillmer et al., 2016).

### **The Proposed Solution to Improve the Self-Efficacy of Parents**

The goals of occupational therapists are to promote performance in meaningful activities, health, and wellbeing (AOTA, 2014). In the NICU setting this means a heavy emphasis on the parental performance and ability to engage with the infant. Family-centered care is a hallmark of best practice for neonatal units nationwide (Coughlin, 2014). Family centered care cannot be accomplished without the knowledge, feedback, and advising of those who understand from first-hand experience, the families of hospitalized children. Family advisory councils exist at most major hospitals to provide feedback, policy change, and promote the experience of hospitalization for families (Planetree International, n.d.). The Family Advisory Council (FAC) was crucial in the provision of guidance for topics, creation of presentations, editing of materials, and discussion of organization of this capstone program development. More details about the FAC involvement in program development will be detailed in chapter three. The capstone student used three perspectives, the logic model, holistic model, and theory of change to guide

needs assessment and program development. More details of these models will also be detailed in chapter three.

The needs of preterm infants are unique, such that even seasoned parents need education to best care for their NICU infants. One way to promote family-centered care is to institute educational groups which foster the parents' confidence and competence with daily tasks specific to the hospitalized infant population. Desired educational topics among families are: handling, reading cues, adjusting ages for prematurity, positioning, postural control, and follow up (Goldstein, 2013). The program described in this paper is generalizable and easily replicable to benefit families in other NICUs. Investigation and interviews regarding the experience of previously hospitalized families, currently hospitalized families and the Family Advisory Council was essential in helping to design this program and the data and stories gathered through program evaluation can be shared with other NICUs to encourage their educational interventions as well. More details regarding dissemination of findings will be discussed in chapter five.

**Purpose:** To create confident and connected families who readily engage in co-occupations with their infants.

**Short-Term Objectives:**

- At least 20% of parents in the NICU will attend the NICU support group at least two meetings per month.
- Parents who attend will complete the focus group follow up discussion to measure confidence and self-efficacy in parental skills.
- Parents who attend will identify at least three stress signs and approach signs during infant movements to improve competence in the occupations of parenthood.

- Parents who attend will perform kangaroo care with proper prone positioning and minimal assistance from staff.
- Parents will identify one fellow parent or staff member who helped them on their journey into parenthood, thus, improving their feelings of connectedness and community.

**Long-Term Goal:**

- Parents will report greater self-efficacy in the co-occupations of parenting.

**Operational Definitions.** Conceptual definitions tell us what a word means, operational definitions tell us how to measure it (Galvin, Wills, & Coffrey, 2017). Three words from the capstone purpose above need further definition and clarity: confident, connected, and self-efficacy. These words often have variable meanings depending on the context and would benefit from operational definitions in this context specifically.

Confidence is a self-reflective measure and is measured by self-assessment and no one else can define it for a person. Confidence means one's familiarity with and conviction with their own knowledge. Therefore, parents can feel confident that they can assess and provide the needs of their children.

Connection means the interrelatedness or dependence of two bodies. In this case, parents can feel connected with staff members, other families, or other support systems. Connectedness can be sensed in physical or spiritual levels and is best measured by self-report (Flannelly, Jankowski, & Flannelly, 2014). Therefore, the best method to operationalize the measurement of confidence and connectedness is through a qualitative feedback from the families served.

Self-efficacy is a related topic that is heavily measured in parents and can be defined as one's confidence in their own skills (Wittowski, Garrett, Calam, & Weisberg, 2017; Barnes & Adamson-Macedo, 2007). Therefore, self-efficacy encompasses the ideas of confidence and

competence in a self-reflective manner (Crncec, Barnett, & Matthey, 2008). This operational definition allows parents to respond with their confidence level in their skills of parenting, and even more importantly, in the role of parent, a valued role for many people.

### **Family-Centered Care**

Family-centered care is an “approach to health care that is respectful of and responsive to families’ needs and values” (Davidson et al., 2017, p. 104). Family-centered care is evidence-based, effective, and is considered a best practice guideline in ICU care nationwide (Coughlin, 2014) Family-centered care is the driving force for this capstone project. Families must be partners in care, not just consultants for they are the constants in their children’s lives. We, as health care professionals, are the visitors. The idea, organization, and implementation of this program was designed in partnership with the Family Advisory Council. Incorporating strong partnerships with families who have traveled the NICU road before was crucial in designing a program to improve the self-efficacy of parenting for families currently admitted with their infants.

### **Summary of Introduction**

The current state of parents in NICU is less than ideal and the role of parent is disrupted by the environment and by the restriction of occupation. The purpose and mission of this program is to encourage parents to act and feel like confident, competent, and connected parents. Therefore, an educational program is proposed offering weekly education sessions led by an occupational therapist and child life specialist for all hospitalized families to improve community, carryover of skills, and influence the infant/parent dyad positively. Child life specialists focus on the experience of hospitalization, illness and disability for the child, siblings, and parents from a social emotional perspective (Association of Child Life Professionals, n.d.).

Therefore, they are natural partners in this project. The topics were chosen based on research of needed intervention in NICUs around the country as well as based on interviews with stakeholders during the needs assessment portion of this project (Goldstein, 2013). Performing educational intervention on general educational topics common in preterm infants can potentially improve the self-efficacy of parents, prevent injuries, and dispel the need for rehabilitation later (Jeanson, 2013).

Successful achievement of the mission and objectives will encourage parents to act and feel like the primary caregivers for their infant. This will have an impact on care and consistency of skill development not just within the hospital setting, but potentially after discharge as well. The goal of this program is to promote parental co-occupation skills to improve the health of both families and infants during hospitalization and after discharge. This program aims to affect the health of vulnerable infants and their families and, if successful, will be a long-term investment in the health and development of the community.

## **Chapter Two**

### **Literature Review**

Having a baby is usually a welcomed arrival full of excitement and celebration. However, the birth of a preterm infant is usually unexpected, and creates trauma and stress within the family system (Heidari, Hasanpour, & Fooladi, 2017). This stress can affect a parent's ability to interact with and parent his or her child comfortably (Gibbs et al., 2016). Stress due to an infant's hospitalization also affects a parent's ability to care for him or herself, which affects the infant's health, creating multiple levels of poor health (Heidari et al., 2017). When the time comes for the baby to discharge, many parents feel ill-prepared and verbalize concerns in their knowledge of parenting skills and often their own occupational performance as well (Fingerhut, 2013). The occupations of the infant are dependent upon the occupations of the parent, which are disrupted by anxiety, stress, and their experience in the NICU (Pizur-Barnekow & Erickson, 2011).

Family-centered care is one method to address the needs of the families during this critical time. Furthermore, improving bonding through interaction, kangaroo care, parental occupations, and hands on care facilitates the role of parent. It is clear from the literature that the current experience of parents with hospitalized infants is defined by trauma, however, much can be done to minimize the trauma (Clotey & Dillard, 2013). This literature review will present the current experiences of parents with infants in the NICU, the need for occupation-based therapy intervention, the benefits of family-centered care, and the benefits of parental involvement in education during the infant's hospitalization. The discussion will conclude with recommendations for a program to address the occupational needs of families in the NICU.

### **PTSD and The Experience of the NICU for Families**

The NICU can be an overwhelming place to parent and families often display maladaptive behaviors or diagnoses after their experiences of hospitalization (Heidari et al., 2017). Post-traumatic stress disorder (PTSD) is a common diagnosis in the parents of preterm infants. PTSD can be defined as “a feeling of extreme anxiety that is brought about by fearful and threatening experiences in which the individual experiences a lack of control” (Clotney & Dillard, 2013, p. 23). Intrusive thoughts, hyperarousal, and avoidance also characterize PTSD (Clotney & Dillard, 2013). PTSD is related to Acute Stress Disorder (ASD) with the main difference between the two being duration of symptoms, not severity (Clotney & Dillard, 2013). Another study, although not about PTSD directly, indicated a high correlation between stress and anxiety, depression, fatigue, and sleep disturbance using the Parental Stressor Scale (Busse, Stromgren, Thorngate, & Thomas, 2013). Clotney and Dillard (2013) indicated the highest prevalence of PTSD among mothers with complicated or traumatic births, which would include most preterm births, with symptoms in 15% of mothers and 8% of fathers one month after admission (Clotney & Dillard, 2013) Furthermore, mothers of very low birth weight infants had the most enduring symptoms two to three years following birth (Clotney & Dillard, 2013). The authors theorized that parents are unable to seek help for their own mental health because they are focused on the health of their infant during this crucial time (Clotney & Dillard, 2013). Another study results indicated that 25% of all families demonstrated symptoms of PTSD after their children were discharged from non-intensive care unit admissions (Franck et al., 2015). Thus, the experience of hospitalization, no matter the level of need for intervention, can be stressful and can affect the family. Therefore, the authors of the same study further urged hospitals and healthcare providers to closely monitor parents of preterm infants for signs of ASD



and PTSD and to provide early intervention for their mental health due to the prevalence of these diagnoses in this population (Franck et al., 2015).

PTSD is not a common diagnosis among parents only in America, rather research studies in South Korea, Turkey, and Switzerland also demonstrated the strong correlation between PTSD and preterm birth. In South Korea, a prospective study of mothers of high-risk infants demonstrated a 25% rate of PTSD among the respondents. The authors of this study used the modified Perinatal PTSD Questionnaire during hospitalization and one year after discharge to track long term responses to hospitalization in 171 parents (Kim, Lee, Namkoong, Park, & Rha, 2015). Furthermore, this study identified patterns of PTSD symptoms in three categories: no symptoms, termed the resilient group, persistent symptoms, and delayed symptoms (Kim et al., 2015). Approximately 25% of respondents demonstrated PTSD symptoms at any time, with 9% of respondents suffering from delayed PTSD (Kim et al., 2015). Therefore, surveying families only during hospitalization may not catch all parents with PTSD symptoms as a subset of those surveyed in this study showed symptoms only after discharge from the hospital. This information is helpful in designing future studies and interventions for this population.

In Turkey, researchers surveyed both mothers and fathers to see the experiences of both parents during their infant's hospitalization using the Impact of Events Scale-Revised (Yaman & Altay, 2014). Results indicated that 81.8% of mothers and 66.7% of fathers experienced posttraumatic stress (Yaman & Altay, 2014). These results are much higher than other similar studies, but also shed light on the severity of the symptoms and the fact that it is not only the maternal experience of stress that needs to be addressed, but paternal stress as well. The authors further highlighted that PTSD affects cognitive processing and could affect a parent's ability to process complicated medical information and decision making in their child's care. Therefore,

addressing the parental health affects infants' health as well. Simple strategies such as guided journaling have been shown to be effective in reducing PTSD symptoms (Horsch et al., 2015). In conclusion, knowledge about the severity of PTSD in this population and strategies to improve the parental experience, which can affect both parent and infant health, should be a part of compassionate and evidence-based practice for NICU care (Kadivar et al., 2017; Marsac, Hildenbrand, Kohser, Winton, & Kassam-Adams, 2013).

### **Post-traumatic Growth**

As with all experiences, there are often unforeseen positive and negative consequences depending on how the individual deals with the challenges. One set of authors (Janvier et al., 2016) all of whom had personal experience parenting in the NICU, conducted a qualitative study and highlighted the positives of life-threatening experiences, which can provide perspective, resilience and grit, which they termed "posttraumatic growth." Medical literature in other researched populations refers to the positive changes in individuals after stressful experiences, such as cancer survivors, trauma victims, or individuals with spinal cord injuries, as posttraumatic growth (Janvier et al., 2016). Specifically, the parents studied indicated that their NICU experiences led to: gratitude, perspective, connectedness, resilience, humility, forgiveness, and dedication (Janvier et al., 2016). Therefore, understanding the positive experiences as well as the negative consequences of hospitalization allows healthcare providers to empathize with parents, but not pity them, for it would be an imbalanced perspective to focus solely on the negative consequences of hospitalization. One intervention that potentially helps avoid post-traumatic stress and promote post-traumatic growth is family-centered care.

### **Definition of Family-Centered Care**

Family-centered care is care that is planned, delivered, managed, and continuously improved upon through active partnership with family members (Frampton et al., 2017). This is a partnership far deeper than asking the family if they have any questions after a lengthy and technical medical discussion in rounds. Family-centered care involves asking the family what observations they have noted in the child, educating them on the medical options, and asking their opinion in how the team should proceed.

Family involvement is championed by the American Academy of Pediatrics, which defines six characteristics of family-centered care:

- (a) honor and respect patient and family preferences, (b) individualize care in response to patient and family needs and cultural values, (c) tailor health information to meet linguistic and literacy needs, (d) family support, (e) partner with families in program development, and (f) support family's strengths. (American Academy of Pediatrics, 2012, p. 354).

Family-centered care is best practice and should characterize all interactions (Coughlin, 2014).

### **Family-Centered Care in the NICU**

Family-centered care means involving parents and caregivers in the identification of impairments and collaborating on a plan to facilitate development and milestones (Baker et al., 2012). Parents can get the impression that their infant is so sick that the staff are the experts and they should not involve themselves in care (Chinchilla, 2012). Family-centered care reminds both parents and staff that the infant belongs to the family and staff should seek to constantly facilitate the parent-infant connection (Baker et al., 2012).

Patient and family-centered care in the NICU includes the following tenets: open and honest communication, interpretation of medical facts and terminology to parents, awareness of negative effects of treatment, family decision making even in high-risk situations. (Harrison, 1993). When the team embraces these tenets, we can work together to improve the experience of the infant and family, improve safety, promote parenting skills, and maximize long-term follow up and development (Harrison, 1993). This change of focus not only helps the attachment of the infant, but improves success in outcomes (Baker et al., 2012). Engagement involves training health care professionals to respect the family's feedback while also educating the family to improve their capabilities and knowledge to be full partners in care (Frampton et al., 2017). One specific recommendation presented by Davidson et al. (2017) was "Family members of critically ill neonates be offered the option to be taught how to assist with the care of their critically ill neonate to improve parental confidence and competence in their caregiving role and improve parental psychological health." (p. 106). Education, reducing of psychological distress, and facilitation of confidence in occupational engagement are among the core goals of NICU occupational therapy and of this capstone project.

**Family-Centered Care and Occupational Therapy.** Parents expect to engage in the occupations of feeding, bathing, dressing, and cuddling their newborn immediately following birth (Gibbs et al., 2016). Admission to the NICU typically delays the parent's ability to engage in such important occupations by weeks if not months. Instead, early parental occupations in the NICU might include participation in medical rounds, assisting with positioning, and providing comfort and containment for one's infant (Price & Miner, 2009 b). Occupational therapists can assist in choosing the appropriate occupation, based on both the parent's and the infant's needs. The occupational therapist can provide opportunity for interaction, psychological support, assist

with care, and manage the medical aspects of the environment to allow improved occupational performance in the occupation of parenting a preterm infant (Price & Miner, 2009 a).

Occupational therapists are skilled at adapting tasks to allow for grading based on the family's health literacy, cultural background, preferences, and individual needs, thus, exhibiting family-centered care in each interaction. Family-centered care can be seen in the NICU by the respectful way caregivers communicate with families, through adult education strategies and through the connection between caregiver and family.

### **Communication between Provider and Parent**

Family-centered care begins with open communication between provider and parent. Poor communication, or poor perceived communication, was a salient issue that triggered anxiety and PTSD in parents in the literature (Comp, 2011). The most common time for parental and provider interaction is during daily rounds. After the institution of family-inclusive rounds, families visited the hospital 30% more often to participate in rounds (Rotman-Pikielny et al., 2007). Furthermore, of the 35 families surveyed, 92.5% of parents expressed strong preferences to continue to participate in rounds, and 91.4% of parents felt staff attitudes had improved following their participation (Rotman-Pikielny et al., 2007). After a trial of different rounding formats, 81% of families with hospitalized children wished all rounds to be held at bedside to increase their participation in rounds. (Landry, Lefranaye, Roy, & Cyr, 2007). Comp (2011) conducted a meta-analysis indicating that parent involvement in bedside rounds consistently improved satisfaction and engagement in the future. Therefore, providing education, information, and communication to families improves their experience of hospitalization and their sense of involvement with their child (Burger, King, & Tallett, 2015). However, the method of communication and interaction also mattered greatly.

Although family-centered care is best practice, inequities still exist (Coughlin, 2014). There is often more weight and clout on the side of the providers compared to the families, and families can report feeling as if their opinions do not matter as much (FAC, personal communication, July 4, 2018). New vocabulary and more complex linguistic patterns distance families from their child's caregivers and decrease satisfaction (LeGrow, Hodnett, Stremler, McKeever, & Cohen, 2013). Small gestures such as the physician sitting down, or providing a summary of the medical information provided during the discussion were large factors in family perception of care (LeGrow et al., 2013). Researchers in another study researched the effectiveness of the Four Habits model, which advocated for: investment in the beginning by obtaining caregivers names and history, eliciting the parent's perspective, demonstrating empathy, and investing in the end with conclusion (Fisher, Broome, Friesth, Magee, & Frankel, 2014). Therefore, the method of education and connection is just as crucial as the content (Russel et al., 2014). Parents value the individual professional who is taking care of their precious child and value a relationship with that person. Therefore, the relationship and connection is as important as the care.

Parents also care about the individuals who are caring for their infant. Families make relationships with caregivers and come to trust their skills and their compassion. One non-experimental correlational study determined that pain management, parental involvement in care, trusting relationships, and staff attitudes were the best predictors of parental satisfaction during hospitalization (Matziou et al., 2011). One meta-analysis indicated that a blend of person-centered, family-centered, and culturally competent care had the best results for family satisfaction (Lor, Crooks, & Tluczek, 2016). This study further indicated twelve attributes which were essential for positive, holistic care: "collaborative relationship, effective communication,

respectful care, holistic perspective, individualized care, inter-professional coordination, self-awareness, empowerment, family as unit of care, interpersonal relationships, cultural knowledge, and cultural skills” (Lor et al., 2016 p. 352). Addressing parental needs through education within this method of whole-person attention and open communication can alleviate the feelings of trauma and improve the experience of hospitalization.

### **Parental Education Strategies**

A second way to promote family-centered care is through parental education, which supports the family-centered care tenet of information sharing. Family-centered care is a hallmark of best practice for neonatal units (Coughlin, 2014). Practitioners discuss how best to educate and improve the health literacy of families for carryover of skills. Goldstein (2013) discussed the benefits of practice and hands on training as all parents are adult learners with individualized needs. Desired topics included handling, reading cues, adjusting ages for prematurity, positioning, postural control, and follow up (Goldstein, 2013). Parents rated informational handouts as the least effective educational tool, unfortunately, they are the most common educational option (Goldstein, 2013). One program with strong research supporting family-centered care and parental education to improve carryover of skills is the Hanen Parent Programme (Baxendale & Hesketh, 2003). The Hanen Parent Programme focuses on language acquisition and facilitating the relationship between parent and child through coaching and reinforcement of reciprocal language production (Pennington, Thomson, James, Martin, & McNally, 2009). Family-centered care is essential in pediatrics as our goals are rarely for the child to achieve independence, but to facilitate skills and performance within the family context. However, with the diversity of family backgrounds, therapists must consider diverse strategies to meet their needs.

Sometimes families are speakers of other languages or from a different cultural background needing adjustment in educational approach (Nieuwboer & van't Rood, 2016). Furthermore, not only do NICU families vary significantly in their background and baseline understanding of health literacy and healthcare options, but they also come from all and socioeconomic and educational statuses. Addressing the individual's needs and health literacy level, particularly if there is a learning disability or communication barrier, is crucial for these families (Jones, 2013).

**Adult Learning.** Tapping into existing knowledge and making education focus on the learning instead of the teacher helps carryover of education (Brown, 2018). Many educators prefer to work 1:1 with families, however, more cost-effective group settings have been proposed and studied (Gilmer et al., 2016). Knowles, Holton, and Swanson (2015) offer six principles of andragogy, or adult education to improve adult integration of knowledge. Adults need to understand the why, or purpose behind actions and feel self-directed and responsible for the outcomes. The use of prior experiences increase carryover of new skills or learning and real life application or examples increases learner buy in. Lastly, motivation for learning is internal rather than external (Knowles et al., 2015). These strategies can be incorporated into program development to ensure the best possible use of the knowledge taught. Knowing the importance of adult education strategies and the crucial time-period of infancy allows the capstone student to see the need for education in this specialized population and provide an effective educational program to promote comfort and skill in parental occupations.

### **The Importance of Connection**

A third method to promote family-centered care is through personal connections with the families. Personal connections and compassionate interactions with families, relate to the



family-centered care tenets of respectful interactions and participation in care. Families consistently reported that they wished to have a relationship with the individuals caring for their children (Fisher & Broome, 2011). Using an inclusive approach and establishing interpersonal connections and nurturing relationships sustained positively perceived communication (Fisher & Broome, 2011). Furthermore, research has indicated the need for healthcare providers to be sensitive to the needs of families to avoid overwhelming them with information (Aarthun, Oymar, & Akerjordet, 2018). Each family has different resource and emotional capacities and may need modified interaction from caregivers (Aarthun et al., 2018). Therefore, education for staff members on the importance of therapeutic use of self, positive and healthy coping skills, and connection with families assists in positive communication and outcomes (Aarthun et al., 2018). These strategies allow families to view providers as allies, and vice versa, both working for the health of the child, instead of against each other. Every occupation in the NICU is a dance between the infant and the caregiver. Recognizing the necessity of co-occupations in infancy assists in addressing the desire for parents to step into the role of parenting.

### **The Co-Occupations of Parenting**

The latest data regarding occupation-centered practice in the NICU discusses the interplay of co-occupation between infant and parent or infant and caregiver (Gibbs et al., 2016). Parents often feel occupationally imbalanced or restricted due to the complexity of their child's needs. Education and facilitation of the infant/parent dyad is needed in this unique population to promote competent and confident occupational performance in both parent and infant (Goldstein, 2013). Occupations occur in relationship between an infant and a caregiver who listens to cues and adjusts accordingly (Poskey, Pizur-Barnekow, & Hersch, 2014). There is no other period during a person's life that is so heavily characterized by co-occupation than infancy (Poskey et

al., 2014). Occupational therapists help to guide and facilitate the partnering of parent and child in co-occupations (Price & Miner, 2009 a). A foundational skill is a parent's ability to read their infant's cues or communication. Infants demonstrate stress signs when overwhelmed by the environment or occupational demand, thus communicating to their caregivers the need for adjustment (Price & Miner, 2009 b). For instance, eating is an occupation which demands collaboration between the infant and the caregiver (An, 2014). The ability to feed an infant the necessary volume and make the experience positive to promote future skills in feeding is an art. Feeding benefits from co-occupation and adjustment of nipple, flow rate, position, pacing, and environment to maximize success and reduce anxiety for both parent and infant (An, 2014).

The skill of communication and co-occupation can be used when the infant is exhibiting stress or irritability (Poskey et al., 2014) as well as when the infant exhibits a desire to play or interact with his or her parents (Pizur-Barnekow, Kamp, & Cashin, 2014). Facilitating attachment and connection when an infant is upset reduces the risk of shaken baby syndrome and negative sequelae of injuries (Poskey et al., 2014). Conversely, facilitating attachment and reciprocity when an infant is playing creates pathways for learning and social and motor development (Pizur-Barnekow et al., 2014). Therefore, the ability to educate and facilitate co-occupations and communication between infant and parent not only addresses the restriction of occupations that can happen in the hospital environment in the present, but also provides the best possibility for long-term development well into the future (Pizur-Barnekow et al., 2014).

### **Occupational Justice**

Many occupations are restricted in the NICU. Parents are told their infant is too sick to be held or fed or changed. Parents are unable to fully express the role of parent due to occupational restriction by hospital policies or occupational marginalization by hospital staff. Occupational

justice is a theoretical model that promotes the inherent right of individuals to engage in occupations and addresses why occupations are at times restricted (Townsend & Wilcock, 2004). Occupations are paths to health, wholeness, enjoyment, and self-actualization and should not be restricted (Townsend & Wilcock, 2004). The restriction of important and valuable activities, roles, or occupations can vary based on longevity and severity of the restriction.

### **Types of Occupational Injustice**

Occupational apartheid, the most extreme form of occupational injustice, describes extreme situations where occupations are restricted to a subset of society based on factors such as gender, race, age, disability, or other personal characteristics (Durocher, Gibson, & Rappolt, 2014). Occupational deprivation is considered the most prevalent type of occupational injustice as it describes “a state of preclusion from engagement in occupations of necessity and/or meaning due to factors outside the immediate control of the individual” (Durocher, Gibson, & Rappolt, 2014, p. 421). Due to the prolonged restriction from engaging in occupations that could lead to health, the effects of occupational deprivation are long-term and pervasive (Durocher et al., 2014). Occupational deprivation commonly occurs in restrictive environments such as prisons, refugee camps, and health care facilities (Nilsson & Townsend, 2014). Families in the NICU are at risk for occupational deprivation as the typically valued occupations of parenthood are often restricted by the medical staff (Chinchilla, 2012).

Occupational alienation is described as a lengthy period of restriction from meaningful occupations or forced participation in meaningless occupations leading to feelings of isolation and meaninglessness (Durocher et al., 2014). Lastly, occupational imbalance is used to describe an abnormal allocation of time or energy toward one area of life often at the expense of other areas. In the NICU setting families experience occupational imbalance with the potential for

more severe forms of occupational injustice, such as occupational deprivation, depending on the length and severity of restriction of parental occupations. Although each type of occupational imbalance varies in prevalence and severity, all forms of occupational injustice affect health and well-being (Wilcock & Townsend, 2000; Malfitano, Gomes da Mota de Souza, & Lopes, 2016).

### **Summary of the Literature**

The current state of parents in the NICU is defined by occupational deprivation, stress, trauma, and a lack of co-occupations of parenthood. There is a great need for education to parents to improve their self-efficacy in the NICU. Occupational therapists can address these needs through education, connection, and facilitation of co-occupations. This capstone project will address the needs of parents whose infants are in the NICU through an educational program developed in conjunction with those who are best able to speak to the need and struggles during hospitalization, the parents of NICU graduates.

## **Chapter Three**

### **Methodology**

Parents often do not feel like parents while their infant is in the NICU. The occupations of parenthood are restricted and the role of parent is delayed. Trauma is experienced by both infant and parent and bonding is disrupted. One way to address the need of hospitalized families is through education. Program development in the NICU can address the needs of a unique community of parents to improve their self-efficacy and connection with their infant. Knowledge of the current experience of parents leads us toward creative solutions to enhance health literacy to equalize the partnership between parent and provider and therefore, to improve self-efficacy during hospitalization for parents. After thorough review of the literature and awareness of topics that proved helpful with this population, the capstone student sought feedback from those knowledgeable in this area, the families of previous NICU graduates. Therefore, this project was developed in conjunction with the Family Advisory Council at through regular monthly meetings from June 2018 to April 2019.

#### **Family Advisory Council Input**

The Family Advisory Council (FAC) at the hospital where the program was implemented was created in 2010 to assist in providing feedback to improve initiatives and patient experience. The committee split into two councils, a NICU specific and pediatric specific council in 2018 to address the unique needs of each population. The NICU FAC includes 15 persons and consists primarily parents of NICU graduates, as well as staff members who work in the NICU. Each member provided feedback throughout the course of this program development and implementation.

The capstone student met with the NICU FAC in July of 2018 initially to discuss the topics and organization of educational offerings. Family members present at this meeting discussed the feelings of being overwhelmed in the NICU environment and encourage the capstone student to provide immediate resources and offerings. Whereas, prior to the FAC meeting, the resources and capstone focus was on education to facilitate discharge and the transition home, the family advisors discussed the need to focus on parental mental health in the immediate context, within the NICU and offer resources within the hospital (FAC, personal communication, July 9, 2018). The need for more education regarding NICU specific medical terms was also discussed and organized. The FAC chose the topics and recommended the order of educational offerings. They also shortened the topics from six to four weeks stating that too much information could be overwhelming (FAC, personal communication, July 9, 2018).

Partnering with families exemplifies the collaboration tenet of family-centered care, where families have input into system wide education. Therefore, the capstone student took FAC feedback and began creating the program's PowerPoint slides to promote education and carryover of information (See Appendix B for more details). The NICU FAC provided feedback and reorganization to the slides in October of 2018 and January of 2019. The FAC provided critical feedback on wording of questions and improvements to the organization of slides for appeal and readability. They chose the medical terms that were most confusing and most in need of clarification to be discussed, and provided feedback on the tone of the educational offerings. Furthermore, the FAC reorganized the order of the topics to make them more suited to typical developmental progression.

Through consistent feedback and guidance from the FAC, a program was devised which would meet the needs of families through educational sessions. Offering weekly meetings with

rotating topics in a safe environment led by staff familiar to families allows for connections between staff and family and connection between family and baby. Through literature review and personal interviews with families who have experienced hospitalization, the following topics of education were repeatedly cited as helpful and necessary to understand the unique challenges of preterm parenting: orientation to the unit and medical terms, kangaroo care, positioning, infant communication, and feeding. This program was guided by the Kawa Model as a theoretical basis.

### **Kawa Model**

Although occupational justice guides the need for a solution to the problem of the restriction of parental occupations, a different occupation-based model was identified to guide weekly meetings and provide consistency to discussions. The Kawa Model, a theoretical model viewing life as flowing river full of assets, challenges, activities, and the environment, guided discussion about the sense of flow in each family's life (Leadley, 2015). Kawa, the Japanese word for river, provides a mental image for the flow of life. Life is "a complex, profound journey that flows through time and space, like a river" (Iwama, Thomson, & MacDonald, 2009, p. 1129). The river flow could be likened to the concept of wellness (Wada, 2011). Families with hospitalized infants experience blocked goals and dams in their rivers. They also have driftwood in the river, or assets and skills that will help them successfully navigate their time in the NICU. Exploring both categories will guide discussion of parental skills throughout this program. Sharing difficulties can facilitate with connections between participating parents and between parents NICU staff. The Kawa Model provided guidance to discuss maximizing future driftwood, skills, resources, and collaborators. It shifted the focus on the uncontrollable environment to an internal locus of control and can address the feelings of disorganization,

trauma, stress, and a loss of control often reported by families in the hospital. The Kawa Model helped to guide discussions and improve the river's flow of this underserved community to improve wellness in the near and far future of both infant and family. The overall goal of the proposed program is to provide educational sessions which help create confident, connected families who readily engage in co-occupations with their infants. It is believed by the capstone author that improving the family connection and education will improve carryover of education provided and will positively influence the infant's development and well-being as well. This program is aimed to address and enhance the current state of families in the NICU by improving the family-centered care approach, improving self-efficacy and engagement in co-occupations, and reducing the feelings of occupational injustice common among many families in the NICU.

### **Description, Setting, and Consumer Group**

This program is designed for parents of infants admitted to the NICU. They are representative of the community of Orlando at large as preterm birth can happen to anyone. They are united by the experience of a shared journey into parenthood that can be quite tumultuous at times. Therefore, education and clarify of expectation for the road ahead is crucial for this population to feel confident in their skills of parenthood. This program was advertised in every patient's room who met the inclusion criterion: parents and caregivers with loved ones on occupational therapy caseload with an expected NICU stay of at least one month. The educational sessions were held Mondays at 10 am in the NICU family resource room for ease of attendance. Four weekly rotating topics, supported by the latest research, which increased in complexity and included: the occupations of parenting, resources within the hospital, kangaroo care, handling and positioning, and infant communication skills. These topics applied to all hospitalized infants no matter their diagnosis. Limiting education to those on occupational



therapy caseload indicated a level of health and stability in the infant and prevents unsafe educational practices, such as training a family member to position and infant who is still intubated when protocols prevent movement for the sake of the endotracheal tube. Providing educational intervention on general principles common in preterm infants can prevent injuries and dispel the need for rehabilitation later (Jeanson, 2013). This would be best practice, in line with the tenets of family-centered care, and cost effective program development for this practice setting (Matziou et al., 2011). The current hospital practices fail to produce confidence in parents as reflected on parent satisfaction scores after discharge. Therefore, this program is essential to potentially help to fill the current gap in practice and skills.

**Inclusion Criteria.** This program was advertised to parents over the age of 18 whose children were on occupational therapy caseload and those who desired self-selected to attend the program. Although it was not required that family members attend all four educational sessions, the effectiveness of the program would be best tested in families who are able to attend all four sessions. Therefore, families with infants who had an anticipated stay of one month or more were encouraged to attend this program and used in the focus group post program completion for evaluation purposes. The topics offered were chosen and ordered with the guidance of the family advisory council, made up of families with preterm infants, and chosen to increase the feelings of confidence and self-efficacy in the occupations of parenting.

### **Program Description**

Through discussions with all the stakeholders, including hospital administration, FAC members, and NICU staff, an educational program was developed and implemented at a local hospital. As discussed above, the family advisory council was involved at all levels of program development and was the core stakeholder throughout program development. The FAC

helped choose the topics, order them, and co-created all literature, handouts and presentations to ensure that language, topics, and resources were family-friendly, appropriate for the population, and guided by those who knew the turmoil of hospitalization first-hand. The FAC decided upon four weekly rotating topics, which will be described below.

### **Week One: The Occupations of Parenthood and Resources**

A key theme in FAC parent's responses to interview questions was the necessity to address parental mental health during their children's admissions. In focus groups and interviews it was clear that families felt the initial days of their infant's NICU admission to be an overwhelming and information-filled time. They reported having difficulty assimilating new vocabulary and were unaware of resources even when they had been introduced due to high stress. They reported a desire to take advantage of resources within the hospital setting that could assist their journey. Awareness of common terms, conditions, diagnoses, and medical terms would help their ability to feel like an essential part of the care team. Likewise, awareness of resources such as chaplains, lactation consultants, social workers, educational meetings, support groups, and financial resources would sustain parents' abilities to care for their child and feel supported by the team.

Week one of this program would involve education on common terms, knowledge of available resources, and discussion of the Kawa Model including creating a physical image of one's own river. Discussing the rocks, barriers, and flow of the river provides an image and a starting point to discuss how and where occupational performance is hampered. Education on resources, driftwood, and allies along the journey of the NICU allows families to work in the spaces and improve occupational performance. These river images could be crafted or created as each parent desired with self-identification of rocks and driftwood. Such discussions set the tone

of this program to ensure all involved that leaders and participants are in this together and are working to maximize the flow of each person's river. The Kawa model discussion would further highlight the family-centered care tenet of facilitating partnerships between health care providers and parents to enhance their parental capacities and the health outcomes of their preterm infants. Sharing difficulties can help with connections between parents and staff and parents and each other. This aligns with the need for community assessment and capacity building to maximize the assets already present and allowed the members of the community to be active participants in planning their programs (Minkler, 2012). The Kawa Model provided guidance to discuss maximizing future driftwood, skills, resources, and collaborators, and could be drawn throughout the future topics as well.

### **Week Two: Kangaroo Care**

Kangaroo care is a method of holding an infant such that the infant is skin to skin against a parent's chest (typically the mother). This position is thought to improve the feeling of being in the womb as the infant is cradled, warm, and can smell and hear mom in unique ways (Ghavane et al., 2012). Kangaroo care is well-researched and has shown benefits in temperature regulation (Nimbalkar et al., 2014), weight gain (Ghavane et al., 2012), pain reduction (Freire, Garcia, & Lamy, 2008; Pinheiro da Motta & Chollopetz da Cunha, 2015; Tessier et al., 2009), milk production (Ghavane et al., 2012), maternal stress level (Correa Castral et al., 2012), and maternal self-esteem (Lee & Bang, 2011). These many and varied benefits are based on a relationship that no one else can have as according to hospital policy, only parents can kangaroo their infant. It is a special moment between infant and parent and can safely begin at a young gestational age. It should be encouraged within the NICU setting to help alleviate the stress and broken moments of bonding that often occur in the hospital. Infants are reliant upon their

families for care. Everything in the hospital is a co-occupation, or collaboration between two people for success. When collaboration and co-occupations are restricted, occupational imbalance occurs. Kangaroo care alludes to the benefits of proper positioning, but the topic of positioning would be dealt more fully as the focus of week three.

### **Week Three: Positioning**

A third topic of education to promote occupational performance in infancy would be proper positioning, which is both a science and an art. It can have a large effect on the outcomes of patients which we know from improper positioning. Poor cranial molding, torticollis, asymmetric movement patterns, anterior tilt of the pelvis, and hip dysplasia are all possible maladaptive patterns due, in part, to poor positioning in the NICU (Infant positioning and development, 2013). Conversely, proper positioning can promote temperature regulation, calorie conservation, reduce stress signs, improve midline orientation, improve postural flexion, maximize organization and state regulation for synaptic connectivity (Bellefeuille-Reid, & Jakubek, 1989). Proper positioning affects short-term and long-term outcomes and development and can prevent rocks from damming up the flow of one's river. When an infant is organized, and provided with positive input for neuroprotection, it can affect cognitive processing and milestone development potential for a lifetime (Grenier, Bigsby, Vergara, & Lester, 2003). Furthermore, in this practice setting occupational therapy typically does not get orders until 32 weeks post-menstrual age, or about two months preterm, at which point some infants have been alive for two months during which they could have been mishandled, malpositioned, with head shaping anomalies and a heightened distance between infant and parent due to the stress of the NICU (Hummel & Fortado, 2005). Perhaps, if more education is provided to parents, we could

prevent maladaptive patterns, support the infant/parent dyad, and decrease the need for rehabilitation through preventative education and care (Tanta & Langton, 2010).

#### **Week Four: Infant Communication and Feeding**

Occupations early in a preterm parenting include bonding, attachment, and responsiveness (VandenBerg, Browne, Perez, & Newsetter, 2009). Finger splaying, arching, gaze aversion, or sitting on air are examples of infant stress responses (VandenBerg et al., 2009). Preterm infants demonstrate stress signs and physical indicators of stress or discomfort and families must learn to respond to such signs appropriately to avoid increasing both their own and their infant's stress response (Whitcomb, 2012). However, these signs of stress are often different from full term infants. Preterm infants cry less due to the aerobic efforts that crying requires (VandenBerg et al., 2009). Instead, preterm infants are more likely to show discomfort and stress through stiff, extensor movements and facial expressions (VandenBerg et al., 2009). Improving parental responsiveness has been shown to optimize the infant's brain development in the long-term (Price & Miner, 2009 b). Furthermore, strong parental responsiveness skills decrease the risk of abuse and Shaken Baby Syndrome (Poskey et al., 2014). Therefore, involving the parent in the care of his or her infant, providing information, connection, emotional support, and guidance for infant responsiveness enables the occupation of parenting and can have strong positive long-term developmental and health effects.

The primary reason for delayed discharge from the NICU is feeding difficulties (Shaker, 2013). The co-occupation of infant feeding is heavily influenced by cue-based strategies to promote success (Shaker, 2013). Volume-driven feeding techniques can provide negative input to infants who are just learning how to regulate their swallowing and breathing mechanisms (Whetten, 2016). Therefore, a discussion about the importance of cues in infancy aligned well

with parental desires to address feeding needs. Week four of this program returned to the idea of the Kawa Model and concluded with a discussion of how the educational topics provided have altered the perceived barriers in each family's river flow.

### **Program Operations**

To make this program a reality supplies, staffing, and physical items would be necessary. Firstly, a reserved meeting space, a projector, and password protected recording device for program evaluation would be required. Secondly, administrative support to allow for staff to devote time weekly to this program would be essential. It would initially cut into productivity standards and other tasks for staff and administration would have to be on board to ensure success. This is one major reason that hospital administrators are such key stakeholders in this program development. The hospital stands to benefit financially if this program is a success as occupational therapy intervention would be provided in a cost-effective group manner instead of solely individually. Thirdly, supplies such as copy paper, toner, folders for easy reference, baby dolls for practicing of positioning or kangaroo care skills, and crafting supplies that parents can use to craft their Kawa river model are needed.

Additionally, awareness and marketing efforts to ensure parents attend this program are essential. Flyers, posters, and invitations would improve awareness and invite parents to learn more. Lastly, skilled staff members are needed who adapt as the needs of the group indicate and redirect to the topic at hand. Not any staff member could step in and run such groups smoothly. Training and practice leading programs benefits all involved. These supplies, support, staff and skills would allow this program to be implemented and evaluated to see how effectively it met the proposed goals.

### **Evaluation Foundation**

Program development is incomplete without a plan for program evaluation. Therefore, after the needs assessment portion of program development and thorough discussions with stakeholders, program developers must begin the arduous process of determining how to track, measure, and define what it is they hope to change through this program. Incorporating a theory of change and ensuring all stakeholders' opinions and perspectives are addressed are crucial for program evaluation.

### **Logic Model**

A logic model is a method by which one can organize and draw connections between the inputs, outputs, and outcomes in a program. All programs require inputs or resources to begin and continue. Inputs would include staff time, expertise, and efforts to organize and run this proposed program. Furthermore, hospital administration support and funding to allow for space, snacks, and staff time to be devoted during these weekly meetings. Inputs allow the program to begin; components or activities define the crux of the program, which in this case are educational resources and practice. (See Appendix B for the logic model diagram).

Activities would primarily be the weekly education groups covering topics necessary for parenting preterm infants to help prepare parents for discharge including activities of daily living, kangaroo care, infant communication, and bonding. Education on the idea of the Kawa model would bring the idea of the river's flow of occupation both now and into the future. Parent interviews would take place to provide feedback at the conclusion of this program. This provides a natural feedback loop to better the activities and educational delivery for the needs of these families.

Outputs are the results of the activities. In this case, the recorded output was the number of parents in attendance. Other longer-term outputs for future study could include decreased length of stay due to improvements in parent education and self-efficacy. Outputs mark the transition between the program and the evaluation or outcome phases of program development.

Although the program would be provided solely within the NICU environment, the outcomes would span the inpatient, home, and broader community environments after discharge. The desired outcome of this program was to create parents with strong self-efficacy measured by their own words through qualitative research. Measurements on this desired outcome would help to revise enhance family-centered service delivery in the unit and determine the effectiveness of the program.

In this way, following the logic model, this program addresses the current state or problem of ill-equipped, unconfident, disconnected parents and the subsequent parenting limitations. This program seeks to interrupt the current cascade of negative emotions and instead potentially provide positive outputs and outcomes for the near and distant future.

### **Theory of Change**

The large goal for this program is to improve parental self-efficacy and thereby improve infant health and wellbeing. Although the context does not allow for such long-term measurements of outcomes, they are the desired outcomes nonetheless. Theory of change takes a wide angled lens view of the context and addresses the needs and desires of a broad range of stakeholders and create motivation to result in long-lasting change (Doll, 2010). For instance, the stakeholders in this program are not just parents, infants, and bedside staff, but should also include the administrators of the children's hospital as well as the rehabilitation administrators (Minkler, 2012). Having a coalition to move toward change and culture shift is imperative



(Kotter, 1996). Shifts in culture require buy in from a variety of sources, which often have competing goals. For instance, the children's hospital administrators seek improved patient experience and shorter length of stays to help the budget and metrics they track regularly. Whereas, the rehabilitation administrators focus on improved productivity and discharge planning from their rehabilitation employees because these are tracked by their metrics of progress. These two groups can compete at times, however, both desire improved family bonding and function for the infants. They both desire health, they may just take different paths and track different measures to arrive at that goal. These stakeholders do not fit in the neatness and linearity of the logic model, yet they have significant impacts on the success of the program and are rightly incorporated into the theory of change model.

### **Holistic Model**

A holistic approach can be defined as “seeking patterns that provide an overall understanding of the evaluation data, including an integrating the perspectives of different stakeholders.” (McDavid, Huse, & Hawthorn, 2013, p. 201). A keystone of holistic evaluation is the fact that stakeholders are key components from start to finish. Beginning with the needs assessment and extending throughout the program evaluation, a holistic evaluation approach is stakeholder-centered. It acknowledges the dynamic nature of program development and evaluation and consistently adjusts for the feedback received (Chen, 2015).

Before beginning program development, the stakeholders consulted for this program were: The Family Advisory Council, made up of family members of NICU graduates; hospital administrators, both of rehabilitation and the children's hospital, who would allow time and space for the program. Further stakeholders included: bedside staff and members of the Developmental Care Committee, who would assist in designing and administering the program;

and families, who would benefit from the program. Families were interviewed both whose children were currently admitted in the NICU and those who had NICU graduates at home. For this program's design, effectiveness should be measured, not efficacy, as we desire real world outcomes, not research/ideal outcomes (Chen, 2015). Therefore, the interviews of all stakeholders, as well as those who understood the complexity and stress of the NICU, but were no longer in the same setting assisted in encouraging program design around the idea of effectiveness, that is, asking the question: Would this program help the families that we interact with every day? This question is contrasted with the idea of efficacy, which deals with ideal or clinic-based environments for intervention (Doll, 2010).

Program development is a dynamic process that is consistently in flux and adjusting for the needs of the program beneficiaries, budget needs, and cultural shifts. But no matter the changes, program development should both start and end with a consideration of the stakeholders and with the promotion of the tenets of family-centered care. Many families were consistently involved in developing and allowing this program to flourish and their opinions mattered. Monthly meetings of the capstone student and the FAC were held throughout the development, implementation, and evaluation of this program. Family-centered care is not complete without the opinion and feedback of actual families being held in the highest esteem. The people for whom the program is being developed should be able to report how the program was helpful and what areas need further investigation or revision.

### **Program Evaluation Questions**

Families reported feeling underwhelmed at the hospital's preparation for discharge in preliminary interviews (FAC, personal communication, July 9, 2018). Therefore, a parental education program was developed to fill in these needs in the NICU. Through participation a

four-week parental education course, it is believed that parents will feel more confident in their parental occupations. The questions seeking to be answered through this program development and subsequent measurement are:

- Do parents demonstrate self-efficacy in the occupations of infancy after intervention?
- Do parents feel more confident and connected in their parenting skills with more education?

There are several ways to answer these questions through program evaluation, which will be discussed and a recommendation provided.

### **Methodological Approach for Program Evaluation**

Although there are many options for measurement and program evaluation, for the purposes of this capstone, program evaluation will follow a qualitative design with focus groups of program participants which will help guide future intervention and revision of the program. This program was considered a pilot study of a possible new offering within the rehabilitation department. The feedback from the focus groups and interviews will guide revision and future education for families.

### **Qualitative Method**

A method to measure program efficacy is through interviews, focus groups, and thematic coding to look for themes in discussion (Creswell, 1994). Qualitative research has been used extensively with program evaluation in other settings including measuring cultural adaptation in Native American families and rehabilitation of young sexual offenders through program development (Roulette, Hill, Diversi, & Overath, 2017; Draper, Errington, Omar, & Makhita, 2013). Qualitative methods through interviews and focus groups in the above studies helped to

indicate the effectiveness of the programs designed to assist in and cultural sensitivity and recidivism reduction (Roulette et al., 2017; Draper et al., 2013). Therefore, a variety of stakeholders could be interviewed to show program effectiveness through qualitative research.

Qualitative research involves guided interviews, coding of such interviews to draw out themes and repeated narratives (Roulette et al., 2017). Qualitative research is beneficial because it allows quotes and direct words from those benefitting from the research to be included in the discussion. It is often also done in a natural environment, such as a person's home instead of a sterile research facility (Creswell, 1994). Qualitative through focus groups, coding, and thematic observation is an excellent option for program evaluation in this situation.

**Focus Group Prompts.** Parents who self-selected to participate in this program were invited to one of two focus groups that were conducted by the capstone student after the conclusion of the program in the same time and location as the program for ease of attendance. If families were unable to attend a focus group, they were interviewed bedside and the results were likewise transcribed. Each focus group or interview was recorded, transcribed, and thematically coded by the capstone student to provide feedback, assessment, and guidance for future programming. The focus groups were recorded with a password protected digital audio recorder and families were informed regarding the purpose of program evaluation and were able to opt out of participation if desired. This capstone was a quality improvement measurement at the hospital as it is a way to improve the quality and offerings of a core tenet of the hospital: family-centered care. The following prompts were used to encourage discussion during the semi-structured focus groups and interviews:

- What has it been like to have a baby in the NICU?

- Where have you felt the most restriction of flow in your river of life during this time?
- How have you grown as a parent over the past month?
- How confident do you feel caring for your child?
- What was most helpful to learn about during your NICU stay?
- What encouraged you to attend this program?
- What made it difficult to attend the program?
- If you could determine an ideal day and time for this program what would you suggest?
- How could the educational topics or structure of this program be improved?
- What do you most wish you would have known when your baby was born?
- What advice would you give future parents with children in the NICU?

The interview prompts allowed families to discuss where they started from, where they are now, and what they hope for the future, thus encouraging the ongoing role of parent and promoting occupations in the future. This capstone project educated families about a narrow portion of the river with a desire to affect the flow of the river far in to the future. Feedback from families who participated in the program will allow revision and improvements for future families.

### **Institutional Approvals**

Prior to initiating this program and evaluation approval was received from the capstone student's advisor and the Nova Southeastern University Institutional Review Board (IRB) for human subjects. All participants who chose to attend signed informed consents after a thorough discussion with the capstone student who was also the primary investigator. Institutional approval from the director of the neonatal ICU as well as the director of rehabilitation was

received in writing. Care was taken to ensure minimal psychological risk for the families who chose to participate in this research. The primary investigator abided by the IRB guidelines throughout the program and all paperwork including informed consents will be stored securely for thirty-six months. With all the necessary regulatory, safety, and institutional approvals in place, the primary investigator then began the recruiting participants for the program.

## **Chapter Four**

### **Results**

Although the program was well researched, approved by all necessary parties and designed to improve the self-efficacy of parenting in the NICU, it had some unexpected barriers. Attendance was lower than anticipated and a few unforeseen barriers including changes in acuity and fluctuating rounding times limited participation, which could affect the effectiveness of the program. The program was modified to provide maximal benefit to all participants. When group sessions could not be attended, education was provided individually bedside and interviews were performed regarding barriers to attendance and feedback on education provided. Details of the recruitment, participants, and qualitative feedback will be discussed.

### **Recruitment**

The inclusion criterion for this program indicated that family members, over the age of 18, of patients on occupational therapy caseload with an anticipated length of stay of one month or more would be invited to the program. The family members then could self-select to attend. Each week the primary investigator would ensure that all who met the inclusion criterion were personally invited to attend the program and given the chance to ask questions regarding purpose and logistics. Throughout the course of this pilot study, 99 families were on occupational therapy caseload. The primary investigator invited all in person if possible, and if no family members were present, left a flyer with details about purpose, goal, and location of the program. Of the 99 eligible parents, 20 were bedside and able to meet with the capstone student to be personally invited to the program. Twelve parents signed informed consent and agreed to participate in the program. Of the 12 parents who signed informed consent, none of their babies were discharged

prior to the end of the program. Thus, there were not barriers identifying babies with an anticipated length of stay of one month or more according to the inclusion criterion.

Recruitment was an ongoing feat beginning two weeks before the start of the first session and extending throughout the program. The occupational therapy caseload was revisited weekly to ensure all families had the opportunity to attend. Each week approximately five new families met the inclusion criterion and were likewise invited to the program. Other disciplines and therapists assisted the primary investigator in identifying and recruiting possible participants. The capstone student is confident that all who met the inclusion criterion during this study were provided with information about the program and an invitation to attend.

Of the 20 parents who were personally invited by the capstone student, 12 agreed and signed informed consent, three declined immediately, and the remaining five initially indicated interest in the program, but later did not sign informed consent or attend the program. The primary reasons given for why families declined participation were: the time and day of the program, the stress of the NICU, and the anticipation of an imminent discharge. Some families reported that Mondays or mornings were difficult with a work schedule or traffic. One mom misunderstood the date and arrived on a Sunday. Psychological stress due to hospitalization is an ongoing barrier in the NICU environment; this reportedly affected some family's participation in the program as it felt like adding another thing to an already full plate. Other families who were invited reported that they anticipated their baby would be discharged within the week. One mother declined participation as the admitted infant was her seventh child and she felt she knew enough about the occupations of parenting without this program. All other families who were personally invited to the program reported that they thought it was a good idea and would be helpful. Responses to invitation was overwhelmingly positive. Small gifts, snacks, and



encouragement were provided to increase attendance. (See Appendix D for details on participants)

### **Participants**

During the recruitment portion of this program a few trends were seen by the capstone student. First, the majority of families were not bedside and, therefore, unable to be invited in person. Overall, the informational flyer had little impact on attendance. Families were far more likely to attend if invited personally and if they already had a relationship with the capstone student. Secondly, although detailed statistics about the health of the infants in the unit were not kept, anecdotally the families who were bedside and personally invited tended to have children with the highest acuity. Their infants required more oxygen intervention, had more status changes, underwent multiple surgeries during the month of program implementation, and necessitated more intervention overall. Therefore, these families may have spent more time bedside because of the illness of their children. They also verbalized difficulty attending the program due to changes in status for their child and a desire to attend rounds each day to know the ever-changing medical plans. Of particular note, was that in three instances, the families who had signed informed consent and verbalized commitment to the program, had significant changes in plans or received negative news about their infant during rounds Monday mornings and missed the program due to “a need to clear my head after those changes” (T.H., focus group personal communication, March 1, 2019). These factors affected the parents’ ability to attend the program with consistency. All families who signed informed consents remained positive about the purpose of the program and verbalized a desire to attend the following week after one session was missed. If a session was missed, the primary investigator met bedside with the families during occupational therapy sessions to provide education and information. Throughout the

course of the program, twelve parents signed informed consent, three attended the program, and the other nine were provided bedside education.

Regarding the community within a community in the NICU, ten of the participants were biological parents and two were adoptive parents. One participant was a mom of twins, all other infants were singletons. One mom was a non-English speaker and interpretive services were used for all education provided. Eight mothers and four fathers participated. When a father participated in the program it was always in conjunction with the baby's mother. When a mother participated, it was equally likely to be with or without a partner. The ages of participants ranged from 20-39 years old. About half of the families lived in another county and therefore, were eligible to stay at the Ronald McDonald House while their child was hospitalized, which they took advantage of. The methodology of this capstone project did not define methods of gathering or controlling for such demographic variables in analysis, however, awareness of many factors about the make-up of any community is helpful for future programming.

**Attendance.** This program included four weeks of classes and two focus groups to allow for data collection. Weeks one and two, no families attended, but two staff members attended to learn more about the program and its design. Week three no families attended, however, three families contacted the capstone student to apologize for missing, explain why they missed the session, and ask if they could get the handouts. The capstone student provided handouts to all families who signed informed consent in a notebook for easy reference, even if they did not attend the program meetings. This was paired with an invitation to attend the following week and ensure that all families who were interested felt "caught up" on the topics and able to attend the following Monday. During week four, three parents and two staff members attended. Focus groups captured the data from three parents, interviews gathered data from an additional five

participants. One family gave feedback specifically focused on the barriers to attendance due to time constraints or their own stress levels. One infant had a significant status change and was placed on hold for OT services, therefore, his mother was outside the inclusion criterion at that time. Finally, one father returned to work in another state and was unavailable for interview, but his wife participated in the program and the first focus group. Therefore, qualitative data were collected all families who signed informed consent and met inclusion criterion throughout the program's duration, either focusing on their feedback on the program, if they attended, or focusing on the barriers if they were unable to attend. (See Appendix D for more details about attendance).

### **Program Feedback from Participants**

Focus group data were recorded on a password protected device and transcribed for analysis. The capstone student then coded repeated themes in the data to identify trends in feedback. These themes and trends were then reviewed by the capstone student's advisor for consistency of interpretation. Of interest to the capstone student was the ways in which parents readily used the language of Kawa such as rocks, driftwood, barriers and assets in their feedback when interviewed. Families had strong feelings about the stress and shame of parenting in the NICU, the desire for education, the benefit of connection, and the necessity for self-care and celebrating small victories.

### **Stress in the NICU**

All families interviewed reported finding the NICU environment stressful. Several were confident that their son or daughter was getting excellent care and that "this was the ideal place for them," however, they did not find the environment easy to navigate (L.L., interview personal communication, March 1, 2019). When responding to the question, what has it been like to have

a baby in the NICU, one father responded, “A struggle. The struggle is real. Sometimes we feel like we’re not real parents. We can change a diaper, but that’s it. It just doesn’t feel the way we thought.” (C.W., interview personal communication, February 14, 2019). Another mom agreed that parenthood felt differently than she imagined saying, “I’m definitely not the mom I want to be. I want to do everything for them and I feel like that was taken away from me. Yes, I am their parent, but I can’t be here all the time and make all the medical decisions for them.” (K.B., interview personal communication, March 26, 2019). Another mother used Kawa language in her response saying, “Being away from [my son] and in Tampa. Being alone here. Being away is a big rock.” (L.L., interview personal communication, March 1, 2019).

All families interviewed reported that life was stressful in the NICU. Stress and changing levels of stability and acuity was also the primary reason reported for missing a class. Three families contacted the capstone student after missing week three’s class to explain that they received difficult news during rounds and felt the need to stay with their baby who was currently unstable instead of attending the class. Stress affects nearly all aspects of parenting in the NICU. Furthermore, many families verbalized feelings of shame and guilt that their baby was unstable or admitted.

**Parental Shame.** Many families reported difficulties with guilt and shame throughout the NICU stay. This language was more common among the mothers interviewed than the fathers. One mom felt guilty for leaving for any feeds even though she lived far away. Others felt responsible for their child’s current health condition. Several families used the phrase “good mom” or “bad mom” when talking about balancing caring for their infant and caring for themselves. Brene Brown is a researcher who focuses on the effects of guilt and shame. She distinguishes the two topics in this manner: guilt means I did something bad, shame means I am

bad (Brown, 2012). The parents in the NICU focus groups used shame language by indicating their choices made themselves or others feel like a “bad mom” indicating the movement of negative feelings from situation to personhood.

One mom feared, “I feel like if I need to miss a feeding just to get out, they’re gonna say I’m a bad mom. So, I try to be here for every feeding, but my husband had to go back to Chicago so I’m here by myself.” (B.G., focus group personal communication, March 4, 2019). The other family present at the session responded:

Trying to leave and take time for yourself is a brick wall that you have to break through. You will break through it, but it will take time! The initial overcoming of the feeling that you’re a failure as a mom is tough. It was nice to have more than one person say, “Yeah you’re a good parent and you’re doing what is best.” Because I thought all if it was my fault. I could have controlled my diabetes better. I could have exercised more and not drank that coffee and if I had done all of that my baby would have been full term and would have not been born early and wouldn’t have spent the first six weeks of his life in the NICU. [My husband] has had to talk that out of me, it’s crap ton of myths. (J.H., focus group personal communication, March 11, 2019).

Another mom sought to help other families fight parental shame with her advice, “For future families I would give the mom’s advice that it’s not your fault that your baby is in here. Don’t be afraid to move and change diapers.” (C.K., interview personal communication, March 4, 2019). Her husband responded, “Yes, fight for your baby. Ask all the questions.” (C.W., interview personal communication, March 4, 2019). Most families reported having to work through their feelings of stress and shame throughout the NICU stay. None reported absence of

these feelings and many reported feeling supported throughout the education provided in this program.

### **Quality of Program Content**

All participants were asked for their feedback regarding the quality and medium of education provided in this program. Responses were overwhelmingly positive whether the education was received verbally (attending live classes) or printed (notebooks provided if classes were missed). Families commented when interviewed: “Your notebook is like a NICU journey binder. It’s awesome.” (C.W., interview personal communication, February 28, 2019). One mom even used the information provided to assist in educating her older children in medical jargon and diagnoses.

I’m putting all the initials for diagnoses on Facebook and I’m telling other people what they are. I’ve done a lot of googling, but I don’t recommend people doing that. Actually, your book had a lot of sayings and words in it and I used your book to help explain things to my other kids when they had questions. They would say, “Is he okay?” And I used the notebook to help them. (C.J., interview personal communication, March 11, 2019).

All families interviewed reported reading the information and using it when interacting with their infants. The definitions and the education on stress signs were the most heavily praised sections of the program.

One couple appreciated the multimodal design of the program with integrated visual, auditory, and kinesthetic practice. When asked about the amount and type of education, this couple responded:

- (D.H. Dad) It’s not too much, and definitely not too little. It works.

- (J.H. Mom) You have it very well organized. You hit key points and humanize it. Anyone can follow and understand it. It's not just, "Here's all the information about baby. Absorb it." You have it broken down and we can absorb it.
- (D.H.Dad) With the sleep deprivation... I like that it's dumbed down. it's helpful to have it in laymen's terms. (D.H.and J.H., focus group personal communication, March 4, 2019).

Therefore, although the program was not well attended, the capstone student believes that many families benefitted from the program design and content. Parents consistently discussed the benefits of education, and believed that beginning such education earlier in their stay would have been beneficial.

**Timing of Education.** Families consistently responded positively to the handouts and booklet provide throughout this program, whether they could attend the classes or not, they reported finding the information helpful. One mom said, "Yes, everyone needs this. I fully support it." (C.W., interview personal communication, March 1, 2019). Another parent concurred, "More of this. And earlier. I had questions and this would have helped so much to have this resource because I have a lot of rocks, huge ones." (L.L. interview personal communication, February 19, 2019). The theme of the need for earlier intervention continued, "Have families come earlier. Straight away. From the first week, start learning stuff." (C.W., interview personal communication, March 4, 2019). One mom, who had one of the longer length of stays commented, "I think it's a good amount of information. The only thing I would say is that if you would have given me that book when I first got here, I would have felt more

confident.” (C.J., interview personal communication, March 11, 2019). One family who was discharging the last week of class commented,

I think also having something like your class at the beginning, even though when you get to the NICU everything is overwhelming and overstimulation, at the same time the class at the beginning of the stay, having that option to participate at something earlier than at the end of the stay would be beneficial in my opinion, so that when we’re sitting in here and listening to rounds and has tubes coming out of every orifice, we have a sense of knowledge that it’s not just jibber jabber jargon. You have the book, you have the definitions and you have cues to survive the whole time. This information is giving confidence when you have no control over your child. (J.H., focus group personal communication, March 11, 2019).

Parents consistently reported a feeling of confidence with education, which is consistent with the goal of this program. This addressed the proposed goals of improving parental confidence and self-efficacy desired for this program. Therefore, although the attendance was sub-optimal, the goals were still addressed during this program implementation.

### **Importance of Staff Connections**

Another goal of this program was the importance of connection between families and caregivers. This program was designed to bring families with unifying factors together and allow support to emerge from the discussions of their children’s unique needs. However, the data consistently reported the importance of connection, but with staff instead of with other families. Parents consistently reported that their bedside nurses were vital and crucial in their experience in the NICU. One mom responded during interview, “Yeah, the nurses have been vital in the day



to day survival of not only the baby, but for our sanity.” (J.H., focus group personal communication, March 4, 2019).

One mom discussed the benefit of occupational therapy for her son’s experience, “People like you have been such a huge resource and asset to me. [My son] has a fatal diagnosis, but you come and stretch him and make him comfortable and add life and comfort to him.” (L.L. interview personal communication Feb 19, 2019). This mom continued to discuss the importance of connection not just for her son, but for her experience as well, “I mean through the people here, like you, and I absolutely love his nurses. They’ve become friends...A friend, where I don’t have any friends here.” (L.L., interview personal communication, March 1, 2019).

Another mom reported finding friends in the staff members when her own friends were not available,

The nurses and talking with the nurses or for instance you. Any of the staff around here has been a big support system. And my husband. Even though I have 8,000 friends, when I go to look for them, they’re lost in the woodworks. I’ll post stuff on Facebook and they’ll comment like I’m here for you if you need me, but when I ask them to help, they’re nowhere to be found. (C.J., interview personal communication March 11, 2019).

One mom reported feeling cared for by the staff just as much as her twins were. “[The nurses] have been supportive and listened to me vent they’ve done everything. Not only are they taking care of them, but they’re taking care of me too.” (K.B., interview personal communication, March 26, 2019). This mom spoke highly of the nurses who cared for her twins and promoted self-care for parents as well.

### **Self-Care and Celebrating Small Victories**

One other theme that was heavily saturated in the data was the importance of self-care and celebrating small victories. Nearly all families interviewed had the same response to the question “What advice would you give future parents in the NICU?” as they consistently responded, “Take it day by day.” Many families elaborated to discuss the importance of self-care and celebrating even the smallest of victories to maintain positivity and forward movement. Here are three parents’ responses to the above question:

- I would definitely say to take it day by day. Don’t over analyze. Definitely find some kind of support because it’s a big thing. And take time for yourself. Me, I struggled with that. My husband helped me. I felt like a piece of shit because I couldn’t be here. When I leave here, knowing that my child is stuck here. Taking time for yourself is hard. I left a few weeks ago and got my hair done and then sat in the chair and felt guilty for getting my hair done. I texted one of the girls and asked, “How big of a POS would I be if I went on vacation for a few days and left him in the hospital?” (C.J., interview personal communication, March 11, 2019).
- Just take it day by day. Your baby is in the best possible care. It is the best possible place that they can be right now. Trust the nurses, trust the doctors, but always ask questions and don’t ever feel embarrassed by your questions or unconfident in talking or unconfident in your role. You and only you can take the best care of your baby. (L.L., interview personal communication, March 1, 2019).
- Take it day by day. Celebrate the small victories and don’t let any set back get you down. It is a roller coaster. You’re gonna have your highs and lows and everything in between so any little victory, celebrate it. It took us a little bit to

learn that and it helps bring up the morale. (T.H., interview personal communication, March 4, 2019).

Not only did families respond with similar themes to this prompt, but they used very similar language. The balance between parental shame and the need for self-care also emerged as many parents discussed guilt when taking time away from their baby. Self-care needs voiced included haircuts and showers, a full night's sleep, or a need for time away for improved mental health.

One mom articulated her self-care needs when asked:

In the beginning, I didn't [practice self-care]. I was focused on them all the time, I'd be here all the time, but then after a while, I made sure that even if I didn't want to I'd make time for myself even and wouldn't think about them, even if that sounds harsh. I'd take a long shower and just listen to some music or something...Almost like take a nap from it, rest again, and come back and regroup. If it's a constant and I'm always, always thinking about it, it wears me down a lot. Having a few hours just to not think about it was helpful. (K.B., interview personal communication, March 26, 2019).

The capstone author asked if this mom was encouraged in her self-care. She indicated that she had to be reminded and that hearing about the importance of self-care from a medical professional was particularly helpful saying, "Actually hearing it from them, it didn't make me feel like a bad mommy. If I'm not 100%, I can't be 100% for them." (K.B., interview personal communication, March 26, 2019). The type of self-care reported or valued varied from person to person, but the need for day to day celebrations, time away, and a chance to express the roller coaster emotions was a strong theme in the data.

### **Qualitative Program Evaluation Summary**

All families interviewed had some responses which could fall into one of the above categories. There was a high level of agreement among families with a variety of backgrounds and with children of different diagnoses and ages. All agreed that the NICU was stressful and shame-inducing at times. All agreed on the benefits of education and the recommendation for earlier institution of this program. All families discussed the benefits of staff relationships and self-care. Therefore, although this program yielded a small sample, the consistency of the qualitative data was encouraging as the results may also be true for larger samples sizes, thus for increasing generalizability in the future.

## Chapter Five

### Discussion

Many researchers have discussed the impact of a NICU stay on parental mental health and stress levels, both in the NICU time-period and beyond (Treyvaud et al., 2014). Treyvaud et al. (2014) found that parental stress from the NICU continued up to seven years post discharge. The findings of this program evaluation were consistent with the body of literature presented in this paper. All parents who participated in this study reported feeling stressed and overwhelmed in the NICU environment. Several families voiced feelings of shame over the diagnoses or fear of an unknown future. This, too, was consistent with existing literature (Barr, 2015). However, although the capstone student was aware of the literature regarding parental stress, the presence of such stress affected program attendance in unforeseen ways. The program evaluation data in this study was consistent with the literature on the presence of stress during hospitalization and the disruption caused by such stress (Barnes & Adamson-Macedo, 2007). Families consistently report living in survival mode (L.L. interview personal communication, February 28, 2019) One mom reported, “Parental hazing, yes, that’s a good word for it!” (J.H. focus group personal communication, March 4, 2019). The idea of post-traumatic growth was also present in parents’ responses as many indicated they were stronger because of their trials and struggles during the NICU stay.

Similarly, this program evaluation and qualitative data corroborated existing data regarding the importance of staff connections (Matziou et al., 2011). This data reinforces what has been previously shown: that families and staff bond due to the stress, complexity, and often lengthy hospital admissions and that these relationships are important for parental experience (LeGrow et al., 2013). Previous studies indicated the benefits of families feeling connected to

those providing care to their infants (Fisher & Broome, 2011). Families in this data as well as the literature broadly reported the importance of participation in rounds and decision making even in stressful situations (Rotman-Pikkielny et al., 2007).

What was most interesting was the fact that all families interviewed reported the importance of staff connections, but did not indicate the same level of connection to other families in the NICU. The capstone student hypothesized that a large benefit of this program was the chance to get families together to discuss their barriers with others who would understand. However, parents consistently reported that the bedside nurses and therapists, rather than fellow NICU parents, were their greatest support systems in the hospital. This may explain why the program was effective in group form as well as individual form as the families felt connected to the capstone student more than other parents during admission. Further investigation of this trend is warranted.

Thirdly, the theme of the importance of self-care and celebration of small victories emerged in the data. Interestingly, the FAC recommended more intervention regarding parental mental health from the start of this program's development. Families discussed traditional types of self-care such as showering, eating a meal, and getting some sleep and they also discussed methods for self-care of their heart and spirit such as clearing my head, seeking support, and taking a vacation. It also appeared from the data that celebrating small victories for their infant was a form of self-care to keep hope present despite the stressful environment. There is strong evidence of the value of self-care in general and more research regarding health, wellness, and emotional wellbeing has emerged in recent years (Brown, 2017). One research article on the importance of self-care specifically in the NICU family population was identified (Mendelson et al., 2018). Mendelson, et al. (2018) discussed the benefits of mindfulness as a method of self-

care for psychological distress for mothers in the NICU. The cited study was a pilot study published in December 2018, suggesting this is an area of future research worthy of more study. Furthermore, as one mom reported, the encouragement from nurses for her own self-care was profound. Further research investigating the connection between caregiver relationships and parental self-care encouragement would be warranted from this data as well.

### **Project Strengths**

This program was designed to meet families at a time of intense stress and provide education, connection, and confidence. The ability to put words to the stress that many families are feeling and have a space to connect with others was beneficial. Multimodal education was also a strength as it allowed people with a variety of learning styles to read, hear, and practice what were likely new skills in a nonjudgmental environment. Several parents remarked that the slides were easy to understand and even usable for third parties including grandparents and siblings when they had questions. Thus, the level and type of education was appropriate and improved the health literacy of the audience. As discussed earlier, health literacy has a large impact on health and wellbeing (Muscat et al., 2017).

A significant strength of this program was the work in conjunction with the Family Advisory Council throughout design, implementation, and evaluation. The FAC members provided direction on topics chosen, order of education, method of education, time of day, and preliminary results about program evaluation were shared with them for debriefing and future options. This program was created by those who were most knowledgeable about the environment and stress of the NICU, parents of NICU graduates. However, as with any program, strengths are balanced with limitations. The project limitations as well as implications for future practice, research, and education will be discussed.

### **Project Limitations**

The primary limitation of this program was poor attendance. Although significant efforts were made to make all eligible families aware and for an easy to attend time frame between handling times, this time slot proved difficult for many who signed informed consent and verbalized commitment to the program. One mom asked for a text message reminder just before the class started as she wished to come, but felt overwhelmed with the amount of information told her each day and she feared losing track of time and missing the class. The primary reason why families reported missing a class session was receiving bad news during rounds or fear of a change in status encouraging them to remain bedside with their infant. Three families contacted the capstone student after missing a week of class to ask for the information, explain their absence, and apologize for missing the program.

A second factor limiting the participation was the narrow inclusion criterion. The rehabilitation administration felt strongly that this program was offering a skilled service and, therefore, all families invited should be on occupational therapy caseload. However, this shift had a few negative effects. First, since the inclusion criterion mandated that families invited had to have infants on occupational therapy caseload, the program could not be freely advertised on the unit. Rather, each family had to be individually invited to ensure all aspects of the inclusion criterion were met. This greatly limited the methods of advertisement such as NICU calendars, posters in family lounges, and word of mouth from nurses. It increased the burden of invitation on the primary investigator. Secondly, all families interviewed reported wanting information earlier. Since infants do not typically receive OT orders until about 32 weeks postmenstrual age, some families were admitted in the NICU for several weeks to months before being eligible for this program, thus, delaying information and education. Due to these factors, it would behoove



the capstone student to revisit this requirement with rehabilitation administration. Providing earlier intervention, education, and resources to families, even prior to occupational therapy orders could promote preventative and habilitative care instead of rehabilitative care. This shift could empower families to engage with their infants at earlier ages, improving bonding, and even infant health and development during hospitalization and after discharge.

Even though attendance was less than expected, families still benefitted from the program through individual education on the program topics. All families interviewed found the information helpful, easy to understand, and immediately integrated in their care for their child. However, due to stress, changing acuity levels, and difficulty arriving at class time, attendance overall was less than expected.

### **Future Options**

Parental stress and shame disrupted consistent participation in this program. Although this data is important for practice, research, and education, it did directly impact the effectiveness of the program as well as the number of families who benefitted from the work. The program can be modified based on the data from this pilot study. There were three options discussed with the families and the FAC moving forward based on the data collected. Each will be described below along with benefits and drawbacks of each option.

**Replication.** The first option for this program would be to perform the same program in its current design at a different day and time. A time chosen further away from rounds or in the evening could allow more families to attend based on work or travel schedules. However, when parents were asked to choose the ideal day and time for a program, there were no consistent trends in the data. Therefore, timing of the program may always be imperfect for some families.

**Individual Education.** Secondly, shifting the information currently held in lecture form for this program into handout or pamphlet form would allow the occupational therapy team at the hospital to individually educate families on OT caseload on these important topics. Using these topics and handouts as a guide for the first several OT sessions would allow families to understand more about the purpose and goals of occupational therapy. Families who received the lectures as handouts and were unable to attend the class portion of the program reported exclusively positive feedback when interviewed. This option would continue to allow connection between the parents and the occupational therapist, however, the connection between families both experiencing similar stressors would be lost without the group meeting portion of this program.

**Virtual Classes.** The third option would allow the capstone student to utilize technology and present infrastructure such as the Get-Well Network to shift the lectures into webinars available at any time for families in the infant's room. Although this option solves the timing and scheduling conflicts which defined this program, the Get-Well Network videos are underutilized as most families are not aware of their presence. The connection between caregivers and other families is likewise lost during the webinar due to the solitary learning of this information. When families and the FAC were asked about their options for these three options, there was no unanimous answer, however, responses generally encouraged replication or individual education over the virtual option.

### **Implications for Practice**

This program was designed with the input of all stakeholders, particularly the Family Advisory Council. Based on previous literature reviews and knowledge of parental stress in the hospital, NICU practitioners know that families are often living in survival mode (Franck, 2013).

They may not wish to leave the bedside for fear of a change in status or desaturation. Families voiced similar concerns in the focus groups during this program. However, from similar literature, NICU practitioners are also aware of the importance of bedside presence and involvement of family members (Gillmer, et al., 2016). In fact, maternal visits are the single biggest predictor of infant health (Latva et al., 2004). “The impact of the mother’s visits was stronger than the impact of gestational age, birth weight, or medical risk of the infant” (Latva, Lehtonen, Salmelin, & Tamminen, 2004, p. 1155). Therefore, knowledge of both the profound importance of parental presence in the NICU and the stressors keeping the families away from the bedside battle for predominance in many families.

The capstone student believed she was bringing life-giving information to the families and that many families would benefit from her work. However, she learned throughout the course of this program that for some families, having the program on the unit did not feel close enough. Rather, due to stress and a feeling of being overwhelmed, they were unable to exit their defined space and they needed the information to come to their baby’s room to be effective. The impact of stress, anxiety, and fear of the unknown greatly affected attendance for this program. The desire for information is present and strong among all interviewed families, the ability to prioritize this class and attend was variable.

These trends have strong impacts on future occupational therapy practice. When performing OT in the NICU, the baby is not the only client, rather the family members are receiving therapy as well through demonstration, encouragement, education, support, and therapeutic use of self. Awareness of not only the presence of parental stress in the NICU, but methods to address it to encourage occupational performance for both infant and family are imperative when working with this population. The importance of connection with staff

members emerged as a strong theme in the data indicating the need for connection during this stressful time. Encouraging occupational therapy practitioners to prioritize this need during sessions is an unforeseen, yet powerful result of this study. The benefits of therapeutic use of self were strong in the data and could be studied more poignantly in the future as well.

### **Implications for Research**

Families consistently reported during focus groups that the educational information was helpful, but needed earlier. Parents reported feeling overwhelmed and hungry for information at the start of the admission. They heard new medical jargon and googled it. Many reported “Google is your best friend and your worst enemy!” (T.H., focus group personal communication, March 4, 2019). The findings of this program evaluation are consistent with previous literature in regard to the presence of parental stress in the NICU and the impact it has on occupational performance (Gillmer, et al., 2016). Parents reported difficulty entering into the role of parent due to barriers and restrictions. The strong theme of maternal shame and the language of “good mom” and “bad mom” increases the level of stress from an environment or situation to a person. Balancing the stress and shame themes was the consistent encouragement for self-care and celebrating small victories. Future investigation on the methods of parental self-care and the effectiveness of self-care in addressing the feelings of stress and shame would be intriguing for future research. Implementing self-care education or intervention for families could have an impact on the occupational performance of parents and thereby, improve the health of their infants. This would be a way to address the barriers in the NICU in a novel way and could be researched in future studies.

These hypotheses regarding timing of education and importance of self-care which arose from the data analysis continue to indicate the benefits of addressing both parental and infant

health. Due to the connection of occupational performance between infant and caregiver, research regarding the experience of hospitalization for the families, including their self-care skills, would be an interesting line of research stemming from these results. Therefore, data regarding infant development could be correlated with parental education, mental health, or self-care skills to determine the interplay between caregiver health and infant health. Research regarding these themes which arose in the data would continue to guide practice in this population.

### **Implications for Education**

The findings of this program evaluation have strong implications for education of future occupational therapists. Occupational therapists greatly value independence and strive to promote independence in all clients through strengthening, adaptation, education, and modification of the occupation. However, this good desire should be balanced with the fact that all people also need help and support. There is a sense in which none of us is independent, but all need a support system and others along the river with us to help our rivers' flow. Educating students on the barriers that families of hospitalized persons experience and the benefits of connection, education, and self-care can impact all future occupational therapists. Occupational therapy students study a variety of occupational theories; however, they can be expanded. For instance, when practicing from a Person-Environment-Occupation (PEO) Model perspective, identifying the person as not just the client on caseload, but also his or her family or support system behooves the occupational therapist (Law et al., 1996). Likewise, using a Kawa Model approach, identifying persons and environments as a part of the rocks and driftwood can block or improve one's flow (Iwama et al., 2009). In the NICU especially, the infants are dependent upon caregivers for their occupations, therefore, this need to identify the person as infant and caregiver

is easy to see. However, even for adults, the need for support, therapeutic use of self, active listening, and helpers can be crucial and should be taught in the curriculum for future occupational therapists.

Educating future occupational therapists on the importance of therapeutic use of self, connection with patients, and the importance of self-care particularly during stressful times could be included in curriculum. These soft skills are important for full effectiveness in therapy sessions. Families in the literature reported feeling more confident in the care their child received when they were familiar with the provider (Davidson et al., 2017). These were consistent with the data during focus groups. Families consistently reported the importance of connection with nurses and other bedside staff members and that such employees were a crucial part of their support system during hospitalization.

Including the family or caregivers in our intervention allows occupational therapists to be holistic in their view of the difficulties and needs. The effectiveness of holistic care is heavily evidence based (Lor et al., 2016). Of note, the hospital where this study occurred recently rebranded and, as a part of the rebrand, is promoting holistic and whole-person care including the mind, body and spirit in all interactions. This capstone student would encourage holistic care to include the family as well, and advocate for addressing mind, body and spirit, but also the aspects of support, community, and family through our intervention as well by including the needs, barriers, and assets of the families of our patients. The need for parental self-care, support, and connection was strong in the focus group data and should encourage future education to improve skills needed to address these needs.

### **Dissemination Plans**

No study or program is complete without the ability to share the findings with others in a similar position. Of first importance would be sharing the program evaluation data with rehabilitation and NICU administration within the hospital system. These presentations will happen in May and June of 2019. These conversations will help determine how and at what time this program can become a permanent offering within the hospital. Presentation of outputs and qualitative feedback will be of utmost importance to determine the future of occupational therapy education in the NICU setting.

Secondly, although preliminary dissemination has already occurred to the FAC, further discussion of methods to promote the experience of hospitalization for families and maximize their confidence in parenting would be essential in future meetings this summer. The FAC at the hospital where this program occurred is currently exploring a mentoring program to allow parents of NICU graduates to connect with currently hospitalized families. The capstone student will encourage volunteer mentors among the FAC members to attend and provide feedback on future program sessions and allow families to be seen and understood by someone who has walked through a similar road.

The results should also be disseminated outside of the walls of the hospital. Sharing the results of this program development, implementation, and evaluation with other champions of family-centered care would allow further discussion on methods to perfect the program and alleviate distress among NICU families. Planetree International and the Institute for Patient and Family-Centered Care are organizations that exist to promote family-centered care discussion and excellence in the realm of family-centered care (Planetree International, n.d.). Discussions with those who are experts in the importance and difficulties of family-centered care would be

valuable to promote future editions of this program as well as future education throughout the unit. Planetree has a conference in Orlando in October 2019. Since the involvement of the FAC was a defining factor of this program's design, implementation, and evaluation, sharing the benefits of collaboration with families, within and outside hospital system, would be beneficial.

Lastly, many of the results of this program indicated the need for improved education of future occupation therapy students and the need for reinforcement to involve the families in the care and occupational engagement of their infants. Therefore, sharing the results to occupational therapists would behoove the capstone student. The Florida Occupational Therapy Association (FOTA) annual conference will be held in Orlando this fall and would allow the capstone student and possibly a member of the FAC to attend the conference and share about the design, implementation, and evaluation of this program could help other occupational therapists practicing in NICUs around the state and beyond. Improving the involvement of families is crucial for infant health and yet, many occupational therapists practice without a thorough understanding of the experience of families of hospitalized infants. Improving the awareness of the stressors of families in the NICU through presenting at this conference could extend the results of this program to other neighboring NICUs and therefore improve occupational performance across the state. The capstone student will submit an abstract and apply for a slot to disseminate her research at FOTA by July 15, 2019. This program could easily be replicated at different hospitals to compare outcomes and effectiveness. Dissemination of results is a crucial aspect of program evaluation.

### **Conclusion**

The neonatal intensive care unit is a unique place to practice occupational therapy because the therapist always has multiple clients, both parents and infants, to keep in mind when



planning interventions and making goals. Infants are dependent upon their families and caregivers for nutrition, growth, interaction, movement, and development. The infants are under an immense amount of stress in the NICU, however, their families also exhibit stress responses which affect occupational performance and parental skills. Therefore, it behooves occupational therapists to be well-versed in family-centered care tenets, educational strategies, therapeutic use of self, self-care strategies, and methods to promote co-occupations. These occupation-centered practices have been shown to be effective to promote occupational performance in both infants and parents now and in the future and should guide our practice, research, education, and program development with this fragile population.

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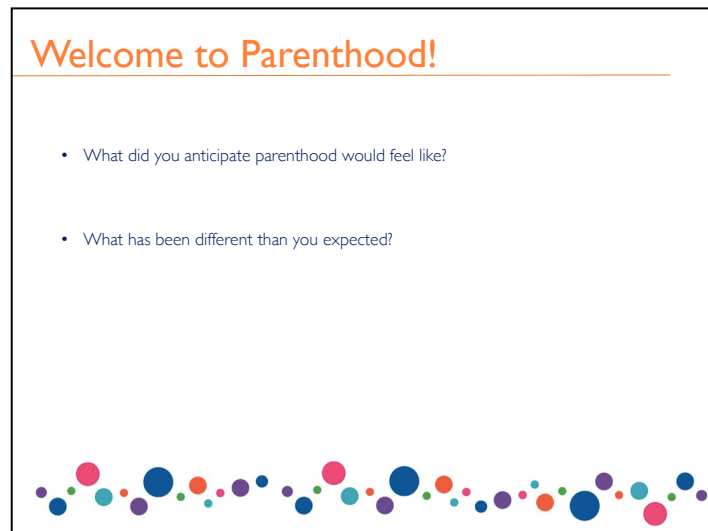
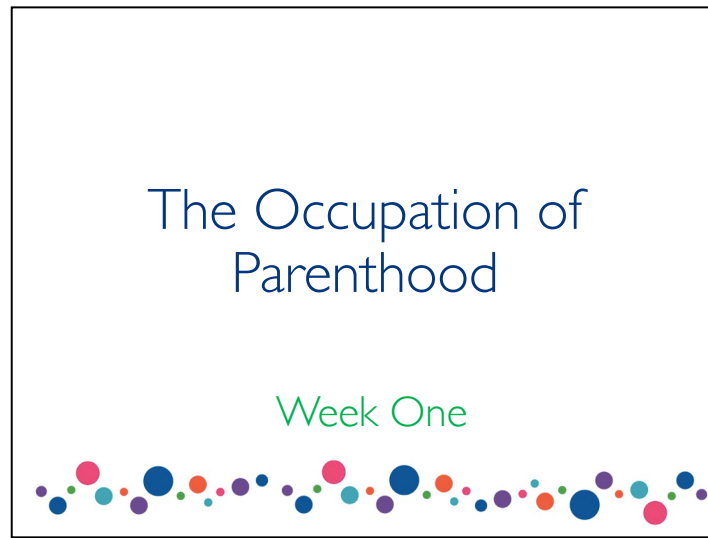
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Appendix A: Program Slides

Creating Confident and Connected Families





## Creating Confident and Connected Families

## What are the jobs of parenthood?

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- What do you do for or with your baby currently?
- What do you look forward to doing with your baby in the future?
- What jobs or tasks make you nervous currently?



## Challenges in the NICU

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- Even parental occupations are disrupted in the NICU-
  - Normal parenting/bonding is interrupted
- Parents face stress over sights/sounds
- Medical terms and equipment are scary and complicated
- Parents suffer from feelings of powerlessness in their parental role
- Both infant and parents have to adjust to this critical care environment
  - (Pizur-Barnekow & Erickson, 2011; Zimmerman, 2012)



Creating Confident and Connected Families


### The NICU Environment

- The NICU is a very different environment from the womb.
- Think about what the baby would
  - See
  - Hear
  - Taste
  - Feel
  - Move
  - Feel comforted
- What would he or she experience in the NICU in the same categories?



### The NICU Environment for YOU

- Life outside the womb is challenging for infants
- Life inside the hospital is challenging for families too!
- What has felt overwhelming for you?
- We hear these responses often:
  1. Medical Terms
  2. Lines, Wires and Alarms
  3. An unknown timeline
  4. Not knowing where to get help
- Let's talk about each of these categories!




Creating Confident and Connected Families

## I. Medical Terms

---

- We speak our own language here! It can be difficult to understand.
- Here is a Top 15 list of things you might hear in the NICU:
 


<ol style="list-style-type: none"> <li>1. Brady</li> <li>2. Desat</li> <li>3. Apnea</li> <li>4. Surfactant</li> <li>5. UAC</li> <li>6. PICC</li> <li>7. IVH</li> </ol>	<ol style="list-style-type: none"> <li>8. Bilirubin</li> <li>9. PO/NPO</li> <li>10. NG/OG tube feeding</li> <li>11. Intubate/ETT</li> <li>12. CPAP</li> <li>13. PFO/PDA</li> <li>14. PMA</li> <li>15. GA/CGA</li> </ol>
--	---
- There is also a more extensive definition list available!



## 2. Lines, Wires, and Alarms

---

- Some of the most common lines were discussed on the last slide.
- The hospital is a noisy place!
- Always look at the baby first
- Monitors give you some information, but can misread
- Your nurses can help determine if an alarm requires intervention.




Creating Confident and Connected Families

### 3. An Unknown Timeline

---

- Every child develops and grows at their own pace. I like to say they each write their own story!
- Trimesters inside the womb and Trimesters outside the womb!
  1. Stabilize
  2. Decrease oxygen and IV support
  3. Feeding!
- In order for an infant to discharge he or she must:
  - Hold their body temperature in a crib (outside the isolette)
  - Gain weight consistently
  - Take all his or her milk by mouth



### 4. Where to get help in the hospital

---



- We have people to help you!
- Here are some of the team members available inside the hospital:
  - Social Workers
  - Chaplains
  - Lactation Specialists
  - Occupational Therapists
  - Speech Therapists
  - Child Life Specialists
  - Discharge Care Coordinators
  - Care Managers
  - And more!
- All are available for consult or support!



Creating Confident and Connected Families

### Life is like a River...

- There is a theory that likens life to a flowing river.
- The river has a river bed and banks to define its shape
- It also has rocks slowing the flow
- And driftwood helping to break up the dams



### Rocks and Driftwood?


- Rocks
  - Barriers
  - Obstacles
  - Things stopping the river from flowing freely
- Driftwood
  - Assets
  - Resources
  - Things helping the river to flow again



Creating Confident and Connected Families



### How is your river flowing?

- Create a picture of your river
- We hope this class will provide "driftwood" to help your river flow again.
- We will talk about how your river has changed at the end of our sessions together.
- We hope to blast through dams to allow your river to flow within the hospital and continue after discharge



### Class Reflections


- What is your biggest take away from today? (Write it down!)
- How will you use this information to help your baby?
- What do you wish you knew more about?



Creating Confident and Connected Families

What questions do you have?

- Next week's topic: Kangaroo Care
- Monday at 10 am in the family resource room



Kangaroo Care

Week Two



## Creating Confident and Connected Families

## What is kangaroo care?

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- Holding an infant chest to chest and skin to skin.



## Why is kangaroo care beneficial?

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- Kangaroo care is one of the most researched interventions in infancy!
- Kangaroo care can help the baby:
  - Hold his temperature
  - Feel comfortable
  - Experience less pain
  - Gain weight
  - Hold his head up
  - Get stronger

(Cooper, Morrill, Russell, Gooding, Miller, Berns, 2014)





## Creating Confident and Connected Families

## Kangaroo Care Helps Moms Too!

- Kangaroo care can help a mom:
  - Produce milk
  - Bond with her baby
  - Increase self esteem
  - Reduce stress



## Comfort Care

- Your baby could have trouble telling us if he or she is hurting
- We want to make you and your baby feel comfortable.
- YOU are the primary source of comfort for your baby.
- No one else can be the mom to your baby. Your job is serious and rewarding!

(Skene et al., 2012)



## Creating Confident and Connected Families

## Kangaroo Care

- Technique highly supported by research that allows parents to place their infant on their chest skin-to-skin to hold
- Benefits include
  - Increased health
  - Weight gain
  - Temperature stability
  - Bonding
  - Decreased pain



## Kangaroo Care Basics

---

- Depending on the lines, breathing tubes, and your baby's story, kangaroo care may not be a safe option today.
  - You may need a respiratory therapist's help for safety with breathing tubes to get your baby out of the isolette
- Let your baby's nurse know you'd like to kangaroo and see what the best time would be.
- Plan to kangaroo your baby for at least an hour:
  - So go to the bathroom first 😊



## Creating Confident and Connected Families

## Positioning During Kangaroo Care

- For the baby:
  - Arms and legs tucked in
  - Head turned to one side
  - Back rounded
- For the Mom or Dad:
  - Reclined
  - Shoulders relaxed
  - Comfortably holding baby



## Conclusions

- There is something powerful happening in these “tiny snuggles”
- You have power. Would you like to hold your baby now? ☺





Creating Confident and Connected Families

### Class Reflections

---


- What is your biggest take away from today? (Write it down!)
- How will you use this information to help your baby?
- What do you wish you knew more about?

### What questions do you have?

---

- Next week's topic: Positioning and Infant Handling
- Monday at 10 am in the family resource room




## Creating Confident and Connected Families



Creating Confident and Connected Families



### What is womb-like positioning?

- Womb-like positioning includes four things.
  - Flexed
  - Contained
  - Aligned
  - And Comfortable




### Flexed

- Flexed means having the arms and legs bent and the trunk rounded forward slightly
- Tucked
- The fetal position





Creating Confident and Connected Families

### Contained




- Contained means the baby has boundaries or borders to make him or her feel safe and comfortable
- In the womb, your baby was touching the womb on all sides, so this makes them feel like home.
- Swaddling, Roos, and blanket rolls can provide containment for your baby.



### Aligned

- Aligned means the baby is symmetric.
- If you drew an imaginary line from nose to navel, this is called midline.
- We want head, arms and legs to be brought to midline.
- This helps with head control, breathing, digestion, and comfort.




Creating Confident and Connected Families

### Comfortable

---

- Does your baby look comfortable?
- He or she will be in this position for the next three or four hours, so we want it to be cozy so he or she can get a good nap to grow big and strong!
- Are the heart rate and oxygen saturation numbers within range? If not, some modification may be needed.



### Why is positioning important?

---

- The squish of the womb is very important for strengthening, joint alignment, and development.
  - Preterm babies are born early and miss out on some of the time in the womb.
  - So they have to stabilize their joints another way. Proper positioning is a HUGE part of this!
- If a baby is positioned poorly he can have trouble with milestones such as sitting or walking later on.
  - We desire to set our babies up for success in the little baby skills (such as feeding, pooping, and sleeping) and the big baby skills (such as rolling over and crawling!)






Creating Confident and Connected Families

### What are the options for positioning?

- Face up
- Sidelying
- Face down

- ALL positions have benefits in the NICU!
- Babies can sleep in any position in the NICU because they are constantly observed.
- When you go home it is only safe to sleep with a baby on his or her back!



### Face Up Positioning

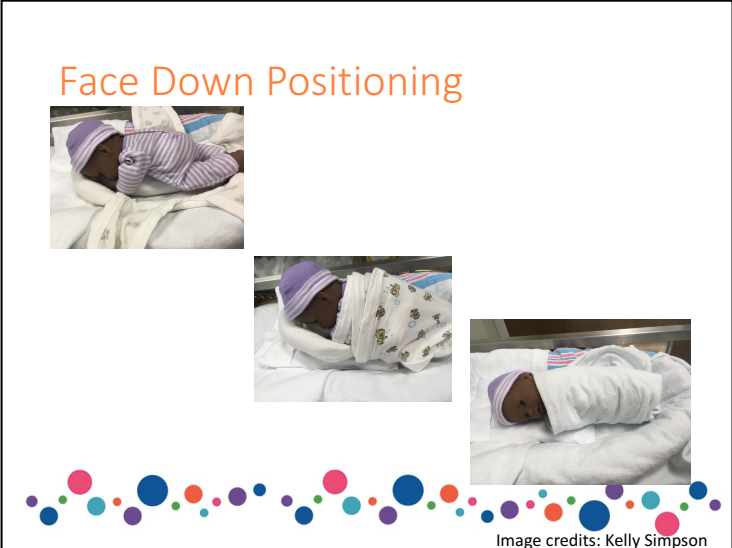


< Blanket Swaddle

Image credits: Kelly Simpson



Creating Confident and Connected Families



## Creating Confident and Connected Families

## All Babies are Unique

---

- Not every options is safe for every baby.
- Your baby's nurse is a great resource to know what might be the best position for your baby each day.
- If your baby has a breathing tube or IV, talk to your baby's nurse before moving them for safety.



## Let's Practice!

---



- Swaddling Face up
- Roo Positioning in tummy time
- Sidelying



Creating Confident and Connected Families


### Class Reflections

- What is your biggest take away from today? (Write it down!)
- How will you use this information to help your baby?
- What do you wish you knew more about?



### What questions do you have?

- Next week's topic: Infant Communication and Feeding!
- Monday at 10 am in the family resource room



## Creating Confident and Connected Families



## Creating Confident and Connected Families

## I. Stress Signs

---

- These are movements that the baby can do to show you he or she is uncomfortable or overwhelmed
  - Arching
  - Saluting
  - "Stop hands"
  - Grimacing
  - Gaze aversion (looking away)
  - Stiffening both legs
  - Changes in heart rate or oxygen saturation



## Why are infants stressed?

---

- Their bodies are being challenged more outside than in the womb to stay warm, digest, move, and breathe.
- They are not prepared to handle bright lights, loud sounds, abrupt movements so these can feel overwhelming.
- Activity all the time!



## Creating Confident and Connected Families

## How does stress affect an infant?

---

- Increased heart rate and breathing rate
- Discomfort
- Pain
- All make the baby burn more calories and affect weight gain
- Can affect learning and brain development
  
- Therefore, we want to make the hospital as comfortable as possible!



## 2. Approach Signs

---

- Babies don't just communicate stress, they also tell us when they are happy and comfortable!
  - Relaxed arms and legs
  - Awake
  - Sucking movements
  - Hands to mouth or hands brought together
  - Soft movements
  - Stable vital signs



## Creating Confident and Connected Families

### 3. Coping Skills

---

- If your baby shows stress signs, how can you help?
  - Talk softly to your baby
  - Let them hold your finger
  - Provide swaddling or containment for comfort
  - Rest a hand on their head or chest
  - Change their position
  - Tuck them into flexion gently
- Each of these remind the baby of the womb and should feel comfortable like home!



### Bonding

---

- Knowing how to listen to your baby's cues and respond is the first step in bonding, infant mental health, and trust.
- It sets you and your baby up for a bright future!





Creating Confident and Connected Families


### What is a HUGE job for a baby?

- Feeding is THE most complicated thing a baby is responsible for.
- It takes an immense amount of coordination to suck, swallow, and breathe safely and take milk by mouth through a bottle or a breast.
- Making the experience positive is the best way to encourage feeding skills.
- Allow the baby to be a part of the feeding process through their communication.
- We call this cue-based feeding



### Cue-Based Feeding

- Feeding based on the infant's cues or signs
- Making the experience positive and not stressful helps the infant eat better and take the needed volumes faster according to research!
- Look at the baby's signals!



## Creating Confident and Connected Families

## Feeding is Individualized

---

- Depending on the age of your baby and her story in the NICU thus far, the providers might not be feeding her by mouth yet.
  - Pay attention to her cues for the future!
  - Learning her interest and skills on the pacifier is helpful for when she can eat by mouth.
- Talk to your doctor, nurse practitioner, or PA with more questions about the feeding orders, amount, or formula for your baby!



## Do you think this baby is ready to eat?

---

- Why or why not?
- What signals do you see?
- What could you do to help her?




Creating Confident and Connected Families

### Do you think this baby is ready to eat?

---



- Why or why not?
- What signals do you see?
- What could you do to help?



### Class Reflections

---


- What is your biggest take away from today? (Write it down!)
- How will you use this information to help your baby?
- What do you wish you knew more about?



Creating Confident and Connected Families



### How is your River Flowing?

- Do you remember the rocks and driftwood you identified in your river a month ago?
- How is your river flowing currently?
- What has your stay been like?
- What knowledge, skills, or confidence have you gained over the past month?



### How can we continue to help your river flow?

- What would you change about your NICU experience?
- How prepared do you feel to go home with your baby?
- What questions do you have?




Creating Confident and Connected Families

### What questions do you have?

---

- Next week's topic: Feedback and Focus Group! This will give us data to improve this program and is essential and appreciated!
- Monday at 10 am in the family resource room



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## Creating Confident and Connected Families

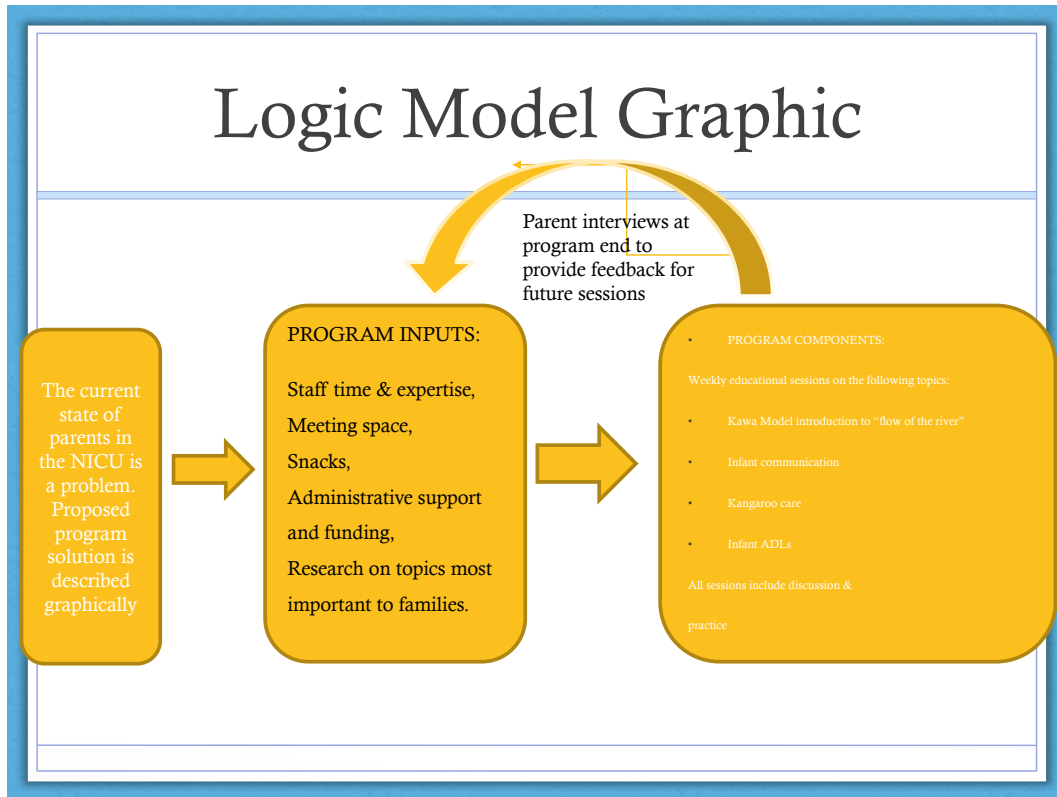
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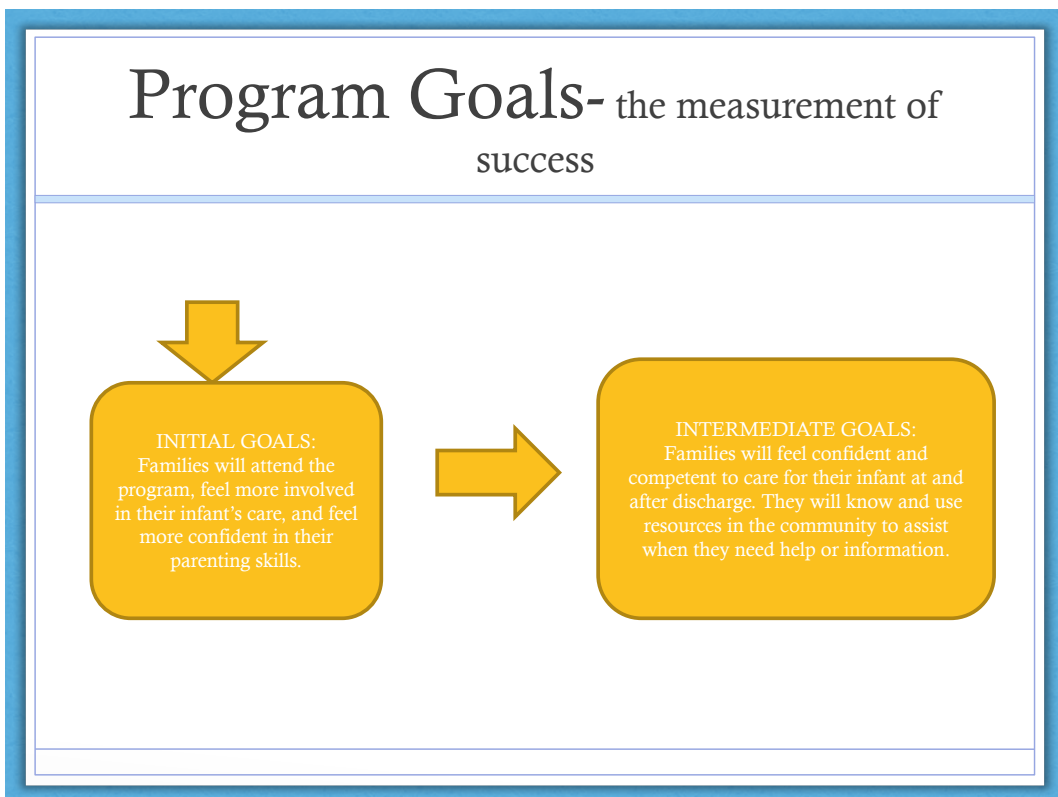
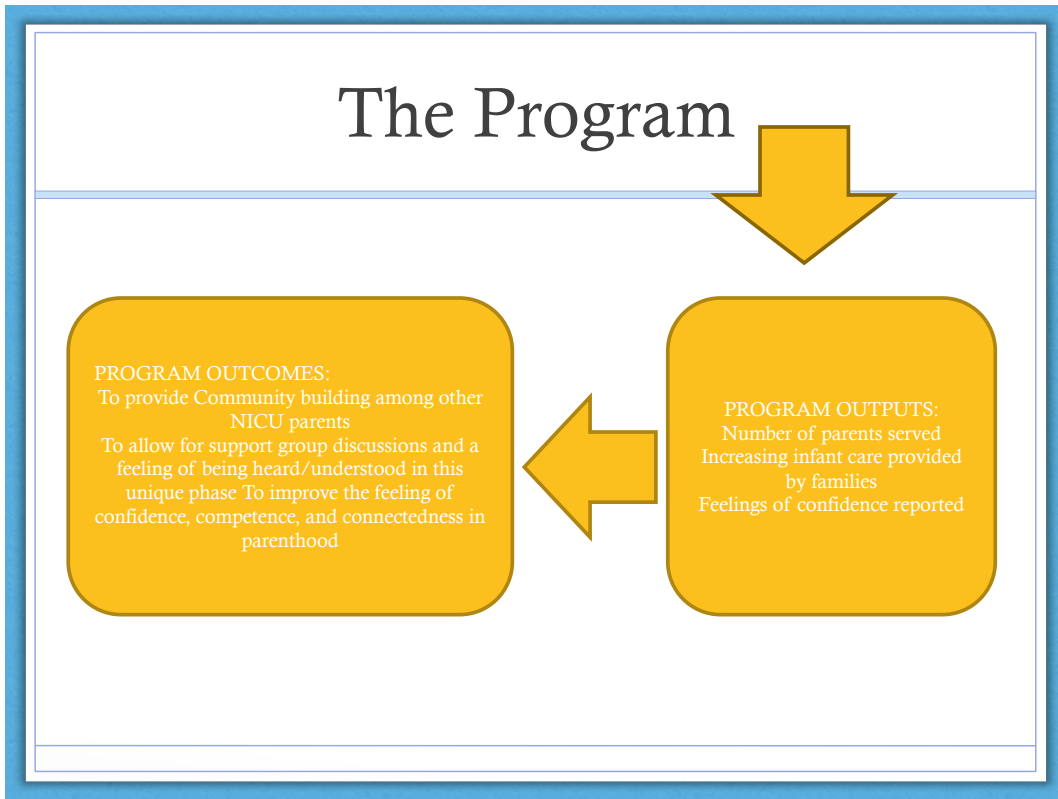
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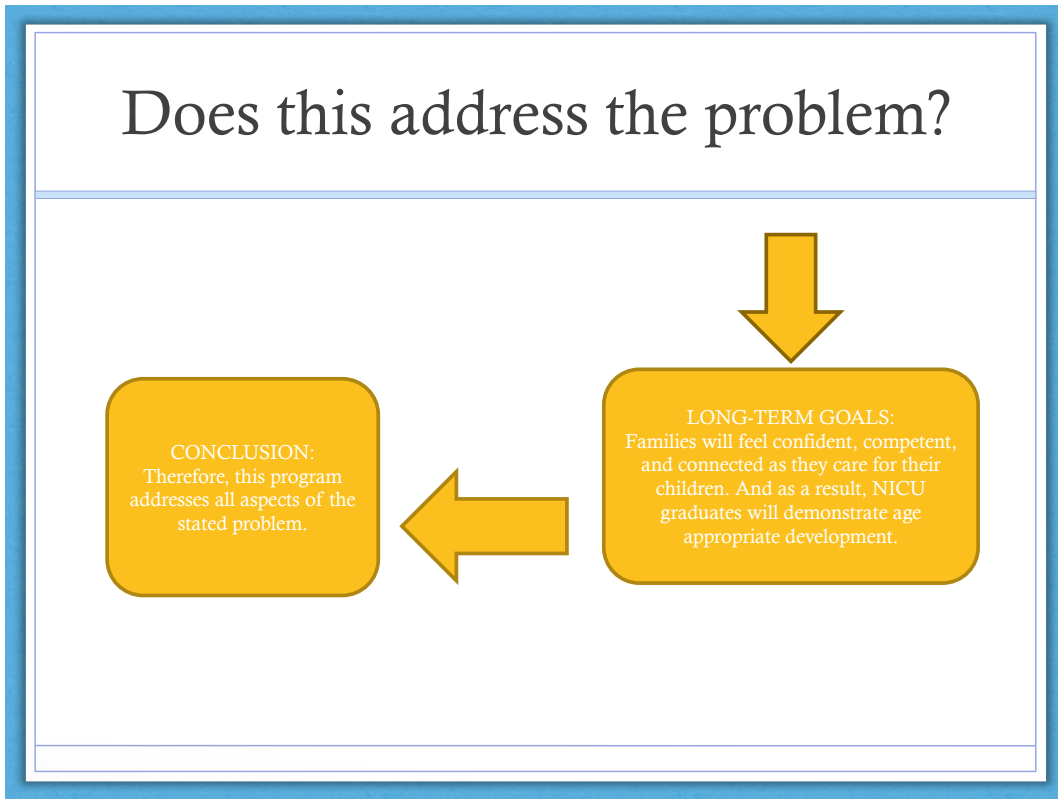




Appendix B: Logic Model Graphic







## Appendix C: Informed Consent

***Creating Confident and Connected Parents: A Program to Improve  
Parental Self-Efficacy in the Neonatal Intensive Care Unit***

**Who is doing this research study?**

College: Nova Southeastern University, Dr. Pallavi Patel College of Health Care Sciences,  
Department of Occupational Therapy

Principal Investigator: Kelly Simpson, MOT, OTR/L, BCP

Faculty Advisor/Dissertation Chair: Elise Bloch, Ed.D. OT/L

Site Information: Neonatal Intensive Care Unit, Orlando, FL

Funding: Unfunded

**What is this study about?**

The purpose of this study is to find out how parents feel when they learn more about the needs of their babies while in the neonatal intensive care unit (NICU). Parents often talk about feelings of fear or restriction from interaction with their baby. Parents may feel nervous about going home since they have not spent time with their baby as planned. The goal of this study is to assess the benefit of an educational program to provide information to and practice for families of preterm infants.

**Why are you asking me to be in this research study?**

You are being asked to be in this research study because you are a parent of a preterm infant at who may benefit from the topics in this program. Your baby may be here for several weeks. This information may help you learn throughout your time in the hospital. It is estimated that this study will include about ten people.

**What will I be doing if I agree to be in this research study?**

While you are taking part in this research study, we request that you attend all four one-hour sessions of education, held each Monday at 10 am in the NICU family resource room. However, if you are unable to attend all sessions, we invite you to attend as many as you can to take full advantage of the education provided. We also request that you attend one of the two one-hour focus groups at the end of the study to provide feedback and to make it better in the future.

Four weekly educational periods will cover the following topics and questions:

- Learning about the occupations of parenting and resources– What are the expected interactions with your infant and what are the resources that can help with those goals within the hospital?

- Kangaroo care – What is the purpose of kangaroo care? How do I hold my baby safely and what benefits does kangaroo care have?
- Positioning – How do I help my baby be as comfortable as possible? What tools are available to help keep him or her cozy?
- Infant communication & feeding – How does my baby communicate with me? How do I know if he or she is comfortable, calm, or ready to eat?

Each week will involve about 30 minutes of teaching and 30 minutes of practice with baby dolls, or talking about how to use the topic of the week. Each week will have time for questions, concerns, and sharing from staff and other parents. Following completion of the four weeks of education, there will be focus groups for feedback. There will be two options to participate in an hour-long focus group to talk about ways to improve the educational group in the future.

### **Are there possible risks and discomforts to me?**

This research study involves low risk to you. To the best of our knowledge, the things you will be doing have no more risk of harm than you would have in everyday life.

**Psychological risk** – In this program, we will be talking about the unique needs of your baby. Sometimes it is hard to hear how much an infant works to survive and thrive outside the womb. If you find any questions we ask or topics we cover stressful, let the primary investigator know. We will have time to discuss such concerns. We can also refer you to someone else on staff at the hospital who may be able to help you with such feelings.

**Privacy risk** – Every effort will be made to ensure your privacy. Documents will be stored in locked offices and shredded or destroyed when it is time to dispose of them. Being recorded means that confidentiality cannot be promised. During the focus groups, you may choose not to answer any questions. If, at any point, you become upset or feel uncomfortable, you may ask to take a break or resume the focus group at another time.

### **What happens if I do not want to be in this research study?**

You have the right to leave this research study at any time, or not be in it. If you do decide to leave or you decide not to be in the study anymore, you will not get any penalty or lose any services you have a right to get. Nothing about the care your baby receives will change if you do not join this study. If you choose to stop being in the study, any information collected about you **before** the date you leave the study will be kept in the research records for 36 months from the end of the study. You may request that such info not be used.

### **What if there is new information learned during the study that may affect my decision to remain in the study?**

If the researchers learn anything that might change your mind about being involved, you will be told about it.

**Are there any benefits for taking part in this research study?**

The possible benefit of being in this research study is better knowledge of how to care for your baby. Feelings of confidence as a parent may grow due to our sessions. There is no guarantee or promise that you will receive any benefit from this study. Indirectly, we hope the information learned from this study will help other families in the future.

**Will I be paid or be given compensation for being in the study? Will it cost me anything?**

There are no costs to you or payments made for being in this research study.

**How will you keep my information private?**

Information we learn about you in this research study will be handled in a confidential manner and will be limited to people who have a need to review this information. Informed consent paperwork will be the only record of your name. No record will be made of your child's medical information or name by the PI. Audio recordings of focus groups will not record names or identifying information. Audio recordings will be password protected in recording and storage. Audio recordings will be transcribed by the PI while wearing headphones or in a private room to protect your privacy. Focus group data will be available to the researcher, the Institutional Review Board and other representatives of this institution, and any regulatory agencies. If we publish the results of the study in a scientific journal or book, we will not identify you. All confidential data will be kept securely within a locked drawer of a locked office on hospital property. All data will be kept for 36 months from the end of the study and destroyed after that time by Shred-It privacy protected shredding specialists. Audio recordings will be deleted after 36 months from when the study finishes.

**Whom can I contact if I have questions, concerns, comments, or complaints?**

If you have questions now, feel free to ask us. If you have more questions about the research, your research rights, or have a research-related injury, please contact:

Primary contact: Kelly Simpson, MOT, OTR/L, BCP

**Research Participants Rights**

For questions/concerns regarding your research rights, please contact:

Institutional Review Board

Nova Southeastern University

(954) 262-5369 / Toll Free: 1-866-499-0790

[IRB@nova.edu](mailto:IRB@nova.edu)

You may also visit the NSU IRB website at [www.nova.edu/irb/information-for-research-participants](http://www.nova.edu/irb/information-for-research-participants) for more information regarding your rights as a research participant.

**Research Consent & Authorization Signature Section**

Voluntary Participation - You are not required to participate in this study. You may leave this research study at any time. If you leave this research study before it is completed, there will be no penalty to you, and you will not lose any benefits to which you are entitled.

If you agree to participate in this research study, sign this section. You will be given a signed copy of this form to keep. You do not give up any of your legal rights by signing this form.

**SIGN THIS FORM ONLY IF THE STATEMENTS LISTED BELOW ARE TRUE:**

- You have read the above information.
- Your questions have been answered to your satisfaction about the research.

**Adult Signature Section**

I have voluntarily decided to take part in this research study.

\_\_\_\_\_

Printed Name of Participant

\_\_\_\_\_

Signature of Participant

\_\_\_\_\_

Date

Printed Name of Person Obtaining  
Consent and Authorization

Signature of Person Obtaining Consent &  
Authorization

Date

Appendix D: Program Participant Flow Chart

Program: **Confident & Connected Families in the NICU Participant**

