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A Family Guide to the Neonatal Intensive Care Unit

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A FAMILY GUIDE TO THE NEONATAL INTENSIVE CARE UNIT

by

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Advisor: Gail Bass, PhD OTR/L

A Scholarly Project
Submitted to the Occupational Therapy Department
of the
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In partial fulfillment of the requirements
for the degree of
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This Scholarly Project Paper, submitted by Merri M. Reese and Lori M. Thompson in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS........................................................................................................... v
ABSTRACT .................................................................................................................................. vi

CHAPTER

I. INTRODUCTION .................................................................................................................. 1
II. REVIEW OF LITERATURE ................................................................................................. 3
III. METHOD .............................................................................................................................. 34
IV. PRODUCT ........................................................................................................................... 36
V. SUMMARY ............................................................................................................................ 82

REFERENCES .......................................................................................................................... 84
ACKNOWLEDGEMENTS

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ABSTRACT

One of the many challenges facing health care professionals practicing in the neonatal intensive care unit (NICU) is providing appropriate care that is sensitive, individualized, and supportive to infant development and parental roles (Lawhon, 2002). Because the families are often the ultimate advocates and caregivers for infants in the NICU it is important that they understand and take part in their babies’ care. Therefore, by providing clear and easy to understand explanations of equipment, technology, and procedures that are a part of the NICU environment, professionals can help alleviate parental stress and promote parental involvement.

An extensive review of literature was completed and it included the history of the NICU, current best practice, physical context of the NICU, infants in the NICU, infant occupations, occupational therapy interventions in the NICU, family experiences in the NICU, and continuing care. We also visited area neonatal intensive care units to gather information and examples of resources that are given to parents while their child is in the NICU. It was concluded that families may benefit from the provision of a concise and user friendly resource that can be utilized during their child’s stay in the NICU.

A resource manual was developed to provide families with an easy to understand guide to help navigate the complex environment of the NICU. The manual is divided into sections and includes information about: staff and caregiver roles, common conditions that an infant in the NICU may experience, equipment that is typically seen in the NICU, behavioral cues that an infant may display, tips to promote bonding with an infant, information on feeding and positioning, and information that may ease the
transition home. Each section provides easy to read descriptions of the various topics and pictures to facilitate understanding of the material presented.
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Faculty Advisor

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Date
CHAPTER ONE

INTRODUCTION

We initially developed an interest in the neonatal intensive care unit (NICU) through our pediatric course work. We further explored this area of practice through community experience and contact with local professionals working in the NICU. Our interest was also heightened by personal experiences with individuals who have spent time in the NICU. Our interest in this area led us to seek out additional information on common practices in the NICU.

One of the many challenges health care professionals practicing in the NICU have to face is providing appropriate care that is sensitive, individualized, and supportive to infant development and parental roles (Lawhon, 2002). The neonatal intensive care unit (NICU) is a stressful and often confusing environment for families and infants. In addition to coping with a child who has unique medical needs, families must also learn to adapt to a highly technical environment and to interact with the various professionals who are present in the NICU. Because the families are often the ultimate advocates and caregivers for infants in the NICU it is important that they understand and take part in their babies’ care. By providing clear and easy to understand explanations of equipment, technology, and procedures that are a part of the NICU environment, professionals can help alleviate parental stress and promote parental involvement.

The primary role of an occupational therapist practicing in the NICU is to
promote oral-motor and feeding skills, provide therapeutic positioning recommendations, facilitate the development of parent-infant relationships, and teach parents how to interpret their baby’s behavioral signals (Caretto, Topolski, Linkous, Lowman, & Murphy, 2000). These areas of intervention present an opportunity for parents to take part in their child’s care and learn about their child. Thus, Occupational therapists practicing in the NICU are uniquely qualified to help families adapt to the NICU experience.

The theory used to guide the development of this scholarly project was Occupational Adaptation by Schultz and Schkade (2003, p. 220-223). This theory has a number of guiding assumptions including: stressful life events can overwhelm an individual’s ability to adapt, the more stressful the life event is the greater the demand for change or adaptation, and successful occupational performance relies on an individual’s ability to adapt to a new situation successfully.

This theory is relevant to the experiences of families and infants in the NICU as these individuals are faced with an unfamiliar environment and a stressful life event. The adaptation process proposed in the Occupational Adaptation theory focuses on the interaction between the person and the occupational environment. A person in a stressful situation will seek to adapt their interactions to achieve a sense of mastery. Successful adaptation hinges on an individual’s ability to reflect on their adaptation skills and make adjustments as needed (Schultz & Schkade, 2003). This theory is evident in our product in the areas that allow for parent reflection, such as the discharge checklist, common condition question page, and note pages. Our product also facilitates parental adaptation.
to the NICU environment by presenting information on common conditions, staff
descriptions, and behavioral cues that is educational and easy to understand.

Families in the NICU, through their interactions with staff and the NICU
environment, refine their caregiving skills and their ability to adapt to their child’s needs.
Through their pursuit of knowledge and their development of new skills families gain a
sense of mastery that in turn prepares them for their role as primary caregivers in their
own home.

The scholarly project is divided into five chapters; the information included in this
chapter provides an overview of the problem and the intended outcome of the project.
The second chapter is a review of current research and literature that formed the
foundational basis for the product. Chapter III is an overview of the methodology used to
develop the product and the product is presented in its entirety in Chapter IV. The final
chapter provides a summary of the entire project, limitations of this project,
recommendations for further development of the project, and options for additional
research in this area.
CHAPTER II
REVIEW OF LITERATURE

Introduction

According to Hunter (2001), concerns about the long term developmental outcomes of premature infants triggered the entry of occupational therapists and other highly qualified developmental experts into the specialized care arena of the neonatal intensive care unit (NICU). One of the many challenges health care professionals practicing in the NICU have to face is providing appropriate care that is sensitive, individualized, and supportive to infant development and parental roles (Lawhon, 2002). The NICU environment is not only stressful for the infant but for the family as well. In a study by Dudek-Schreiber (2004) it was found that the sights and sounds of the NICU were the third leading cause of stress for parents. By providing clear and easy to understand explanations of equipment, technology, and procedures that are a part of the NICU environment, professionals can help alleviate parental stress and promote parental involvement.

The purpose of this project was to develop a family guide to the NICU. In order to have validity the content of this guide should have a foundational basis in current research and literature. The following chapter is divided into seven sections. The first section provides an overview of the history of the NICU including current and past
theories related to care. The next two sections describe the physical context of a typical NICU and strategies for altering this context to meet individual needs, age and weight classifications, medical conditions, states of arousal, and behavioral cues that infants in the NICU may demonstrate. The fourth section outlines infant occupations and how they relate to treatment in the NICU, and the next section includes information about several intervention strategies that are commonly implemented in the NICU. The sixth section addresses the family's experiences in the NICU and focuses on parental roles, communication, and sibling involvement. The final section describes continuing care beyond the NICU and specifically addresses early intervention services. The literature reviewed in this chapter provides an overview and description of the NICU and the infants in it and supports the need for a family resource that will help them adapt and cope with the NICU experience.

History of the Neonatal Intensive Care Unit (NICU)

Due to the rapid advancements in technology and medical care, infant mortality has decreased significantly and the need for highly specialized care for medically fragile infants has subsequently increased (Vergara & Bigsby, 2004; Verma, Sridhar & Spitzer, 2003). The NICU was established to meet the needs of this population of infants. This unit provides complex medical and nursing intervention designed to support infants whom are critically ill or technologically dependent (Vergara & Bigsby, 2004). The care provided in the NICU has evolved since its inception in 1893, from a “Special Department for Weaklings” developed by Dr. Pierre Budin, to a state-of-the-art care environment that supports all aspects of infant and family development (Hunter, 2001).
Prior to 1970, care provided in the NICU was primarily focused on providing warmth, safeguarding against infection, and providing nourishment. These measures proved insufficient to meet the needs of infants with severe cardiovascular and respiratory conditions and the mortality rate among this population was high. The development of life support technology provided interventions which better suited the needs of infants with more severe impairments. However, this new technology, while lifesaving, also led to the development of serious secondary disorders in the neonates including: chronic respiratory disorders, cerebral palsy, blindness, as well as hearing and cognitive impairments. Therefore, concerns about the effects of the technology used in the NICU as well as long-term developmental outcomes have arisen (Hunter, 2001). These concerns prompted the establishment of developmentally supportive care and early intervention programs to address the developmental needs of this special population after discharge from the NICU (Vergara & Bigsby, 2004; Vergara, 1993). Theories as to what constitutes appropriate care in the NICU have evolved throughout the years.

The Early NICU

During the 1940s and 1950s the infant in the NICU was considered over stimulated and care involved limiting sensory stimulation. This view manifested itself in the use of low lighting, quiet environments, and restricted access by families and medical professionals (Hunter, 2001; Vergara & Bigsby, 2004).

During the 1960s and 1970s the sensory deprivation theory became popular and the NICU infant was considered to be under-stimulated. This change in thinking was apparent in the development of sensory stimulation programs which consisted of massage, passive range of motion, vestibular input, and auditory input. However, what
the sensory deprivation theory failed to take into account was the unstructured and aversive stimulation that the infants were already exposed to in the technology filled NICU environment. This mode of care also presented a “one size fits all” approach in which all infants were provided with the same sensory input with little consideration to individual needs. These sensory stimulation programs proved to be effective with older, larger, and more stable infants but the younger more fragile infants could not tolerate the additional sensory stimulation (Hunter, 2001; Vergara & Bigsby, 2004).

The sensory overload theory began to emerge in the 1970s as greater emphasis was placed on environmental factors. The premise behind this theory was that infants in the NICU were actually overwhelmed by the additional stimulation produced by the new technology present in the NICU. This technology consisted of a plethora of bright lights, noisy monitors and machines, as well as additional staff which further increased the noise level. In order to limit the amount of sensory stimulation infants received NICU practices were altered. This alteration was evident in the decreased handling of infants and restricted visitation by parents and family (Vergara & Bigsby, 2004).

In the 1980s and 1990s additional focus was placed on the environment of the NICU and how the human and mechanical components affected the infants’ development. Further consideration of the environment as a whole, including animate and inanimate elements eventually brought about the evolution of the current theory of developmentally supportive care (Hunter, 2001).

*The Current NICU Theory*

The evolution of developmentally supportive care was brought about in part by the need to counteract the negative affects of the highly technological environment of the
NICU. Developmentally supportive care operates on the premise of providing sensitive and individualized care to facilitate and nurture each newborn and their family’s strengths and abilities (Lawhon, 2003; Starr & Hoye, 1998). The overall goal of developmentally supportive care is to “support and promote the premature infant’s adaptability to external environments and events” (Ludington-Hoe & Swinth, 1996, p. 691). This approach seeks not only to minimize infant stress but to preserve positive developmental outcomes and facilitate the parent role as a primary caregiver and advocate (Bondurant & Brinkman, 2003; Starr & Hoye, 1998).

Infants’ primary means of communication is behavior, and they use different behaviors and cues to elicit a caregiver response to their needs. Consistency of care is important in order for nurses and other staff to get to know the infants and recognize their unique signals. The caregivers, in turn, can aid parents in gaining a deeper understanding of their infants’ behavior. By learning to appreciate and understand infant behavior parents are able to take an active and collaborative role in their babies care (Lawhon, 2003). The developmentally supportive care approach seeks to help parents recognize their infants’ cues and to respond accordingly (Lawhon, 2003; Starr & Hoye, 1998).

Developmentally supportive care is comprised of four major intervention categories. The first type of intervention involves environmental modifications focused on decreasing excess stimulation. This may include dimming room lights, placing a blanket over the isolet, or gearing unnecessary traffic away from the infants. The second type of intervention, presented by the authors, places an emphasis on appropriate handling and positioning of the infant; these techniques promote physiological stability and reduce stress. The techniques may include: swaddling, nesting, positioning that
promotes physiologic flexion or hand to mouth, and providing breaks from handling and procedures. The third type of intervention involves grouping procedures so as to allow two to three hours of undisturbed sleep at a time; this promotes normalized sleep and wake cycles and facilitates growth. The fourth and final intervention type described by the authors involves the promotion of interaction between the infant, the parents, and the caregivers. Interventions within this category may include: kangaroo care (chest to chest contact), allowing parents to take an active role in care giving, and assisting the parent in interpreting infant cues (Bondurant & Brinkman, 2003, p. 257-258; Starr & Hoye, 1998).

**Physical Context of the NICU**

Prior to birth, the NICU infant was secure within the nurturing environment of a mother’s womb where basic needs were automatically met. After delivery, premature infants are thrust into a care setting, the NICU, where they are expected to maintain their body temperature, adjust to bright lights and loud noises, move against the effects of gravity, and learn to cope with frequent handling and invasive procedures. This setting often presents a mismatch between the immature infants and their highly technical surroundings (Hunter, 2001). The NICU is an environment permeated by loud sounds, bright lights, and numerous health care professionals all of which may negatively affect an infant’s development.

*Sound*

Sound presents a major cause of stress to the NICU infant and can cause a number of serious behavioral changes such as agitation, crying, and decreased overall physiological stability. This stress causes an infant to expend energy on coping, thus, detracting from growth and development. Prolonged exposure to high decibels of sound
can cause secondary conditions such as noise-induced hearing loss and may also interrupt sleep-wake cycles further interrupting recovery and growth (Hunter, 2001; Vergara & Bigsby, 2004).

There are a number of sources that produce sound in the NICU and contribute to the overall noise level. Equipment such as mechanical ventilators, monitor alarms, overhead pagers, ringing telephones, and noises related to human activity can cause the noise level in the NICU to rise to greater than 100 decibels. This sound level is the approximate equivalent of a pneumatic drill or a power mower. For most adults a noise level of 50 to 55 decibels is considered, “moderately annoying”, and the Occupational Safety and Health Administration (OSHA) has mandated that the highest safe level of noise for adult workers is 90 decibels for eight hours. Infants in the NICU are routinely exposed to noise levels between 50 and 90 decibels throughout the day (American Academy of Pediatrics Committee on Environmental Health, 1997).

There are a number ways in which the environment can be modified to decrease the level of sound that an infant is exposed to. For instance, Hunter (2001) identified a number of building materials that can counteract the effects of noise. These materials include: bacteriostatic carpet, acoustical ceiling tiles, and central vacuum systems. Other environmental modifications that were described by Hunter include vibrating pagers, telephones that flash instead of ring, and visual alarms on equipment. It may also be beneficial to position extremely ill infants away from high traffic or noisier areas such as those near sinks, ice machines, and telephones. Utilization of Unit designs that allow for smaller areas for use by individual or small groups of infants was also identified by the author as a technique to decrease sound. Isolette covers present a relatively simple
means by which the noise level within the incubator can be significantly reduced. Noise levels in the NICU can be contained through simple environmental modifications and staff and family training on the potential negative effects of an elevated sound level.

*Light*

Lighting levels in the NICU present an equally worrisome environmental stressor. Hunter (2001) noted that the NICU infant's visual system is not fully developed and continues to mature after birth; this immaturity makes the infants extremely vulnerable to light in their environment. Preterm infants are unable to close their eyes tightly until after 30 weeks gestation making it impossible for them to adequately protect themselves from room light. According to Landry, Scheidt, and Hammond (1985), the mean ambient light in the NICU was 731.68 lux. In comparison, OSHA recommends a maximum light level of 430 to 538 lux for office workers. Continuous exposure to intense, white fluorescent light has been linked to negative outcomes such as chromosomal damage, disruption of circadian rhythms, and possibly retinopathy of prematurity (Hunter, 2001; Vergara & Bigsby, 2004).

The effects of light can be lessened through environmental modifications. A number of accommodations that can be instituted in the NICU have been proposed by Hunter (2001) and Vergara and Bigsby (2004). These accommodations include: adjustable ambient lighting, shades to quickly darken the room, isolette covers, contained procedural lighting that reduces overflow of light onto adjacent beds, and the inclusion of at least one source of natural light. By controlling the amount of light that an infant in the NICU is exposed to, potential harmful effects can be allayed.
Caregiving

Hunter (2001) described a third aspect of the NICU environment that can contribute to infant stress; the numerous caregiving procedures that the neonate is exposed to. Unlike the traditional home environment, touch in the NICU is most often related to medical procedures rather than bonding and social interaction. These procedures may include but are not limited to blood draws, IV insertion, intubation, application or removal of tape, and physical examinations. The medical procedures are necessary for survival, but they are often unpleasant and tax the infants’ abilities to cope. At times, these procedures disrupt the infants’ sleep cycle and can lead to sleep deprivation.

One strategy that can be utilized to minimize stressors associated with caregiving is to cluster procedures to allow for longer periods of uninterrupted sleep. This allows the infant time to recover from each procedure and provides greater time spans that can be devoted solely to growth and development. Being attentive to behavioral cues of stress and assisting the infant in self regulation may also help reduce infant stress levels throughout the caregiving process. Speaking softly before touching the infants and pausing during procedures can help prepare them for and cope with the added sensory stimulation. By remaining aware of infants’ responses to procedural and caregiving interactions professionals working in the NICU can facilitate adjustment and coping of the infant to the NICU environment (Hunter, 2001).

The NICU Infant

Infants born at full term (38 to 42 weeks gestation) are expected to perform a number of physiological functions independently; they are ready to take over all
operations of vital systems from their mother within minutes of delivery. Full term infants should be able to carry out age appropriate metabolic functions, regulate their temperature, breathe without assistance, circulate blood and oxygen throughout their body, and perform gastrointestinal and renal excretory functions. Infants born at term are able to self regulate and participate in expected newborn activities (Vergara, 1993; Vergara & Bigsby, 2004). The infant in the NICU is a medically complex individual and not a miniature version of a full term baby.

*Age and Weight*

Babies in the NICU can be premature, low birth weight, or full term ill infants. Their capability to participate in expected newborn activities is primarily determined by their gestational age, age from birth, and birth weight. Gestational age (GA) refers to the total number of weeks that an infant was in utero prior to birth. A full term pregnancy is 38 to 42 weeks and an infant born prior to 37 or 38 weeks is considered premature. The age from birth, or chronologic age, refers to the infant’s age since delivery. Often the chronologic age is adjusted to account for prematurity to better fit with developmental expectations; the corrected age denotes the age an infant would be if born at term versus prematurely. When referring to birth weight, four of the most common classifications include, normal birth weight (NBW), low birth weight (LBW), very low birth weight (VLBW), and extremely low birth weight (ELBW). Babies with a birth weight between 2500 and 3999 grams (at least 5.5 pounds) are considered normal. Low birth weight infants weigh between 1500 to 2500 grams, VLBW infants weigh between 1000 and 1500 grams, and ELBW infants weigh less than 1000 grams. These categories of
classification apply to preterm, term, and post term infants (Hunter, 2001; Vergara & Bigsby, 2004).

**Medical Issues**

Infants born at term (38 to 42 weeks) have had the added benefit of additional time to grow and mature in the safe and supportive environment of the womb. Even so, there are a number of medical complications that may affect these infants at or after birth. There are two classifications of medical complications that these infants may experience which may require admittance to the NICU: transient medical issues and serious or prolonged medical issues. Transient medical issues are those requiring brief NICU stays and may include: infection, minor respiratory distress, low Apgar scores, temperature regulation problems, and hyperbilirubinemia or jaundice. These conditions are typically resolved within a few days and do not have long term consequences. Serious or prolonged medical issues require longer NICU stays and more sophisticated medical management. These issues may include: cardiorespiratory disorders, congenital anomalies, severe metabolic disorders, perinatal asphyxia, and conditions resulting from maternal factors such as preeclampsia, diabetes, or placental insufficiencies (Vergara & Bigsby, 2004).

There are a number of congenital disorders that evolve during embryologic development which may be seen in the NICU. These disorders may fall into five basic categories. As described by Vergara and Bigsby (2004, p. 98-105) the first category is digestive system anomalies. These disorders typically occur between the six and tenth months of gestation and may include abdominal wall defects, diaphragmatic hernia, malrotation of the intestines, and intestinal constriction or narrowing. The second
category is nervous system anomalies. The neural plate begins to form around the third week of gestation and interruption in this formation commonly results in neural tube defects such as myelomeningocele (spina bifida). A third category described by the authors is cardiac anomalies which occur primarily between day 20 and day 50 post conception. These conditions may include anomalies of the aortic arch, stenosis, transposition of the major vessels, and failure of the foramen ovale to close after birth.

The fourth category is limb anomalies; between the 24th and 36th days in utero is a critical period for limb development and by the sixth week most fingers and toes are recognizable. Limb anomalies can occur at any point within this time frame and include such conditions as syndactyly (webbing of fingers and/or toes), absence of extremities or digits, or club foot. The fifth and final category described by Vergara and Bigsby is cranio-facial anomalies. The most common disorder of this type is cleft lip or palate, which develop most often within the sixth to the ninth week of gestation.

Other medical conditions commonly seen in the NICU are categorized by body system, and three categories have been identified. The first category is respiratory disorders which include respiratory distress syndrome (RDS), pulmonary insufficiency of the preterm (PIP), persistent pulmonary hypertension (PPHN), bronchopulmonary dysplasia (BPD), apnea of prematurity, and pneumonia. The second category is central nervous system disorders which may include intraventricular hemorrhage (IVH), periventricular leukomalacia (PVL), and neonatal seizures. The third category encompasses other neonatal disorders and may include necrotizing enterocolitis (NEC), gastroesophageal reflux (GER), retinopathy of prematurity (ROP), and hospital acquired infections (Hunter, 2001; Hunter, Mullen, & Dallas, 1994; Vergara & Bigsby, 2004).
States of Arousal

Like full term infants, babies in the NICU spend a majority of their time sleeping. However, babies in the NICU demonstrate more active sleep patterns than their healthy full term counterparts. Preterm infants exhibit increased motor activity and less time in deep sleep and are unable to consistently control their states of arousal until after approximately 36 weeks. There are six commonly accepted arousal states, which include: deep sleep, light sleep, drowsy, quiet alert, active alert, and crying. In the deep sleep state the infant exhibits relaxed facial expressions and still arms and legs, regular breathing, and is difficult to awaken. In light sleep the infant’s eyes may move rapidly under closed lids, occasional spontaneous movements, grimacing and facial twitching, as well as intermittent sucking motions. The drowsy state represents a transitional state from which an infant may become more or less alert. In this state eyes may be open or closed, the infant may be fussing, and the infant’s motor activity level is variable. The quiet alert state is the optimal state for interactions with caregivers and family. In this state the infant is able to focus on a source of stimuli, and displays minimal motor activity. In the active alert state the infant’s eyes are open, there is an increase in motor activity, and the infant may be fussy but is not yet crying. The sixth and final state is crying. In this stage the infant is actively fussing and intensely crying. This state represents an infant’s response to an unpleasant stimulus, and indicates that they have reached or exceeded their ability to cope (Hunter, 2001; Vergara & Bigsby, 2004).

Behavioral Cues

Another difference between infants in the NICU and full term well babies is their ability to self-regulate or cope with stimulus. Self-regulation is the ability of an infant to
modulate their subsystems in order to interact effectively with their environment.

Healthy and effective self-regulation means that an infant is able to maintain a balanced physiologic state while exploring and interacting with their surroundings. Infants in the NICU are often unable to do this independently and must rely on assistance from caregivers to help them achieve this balance. Thus, it is important for caregivers to learn to interpret an infant’s behavioral cues (Grenier, Bigsby, Vergara, & Lester, 2003; Vergara & Bigsby, 2004).

Multiple authors (Hussey-Gardner, 1988; Grenier, et al., 2003; Vergara, 1993; Vergara & Bigsby, 2004) have identified the behavioral cues of infants in the NICU; these cues can be divided into three general categories. The first category is self-regulation approach signals which are behaviors that indicate that an infant is ready to interact. These cues may include smiling, cooing, mouthing, relaxed facial expressions, and alertness. While interacting with the infant, caregivers and family should be attentive to changes in behavioral cues that suggest the infant is becoming stressed but is attempting to cope. These behaviors make up the second category the self-regulation coping signals. Signs that an infant is trying to cope include hand-on-face movements, searching for boundaries, flexor posture, averting gaze, and shifting to lower states of arousal. If the infant is no longer able to cope with the stress, he or she may exhibit stress signals which are included in the third category. A number of stress signals have been identified in the NICU infant and are subcategorized into four groups based on their severity. These groups are classified according to the subsystem they affect and include attentional or interactional, state, motor, and physiologic (autonomic). The physiological stress behaviors represent the most severe subcategory because they can induce changes
in heart rate, respiration rate, and visceral signs which can cause serious medical complications

Infant Occupations

Parents and professionals can better meet the needs of critically ill infants by developing an understanding of infant occupations. Infant occupations can be defined as “culturally valued, coherent patterns of actions that emerge through transactions between the child and environment and as activities the child either wants to do or is expected to perform” (Humphry, 2002, p. 172). Vergara and Bigsby (2004) proposed a similar definition of infant occupation in writing that an occupation is considered to be those tasks and activities that are important to the culture in which the infant is expected to participate. This culture is determined by the infant’s family and the NICU environment. When developing a plan of treatment it is important to consider family values because the family often creates a child’s earliest occupational context (Humphry & Case-Smith, 2001). By regulating the child’s activities and environments and establishing daily routines, caregivers are able to create a sociocultural niche and promote occupational involvement. By modifying the NICU environment to better meet the unique needs of the child and their family, caregivers promote the development of childhood occupations that are culturally relevant. By interacting with caregivers and exploring their environment through play infants optimize their development (Humphry, 2002; Humphry & Case-Smith, 2001).

Actions advance into occupations when they reflect intentionality and take on the distinctive aspects of the social and physical contexts (Humphry, 2002). Infants experience occupations primarily through interacting with their environment. However,
the extent to which an infant can participate in expected occupations is dependent upon their physiologic capacities as well as contexts that support their development. An infant’s ability to relate to their surroundings and cope with changes in their environment is related to physiologic stability and nervous system maturity. Often, infants in the NICU are unable to maintain a balanced state; this decreases the amount of time they are able to actively take part in occupations. Furthermore, the NICU environment segregates the infant, through the use of isolates and other life-support equipment, which interrupts engagement with family and caregivers who aid in the development of healthy occupations (Vergara & Bigsby, 2004).

The role of the occupational therapist is integral in the promotion of occupational competence in the infant while supporting the developing skills of the family. To be effective, the therapist working with families in the NICU must gain an understanding of the occupations that the family values and provide education to the family on factors that may be interrupting their infant’s participation in those occupations. The therapist must also be able to discern the infant’s readiness for engagement, and assist the family in recognizing their infant’s unique signals (Vergara & Bigsby, 2004). Once the family is familiar with their infant’s cues, the therapist can provide them with information on interactions that will promote physiologic stability and occupational engagement.

To aid therapists, family, and other caregivers in understanding the occupations of infancy, Vergara and Bigsby (2004) have divided the occupations into two categories, learning occupations and apprenticeship occupations. Learning occupations are activities that facilitate those skills that are considered important to the adults in the child’s culture. Exploring is considered to be an example of a learning occupation. Exploring is
considered to be the most common learning occupation and is the primary mode of learning for infants. Newborns survey their environment by analyzing visual, auditory, oral, tactile, proprioceptive, and vestibular stimuli. They use this information to familiarize themselves with their surroundings. Apprenticeship occupations are activities that assist the child in adapting to their culture. The authors describe apprenticeship occupations as procuring and feeding. Procuring, otherwise defined as solicitation of care, represents a means through which infants interact with their environment proactively. Procuring in infants entails such behaviors as crying in response to hunger, covering their eyes to block bright lights, or turning their head to indicate the need for a break. Deficits in physiologic functioning may inhibit an infant’s ability to solicit care, thus increasing dependence on caregivers to supply additional external supports (Vergara & Bigsby, 2004).

Feeding is one of the most natural infant occupations and is considered to be an infant’s primary work (Glass & Wolff, 1998). The process of feeding is generally considered a dependent task. However, through solicitation infants can take a more active role in this occupation. In the NICU environment, infants are typically fed on a set schedule and thus may require more time to develop an understanding of hunger as well as the cause and effect relationship between crying and being fed. Another issue related to feeding is the affect of multiple care givers because both the caregiver and the infant have to adapt to each other (Vergara & Bigsby, 2004). Social interaction is another example of an apprenticeship occupation and it is a vital component of the successful establishment of caregiver and infant attachment. Infants in the NICU tend to be less responsive to social stimulation than their full term counterparts due to their difficulty in
maintaining alert states (Vergara, 1993). These occupational areas provide avenues through which therapists and other practitioners can help families learn about their infant and develop a lasting and meaningful relationship with their baby.

Interventions in the NICU

There are a number of intervention strategies utilized in the NICU to aid in infant development and promote parental competence. According to a study by Caretto, Topolski, Linkous, Lowman, & Murphy (2000) the primary role of an occupational therapist practicing in the NICU is to promote oral-motor and feeding skills, provide therapeutic positioning recommendations, facilitate the development of parent-infant relationships, and teach parents how to interpret their baby’s behavioral signals.

Feeding

Adequate nutrition is a vital component for growth and recovery and therefore therapists are consulted more often for feeding issues than for any other matter. Occupational therapists are often involved with educating parents about oral stimulation, nonnutritive sucking, bottle feeding, breast feeding, and positioning for feeding. Although occupational therapists are not typically involved in educating parents about types of tube feeding, they are involved with the transition from tube feeding to oral feeding (Caretto, et al., 2000). Types of feeding interventions in the NICU may include: encouraging pacifier sucking throughout hospitalization even if an infant is tube or gavage fed, providing oral stimulation as a warm-up to feeding, selecting a quiet environment free of excess stimuli, changing the infant’s diaper prior to feeding, swaddling the infant to promote flexion, maintaining scheduled feeding times, and holding an infant in an upright position to reduce the risk of aspiration. These are but a
Positioning

Positioning is another intervention category in which an occupational therapist may play a primary role. Proper positioning can help reduce stress for the infant and promote physiological stability and development. Therapists may make positioning suggestions to encourage the best possible functioning of infants in the NICU and to prevent positional deformities. Some of the basic guidelines for positioning presented by Hunter (2004) include swaddling the infant, providing a soft surface such as sheepskin or a warm gel mattress with deep boundaries, and avoiding supine unsupported positions as much as possible because these positions promote motor disorganization. In a study by Grenier, Bigsby, Vergara, and Lester (2003) it was found that sidelying un-nested was the position least favored by the infant, and this position produced the most stress and self-regulatory responses. In the same study it was noted that prone nested was the favored position and produced fewer stress behaviors by the infants observed. Hunter (2001) recommended: repositioning infants every two to three hours to reduce the risk of pressure sores and misshapen heads, respecting infant individuality by using support positions that are calming to each unique infant, assuring proper fit of diapers in order to prevent hip deformities, and handling the infant gently between position changes.

Kangaroo Care

One intervention strategy that promotes the development of parent-infant relationship is skin-to-skin contact, otherwise known as kangaroo care. This strategy was
first suggested in 1978 by Dr. Edgar Rey, in Bogota, Colombia but has only gained popularity in the United States in the last decade. This strategy was used as a means of compensation for overcrowding and minimal resources, and was designed to mimic marsupial caregiving; hence the name kangaroo care (Tessier, et al., 1998). Kangaroo care, involves positioning the infant in an upright position on the caregiver’s chest with direct skin-to-skin contact; this position has been shown to regulate infant temperature as well as, or better than an incubator (Johnson, 2005). The benefits of skin-to-skin contact, or kangaroo care, are broad and are valuable to both the parent and the infant. This intervention is to be carried out solely by the family, and thus promotes increased feelings of competency in caregiving ability, improved feelings of attachment, and decreased parental stress. Benefits to the infant include unlimited access to maternal food source, more stable heart and breathing rates, analgesic effects, decreased agitation, improved sleep-wake cycles, improved state control, and decreased stress caused by environmental factors or medical procedures (Johnson, 2005; Hunter, 2001).

**Infant Massage**

There are also a variety of other complementary intervention strategies incorporated into the NICU that allow the family to take a more active role; one intervention is infant massage. Infant massage is a means through which parents can gain skill in touching and handling their baby in a gentle and positive manner and may be considered for infants who are more than 33 to 34 weeks post conception and are medically stable (Lorenz, Moyse, & Surguy, 2005; Hunter, 2001). Massage should not be introduced prior to this since it can be stressful and overwhelming for younger and less stable infants. A specially trained therapist should teach infant massage techniques to
the parents when the infant nears discharge. Like skin-to-skin contact, infant massage presents a number of benefits for parents and infants. For the parents, infant massage provides an avenue through which they can facilitate bonding with their infant, learn to better read their baby’s signals, and socialize with their child. For the infant, massage can aid in relaxation, can promote improved quality and quantity of sleep, and may have a positive impact on weight gain (Lorenz, Moyse, & Surguy, 2005; Moyse, 2005). Although massage has many positive aspects, the sensory effects of the stimulation should be monitored and if the infant shows signs of stress massage should be halted (Hunter, 2001).

*Auditory Stimulation*

Another complementary approach that may be utilized in the NICU is auditory stimulation, or music therapy. Intentional sounds such as music, the human voice, heartbeat, or recorded uterine sounds are often selected in the NICU for their potential to soothe, calm, promote cognitive and sensory development, and supersede the ambient, potentially harmful, noises associated with the NICU (Standley, 2002; Vergara, 1993). Parents can take part in this type of intervention by recording themselves reading stories, singing lullabies, or taping their heartbeat to play when they are not present. Potential family benefits of taking part in auditory stimulation include increased parent-infant relations, increased feelings of efficacy, and the facilitation of a positive transition home (Standley, 2002).

*Family Experiences in the NICU*

The birth of an infant with serious medical complications is an unexpected and stressful event for families. Compounding this stress is the necessity for specialized care
that often mandates the transfer of the infant to a NICU. Due to the high cost of the lifesaving technology found in the NICU, regionalized care facilities were developed. These facilities are commonly found in more populated areas and are often many miles away from the family’s home (Vergara & Bigsby, 2004; Whaley, Gosling, & Schreiner, 1979). The combined stress of a complicated birth and separation from the infant often exacerbates the natural stress and anxiety associated with delivery. Environmental factors associated with the NICU do little to allay the apprehension that parents may be experiencing. Other sources of parental stress within the NICU may include the inability to fulfill expected parental roles, the appearance and behavior of their child, the significant amount of medical information that they are presented with, and communicating with staff and other professionals responsible for their child’s care (Dudek-Shriber, 2004; Klassen, Lee, Raina, & Lisonkova, 2004; Lawhon, 2002).

**Parental Roles**

Most expectant parents anticipate the birth of a full term, healthy infant. When a child is born prematurely, the parents must adapt their expectations to meet the medical needs of their infant. Frequently parents are neither emotionally nor physically prepared for the arrival of a medically fragile child and therefore they are unsure of what to expect. In lieu of a celebratory atmosphere involving family and friends, parents may instead feel isolated due to the restrictions of the NICU environment. Instead of focusing on nurturing and spending quiet time with their child they must concentrate on their child’s health and survival. These concerns may create strong feelings of fear, uncertainty, or anger; but parents are forced to set their own feelings aside in order to fulfill the more pressing demands of their child’s medical instability. This interrupts the traditional and
expected roles of parenthood which include protecting, caring for, educating and providing for their child. Parents of full term, healthy infants act as advocates, primary care providers, and decision makers (Bialoskurski, Cox, & Hayes, 1999; Lawhon, 2002; Olson & Baltman, 1994; Vergara & Bigsby, 2004). However, parents of children in the NICU must share these responsibilities with a multidisciplinary team focused on sustaining their child's life. According to Vergara and Bigsby (2004):

The lack of clear parental roles, the lack of privacy, and the intensity of the NICU environment are not conducive to parental feelings of self-efficacy and self-esteem, or to early parent-infant interactions. Often, parental opportunities to learn about the baby are limited, which can further compromise parental confidence, participation, and pride in caregiving. (p. 172)

In a study exploring the influence of parent and infant characteristics on parental stress, Dudek-Shriber (2004) found that the most stressful aspects of having a child in the NICU is the alteration of the parental role. This role alteration was found to be particularly stressful for mothers, young parents, and parents of children with cardiovascular diagnoses. Padden and Glenn (1997) made a similar discovery in that the majority of the woman in their study expressed a lack of confidence in their maternal role. These women also expressed a fear that their child would form a stronger bond with the nursing staff than with them. Despite this lack of confidence, the majority of the mothers reacted positively to the experience of holding their infant for the first time and stated that this experience made them feel like a true mother.

According to Dudek-Schriber (2004) a fundamental step in the fulfillment of parental roles is establishing a bond with the infant. The bonding experience between
parents and a newborn infant often lays the ground work for a healthy lifelong relationship. However, placement in the NICU often interrupts the natural evolution of the parent-child bond. Parents of a child in the NICU often bring with them a variety of personal factors that affect how they cope with stress. By developing an understanding of individual parental stressors and coping mechanisms therapists and other health care professionals can better aide parents in developing the skills required to meet the needs of their infant and fulfill expected parental roles. The authors note that practitioners working in the NICU play a vital role in promoting quality parent-infant interactions. By allowing parents to take an active role in their child’s care, therapists can decrease parental stress and promote infant development.

The importance of involving parents in the care of their infant was validated in a study by Van Riper (2001). When asked what advice could be given to professionals working in the NICU, one mother responded, “Give us helpful suggestions even if we don’t ask for them... we need to know about many things that we may not even think of asking about. Letting us do their “cares” really helps us feel more like parents...” (p. 81). Therapists can encourage parents to participate in treatment in a variety of ways. For instance: assisting with bathing, feeding, and diapering; bringing in items unique to the family to place in or near the incubator; supplying breast milk; or choosing clothing for the infant to wear are all ways in which the parents can take part in care (Vergara, 1993). In addition, by educating parents about their infant’s signals and what they mean, therapists can facilitate parental abilities to interpret their child’s behaviors. At the same time, therapists can introduce ways to adjust their child’s environment or position their child to promote a more calm state (Vergara & Bigsby, 2004). As parents begin to learn
about and get to know their infant they become more relaxed and comfortable in their role as a parent and gain confidence in their ability to care for their child (Lawhon, 2002). As parents become more secure in their interactions with their infant they may benefit from non-structured time with their child when they can hold, talk to, and generally get to know their child without the pressures of learning new care techniques or having to associate with the staff (Vergara & Bigsby, 2004).

The occupational therapist’s role in this process is to nurture the parent’s attachment to their infant by helping the family in, “recognizing and responding appropriately to their infant’s cues of stress or stability, providing therapeutic positioning and developmentally supportive handling, regulating sensory input, facilitating functional oral feeding, and meeting the infants long-term developmental needs” (Hunter, 2001, p. 649).

**Communication**

Communicating with staff is another stressor for the family in the NICU. This can be diminished by building positive rapport between the family and other care providers. In order for the parent-therapist relationship to be effective it is vital to establish a partnership. In a qualitative study by Holloway (1994), parents of NICU graduates were asked to share their perspectives on collaborating with occupational therapists. Through their comments and observations a series of guidelines for parent-therapist collaboration were developed. These guidelines included the following: create opportunities for parents to share their perceptions of their infant, consider and respond to parental concerns not just therapy concerns, share information in a manner that demonstrates respect for the parents, keep in mind that each family is unique and their
level of involvement may vary, involve parents in interpreting their infant’s behavior, support parents gains and acknowledge successes, pay attention to parental responses to therapy and provide additional information as needed, establish consistent communication among professionals to assure that the message parents receive is clear, promote parent proficiency and knowledge, and use occupation-based activities to enhance the bonding experience (Holloway, 1994, 536-537).

**Siblings**

An additional area to be considered when collaborating with families is sibling adjustment. Like parents, siblings can be overwhelmed by the NICU experience and may not fully understand what is happening to their brother or sister. In the midst of this confusing and chaotic time, parents and caregivers may have less time and energy to expend on monitoring the daily lives of their other children (Munch & Levick, 2001). There are a number of ways in which professionals working in the NICU can assist in sibling adjustment. One way of relieving sibling anxiety is through staff led groups focused on exploring the siblings’ feelings about having a sister or brother in the NICU. In their book, Vergara & Bigsby (2004) described a program entitled “Kids Klub” which involves preparing the children for what they will see in the NICU prior to their first visitation. The children also create an art project which can be given to their sibling to put in their isolette. A staff member then accompanies the child to visit their sibling and parents in the NICU; the visitation is kept short (20 minutes or less). In the past, siblings have been excluded from the NICU environment for a variety of reasons. These reasons included: fear of increases in infant infection rates, the potential for interruption of the functions of the unit, and the potential for emotional harm for the visiting sibling.
However, in a research study by Schwab, Tolbert, Bagnato, and Miasels (1983) evidence was found to contradict the aforementioned assumptions. In fact, data from this study indicated that siblings expressed a desire to revisit their sister or brother, and described their visit in a positive manner. In conclusion, sibling visitation was found to be an important and integral part of the family bonding process (Schwab, et al., 1983). Another program described in an article by Munch and Levick (2001) was “Sibling Night”. This program incorporates two groups, one for siblings and one for parents. The sibling group uses art as a treatment modality to help the children explore their feelings related to hopes and dreams, social supports, current life events, and self confidence. The projects are not solely NICU focused, instead they explore coping abilities and identify problem areas which will ultimately help parents understand their child’s emotional responses and incorporate interventions as needed. The parent group addresses psychosocial factors relative to the NICU experience, provides educational material to aid in understanding of child development, and provides several strategies and suggestions for supporting their other children (Munch & Levisk, 2001). Another emerging area relative to sibling adjustment is the practice of co-bedding. Co-bedding involves placing multiple-gestation infants in a single incubator after birth. This standard of care has been implemented in Europe for over a decade but only began to be utilized in the United States in 1994 (Byers, Yovaish, Lowman, & Francis, 2001). It is hypothesized that this can help lead to improved physiological stability, regulation of temperature and vital signs, increased growth and development, minimized length of stay and readmissions, and improved transition of the infants to their home environment (DellaPorta, Aforismo, & Butler-Ohara, 1998). However, there is little empirical evidence to support these assumptions.
Even so, co-bedding has proven to be a safe technique to use with multiple-gestation infants as long as infection is monitored closely (Byers, Yovaish, Lowman, & Francis 2001; Vergara & Bigsby, 2004).

Continuing Care

Just as admission to the NICU is a stressful and overwhelming experience for families, the transition home may also induce high levels of anxiety. Discharge means separation from a very structured and supportive environment where a number of highly trained professionals are available to assist with an infant’s care day and night. Though parents or caregivers will most likely continue interacting with a variety of professionals in their home environment, transition home means that the parents or caregivers will be taking a more active and independent role in their baby’s care. Parenting a NICU graduate poses many challenges. Due to their immature nervous system, and unique medical needs, these infants interact less predictably than full term infants and may require additional parental attention upon returning home in order to assess their adjustment to this new environment (Bakewell-Sachs & Gennaro, 2004). It is up to professionals working in the NICU to provide parents with the knowledge and guidance they need to feel comfortable and competent in caring for their child at home. It is also important that parents are aware of available resources that they can access within their community.

One resource is an early intervention program. This program is often the first step in establishing community support and acts as a gateway to other community resources. Early intervention refers to, “a variety of services designed to meet the developmental needs of children from birth to 36 months who have a documented delay...or who have a
high probability of delay” (Bondurant & Brinkman, 2003, p. 259). This program was created under the 1990 amendments to the Individual’s with Disabilities Education Act (IDEA). These amendments created part C, which established an entitlement for the provision of services for infants and toddlers (birth to 36 months). The goals of this amendment strive to enhance the development of children with or at risk for developmental delays, reduce the cost of future educational needs, maximize potential for independence, and facilitate the ability of the family to care for and meet the needs of their child. Part C also mandates that early intervention programs address developmental areas including physical, cognitive, language, psychosocial, as well as self-help skills. Early intervention meets the unique developmental needs of each child and addresses family goals and concerns through the formation of individual family service plans (IFSP) which guide service delivery. The IFSP, “identifies the child’s needs; the families priorities, resources, and concerns related to their child’s development; and the services that must be provided to address the identified needs” (§ 303.304). Part C of IDEA also requires that early intervention services should be provided in the natural environment to the greatest extent possible. This may involve providing services in the child’s home, other care environment, or community settings in which the child may be expected to participate (Bondurant & Brinkman, 2003).

The role of the occupational therapist in the early intervention process is defined in IDEA (34 CFR § 303) as:

Services to address the functional needs of a child related to adaptive development; adaptive behavior and play; and sensory, motor, and postural
development [and is] designed to improve the child’s functional ability to perform tasks at home, at school, and in the community.

More specifically, the occupational therapist may be involved in adapting the environment, as well as selecting, designing, and fabricating assistive and orthotic devices that can be used to improve function and independence. The overall goal of occupational therapy in the early intervention setting is to facilitate independence by increasing motor control, sensory modulation, adaptive coping, sensorimotor development, social-emotional development, daily living skills, and play. In general, the occupational therapist acts as part of a multidisciplinary team to minimize the negative effects of an impairment or disability on daily functioning (Gorga, 1989; Stephens & Tauber, 2001).

Summary

The birth of a medically fragile infant is a stressful and confusing time for many parents and caregivers. They are often bombarded with new sights, sounds, and information that may seem foreign and daunting. It is important that professionals working in the NICU empathize with parents and provide them with the support and knowledge they need to overcome crises, develop coping skills, and interact effectively with their child (Olson & Baltman, 1994).

Developmentally supportive care is one way in which NICU practice has evolved to better meet the needs of the family. This theory looks first to the entire family’s needs and nurtures their strengths and abilities. Developmentally supportive care seeks to facilitate parent-infant interactions and assist parents in understanding their child’s signals and in responding appropriately. Overall, developmentally supportive care strives
to assist infants to maximize their potential for normal development and minimize the effects of prolonged hospital stays (Starr & Hoye, 1998).

As the NICU environment has evolved to meet the needs of critically ill infants, so has the role of practitioners working in this environment. Occupational therapists in the NICU have a primary responsibility to provide developmentally supportive care within their scope of practice. Typically the occupational therapist is responsible for promoting oral-motor and feeding skills, therapeutic positioning, facilitating the development of parent-infant relationships, and teaching parents how to interpret their baby’s signals. Through these interventions, occupational therapist can aid parents in fulfilling their expected roles and gaining confidence in their abilities to care for their child.
CHAPTER III
ACTIVITIES/METHODOLOGY

After an initial literature review and visiting with area NICU personnel, we concluded that families may benefit from the provision of a concise and user friendly resource that can be utilized during their child’s stay in the NICU. The product of this scholarly project is a user-friendly resource manual for parents that is based on information in current research and literature, and the information gathered from area NICU personnel.

An extensive review of literature was completed; it included: the history of the NICU, current best practice, physical context of the NICU, infants in the NICU, infant occupations, occupational therapy interventions in the NICU, family experiences in the NICU, and continuing care. We also visited area neonatal intensive care units to gather information and examples of resources that are given to parents while their child is in the NICU. We also spoke with a registered nurse, and two occupational therapists that specialize in NICU care to gather information about the structure of the NICU, and common interventions. The information gathered was used to supplement the literature findings and guide the development of the product. Finally we obtained permission to take pictures of equipment in the NICU at Altru Health System in Grand Forks, North Dakota.

A resource manual was developed to provide families with an easy to understand guide to help navigate the complex environment of the NICU. The manual is divided
into sections and includes information about: staff and caregiver roles, common conditions that an infant in the NICU may experience, equipment that is typically seen in the NICU, behavioral cues that an infant may display, tips to promote bonding with an infant, information on feeding and positioning, and information that may ease the transition home. Each section provides easy to read descriptions of the various topics and pictures to facilitate understanding of the material presented.
CHAPTER IV
PRODUCT

The product developed for this scholarly project is a guide to the neonatal intensive care unit created for families of infants in the NICU. This guide was designed to be an easy to understand resource that occupational therapists working in the NICU can provide to families. This guide can be included as part of an orientation packet upon admittance to the NICU or it can be presented to families during a treatment session when concepts can be demonstrated or explained by the occupational therapist.

In this guide the sights, sounds, and professionals common to each NICU are defined and specific therapy practices are described. This guide provides a brief introduction to the NICU, it provides descriptions of the various professionals working in the NICU and their role in infant care, it defines conditions commonly seen in the NICU, and equipment that families may see. This guide also includes information on feeding, positioning, activities that can promote bonding, and material about going home and continuing care following a NICU stay.

The theory used to guide the development of this product was Occupational Adaptation by Schultz and Schkade (2003, p. 220-223). This theory is relevant to the experiences of families and infants in the NICU as these individuals are faced with an unfamiliar environment and stressful life event. Families in the NICU, through their interactions with staff and the NICU environment refine their caregiving skills and their
ability to adapt to their child’s needs. Through their pursuit of knowledge and their
development of new skills families gain a sense of mastery that, in turn, prepares them
for their role as primary caregivers in their own home.
A Family Guide
To The
Neonatal Intensive Care Unit

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Merri Reese, MOTS
&
Gail Bass, Ph.D., OTR/L
Table of Contents

- Preface .................................................. 1
- Introduction ............................................. 2
- What is the NICU ......................................... 3
- Handwashing ............................................. 4
- Important Names & Numbers ......................... 5
- Our New Baby ........................................... 6
- My First Picture ......................................... 7
- Staff & Caregiver Roles ................................ 8-10
- Common Conditions ..................................... 11-15
- NICU Equipment ......................................... 16-18
- Your Baby’s Signs ....................................... 19-22
- Kangaroo Care ........................................... 23
- Infant Massage ........................................... 24
- General Bonding ......................................... 25
- Feeding ..................................................... 26-28
- Positioning ............................................... 29-30
- Tips for Parents ......................................... 31
- Siblings & the NICU ..................................... 32
- Going Home .............................................. 33-36
- Continuing Care ......................................... 37
- References
- Note Pages
- NICU Graduation Certificate
Introduction

The purpose of this guide is to help you become acquainted with the neonatal intensive care unit (NICU). The NICU can be a frightening and overwhelming place for new parents. This guide will help you to understand the people working in the NICU, the common conditions babies in the NICU may have, and the equipment you may see here.

This guide will give you some suggestions of ways you can get to know your baby and take part in his/her care. You will find information that may be helpful when you and your baby are ready to go home.

This guide is meant to give you a general overview of the NICU. It is not meant to take the place of advice given to you by the NICU staff working with your baby. Please make sure you always ask NICU staff if you have any questions.
What is the NICU?

The NICU is a specialized nursery designed to care for infants who were born early or are very ill and require extra care. The staff in the NICU are trained to provide the care your baby needs and to help you and your family learn about the NICU.

The care provided in the NICU and the people who work there will help your baby grow and develop until he/she is ready to go home. You can help by taking part in your baby's care.
Hand Washing

Washing your hands is the first line of defense against the spread of germs. By following the hand washing steps below you can help prevent the spread of infection.

- Wet hands with warm running water.

- Apply hand washing agent (soap) and thoroughly distribute over hands.

- Vigorously rub hands together for 10 to 15 seconds, including fingers, thumbs, backs of the hands, and beneath the fingernails.

- Rinse hands thoroughly to remove soap then dry using paper towels.

- If the sink does not have foot controls or an automatic shutoff, a paper towel may be used to shut off the faucet.

The above information was adapted from http://www.infectioncontroltoday.com.
Important Names & Numbers

Neonatologist:
________________________________________ nº ________________

Other Physicians:
________________________________________ nº ________________

Nurses Station / Charge Nurse:
________________________________________ nº ________________

Social Worker / Case Manager:
________________________________________ nº ________________

Psychiatrist (MD) / Psychologist (PhD):
________________________________________ nº ________________

Therapy:
Occupational Therapy: ______________________________ nº ________________

Physical Therapy: ______________________________ nº ________________

Respiratory Therapy: ______________________________ nº ________________

Speech Language Pathology: __________________________ nº ________________

Other: ______________________________________________ nº ________________

Clergy: __________________________________________ nº ________________
Our New Baby!!!

• My Name is:__________________________

• I was born on:_____________ at _______ am/pm

• I weighed:_____________ pound(s), ___________ ounces

• I was __________ inches long

• My Parent(s) Name(s) are:__________________________

• My Sibling(s) Name(s) are:__________________________

• My Address is:__________________________

• I was born at ___________________________ Hospital

• The Doctor who delivered me was:__________________________

My First Visitors

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________
Neonatologists:
Are doctors who have completed additional training to care for premature infants and newborns. This person is ultimately responsible for the medical care your child receives.

Physicians Assistant (PA):
Are professionals who work under a physician. They have been trained to address the symptoms your baby is having and work with the physician to choose the best way to help your baby.

Nurse Practitioners (NP):
Are registered nurses (RN) who have obtained additional training in a specialized area such as the NICU. Although nurse practitioners are supervised by a doctor they may prescribe medications and complete some procedures. Often the NP is the primary caregiver and a good source of information about your child's medical condition(s).

Neonatal Nurses:
Are most often registered nurses (RN), but may also be licensed practical nurses (LPN). These nurses have also received additional training in NICU caregiving. The RNs and LPNs are responsible for the daily care of your baby. Your infant is typically assigned to one nurse on each shift. These nurses often have the most contact with your baby.
Staff & Caregiver Roles

NICU Case Managers:
Are individuals with extensive experience in neonatal care and early intervention services. Your baby will be assigned his/her own case manager, who is responsible for overseeing the care and training you and your baby receive while in the NICU. Your case manager will also help you prepare for your baby's homecoming.

Social Workers:
Are individuals who have completed training in clinical social work and have experience working with families in the NICU. These individuals will help you and your family cope while your baby is in the NICU. Social workers are knowledgeable about resources that may be available to you and your family and can help you access these resources.

Nutritionists:
Are registered dieticians who have pursued additional training in pediatric and neonatal nutrition. These individuals assist doctors in determining the appropriate nutritional needs of your child and will track your baby's growth and weight gain. Nutritionists may also help you solve feeding problems before you take your baby home.

Respiratory Therapists (RT):
Are individuals who are responsible for monitoring your baby's breathing. If your child needs assistance to breathe from a mechanical ventilator, RTs are responsible for making sure the machine is set properly for your baby's needs. These individuals may also perform treatments that will help clear your baby's lungs and make it easier for him/her to breathe.

The above information was adapted from Vergara & Bigsby (2004).
Staff & Caregiver Roles

Occupational Therapists (OT):
Are therapists who have knowledge of pediatric development and have completed additional training in NICU intervention. Occupational Therapy services usually focus on feeding, positioning, and adapting your baby's environment to meet his/her needs. These individuals will also help monitor your baby's development.

Physical Therapists (PTs):
Are therapists who specialize in motor development and have special training with pediatrics and NICU interventions. PTs can also help with positioning your baby so he/she is most comfortable. These therapists may also provide your infant with treatments that help them develop healthy movement patterns.

Speech Language Pathologists (SLP):
Are therapists who have completed training in speech development as well as the pre-language skills that are needed to acquire speech. SLPs may assess your baby's ability to suck and swallow and may recommend special feeding techniques.

Clinical Psychologists:
Are individuals who have completed a Ph.D. in psychology and have experience working with families in crisis. These individuals may provide individual and family counseling to help you and your family adjust.

The above information was adapted from Vergara & Bigsby (2004).
Respiratory Distress Syndrome (RDS): This is a condition in which the lungs cannot inflate or function correctly because they are under-developed.

Apnea of Prematurity (AOP): This is the Most common respiratory condition in premature infants. An episode of apnea is when a baby stops breathing for more than 20 seconds.

Bronchopulmonary Dysplasia (BPD): This condition is most often caused by prolonged oxygen exposure and mechanical ventilation. This condition may cause water and air to become trapped in the lungs and makes breathing difficult.

Pneumonia: An infection of the lungs that may cause symptoms similar to Respiratory Distress Syndrome.

The above information was adapted from Hunter, 2001; Taber, 2001; and Vergara & Bigsby, 2004.
Common Conditions

Cardiac Conditions

Patent Ductus Arteriosus (PDA): This condition results when a heart vessel (tube) that is suppose to close at birth stays open. This causes blood within the heart to mix, lowering the amount of oxygen reaching the body.

Atrial and Ventricular Septal Defects: This condition results when one of the walls separating the four interior compartments of the heart is not well formed.

Persistent Pulmonary Hypertension (PPHN): A condition that results when pressure in the lungs causes blood pressure in the heart to rise. This may cause blood carrying oxygen to mix with blood not carrying oxygen in the heart. This decreases the amount of oxygen that the rest of the body receives.

The above information was adapted from Hunter, 2001; Taber, 2001; and Vergara & Bigsby, 2004.
Intraventricular Hemorrhage (IVH): This condition is bleeding within the ventricles which are specific parts of the brain. This condition has four classifications (1-4) with grade four being the most severe.

Neonatal Seizures: A seizure occurs when there is abnormal electrical activity in the brain. This may result in odd or repetitive movements that are not typical to the infant.

The above information was adapted from Hunter, 2001; Taber, 2001; and Vergara & Bigsby, 2004.
Hyperbilirubinemia: More commonly known as jaundice, this condition causes the skin to take on a yellowish color.

Retinopathy of Prematurity (ROP): This condition occurs when there is damage to the blood vessels in the infant’s eye. This condition may cause vision problems in later years.

Necrotizing Entercolitis (NEC): This disease affects the intestines. It causes damage to the intestines and can make digestion difficult.

Gastroesophageal Reflux (GER): This condition results when stomach acid comes up from the stomach and into the esophagus. This condition may cause problems with feeding.

Hospital-Acquired (Nosocomial) Infections: These are infections that the infant may get after entering the hospital.

The above information was adapted from Hunter, 2001; Taber, 2001; and Vergara & Bigsby, 2004.
Our Baby's Conditions

Name of Condition: ____________________________

Questions We Have: __________________________

Name of Condition: ____________________________

Questions We Have: __________________________

Name of Condition: ____________________________

Questions We Have: __________________________

Name of Condition: ____________________________

Questions We Have: __________________________
NICU Equipment

Temperature Regulation

Radiant Warmer:
This is an open bed with an over-head heat source. This bed is used when nurses and doctors need to be able to watch your baby closely and have easy access for medical procedures.

Incubator or Isolette:
This is a clear plastic box which is heated and has an adjustable mattress. This bed is used to keep your baby warm and let him/her focus on growing and healing. Portholes allow you and staff to access your baby.

Open Crib:
This is a bassinet-style bed with a mattress but no heat source. Once your baby is more stable he/she would be dressed, swaddled (wrapped in a blanket) and put in this type of bed.

The above information was adapted from Hunter (2002) and Vengara & Bigsby (2004). Photographs courtesy of Atrium NICU.
NICU Equipment

Oxygen Therapy

Bag & Mask:
This is a bag attached to a face mask. The bag is squeezed to give your baby oxygen in an emergency.

Oxygen Mask or Nasal Cannula:
The mask is placed over your baby's nose and mouth to deliver extra oxygen. The prongs of the nasal cannula are placed in your baby's nose and this is another way that your baby can be given extra oxygen.

Oxygen Hood:
A plastic hood that is placed over your baby's head to provide him/her with extra warm, moist oxygen. This is used for babies who can breath on their own but need a little extra oxygen.

The above information was adapted from Hunter (2001) and Vergara & Bigsby (2004). Photographs courtesy of Altru NICU.
NICU Equipment

Oxygen Therapy

Extracorporeal Membrane Oxygenation:
This machine is also called ECMO. The ECMO is a life-support machine that takes over the work of the baby’s heart and lungs.

Mechanical Ventilator:
This machine can either breathe for your baby or help your baby breathe. A baby who needs this machine will have a tube in their nose, mouth, or throat.

Continuous Positive Airway Pressure:
This machine is also called a CPAP. A CPAP provides your baby with continuous warm, moist air at a specific pressure. The CPAP is used with infants who can breathe on their own but need help to keep their lungs open.

The above information was adapted from Hunter (2001) and Vergara & Bigsby (2004). Photographs courtesy of Altru NICU.
I AM Happy

These signals tell you that your baby is happy and ready to interact.

**Relaxed:**
Your baby's arms, legs, and face are relaxed and still.

**Alert:**
Your baby's eyes are open and he/she may try to coo.

**Looking:**
Your baby is looking at you or at other objects in his/her space.

**Trying to Smile:**
Your baby's eyes are open and he/she may try to smile.

The above information was adapted from Grenier, Bigsby, Vergara, & Lester (2003); Hussey-Gardner (1996).
I AM Stressed

These signals tell you that your baby is not happy and may need a break or a change.

Crying:
Your baby will begin to fuss and make loud noises that let you know that he/she is uncomfortable.

Finger Splaying:
Your baby's hand(s) will open wide and the fingers will be spread away from each other.

Yawning/Sneezing/Hiccupsing:
Your baby will open his/her mouth wide and take a big inward breath, will sneeze out loud, or will begin to make hiccupsing sounds.

The above information was adapted from Grenier, Bigsby, Vergara, & Lester (2003); Hussey-Gardner (1996).
I AM Stressed

These signals tell you that your baby is not happy and may need a break or a change.

Grimacing/Grunting/Frowning:
Your baby will make unhappy faces, frown, or will grunt to let you know they are upset.

Arching:
Your baby will push his/her head back or will arch his/her back to indicate discomfort or stress.

Turning Away:
Your baby will turn his/her head away from bright lights, loud noises, or people if he/she is overwhelmed.

The above information was adapted from Grenier, Bigsby, Vergara, & Lester (2003); Hussey-Gardner (1996).
These signals tell you that your baby is trying to cope with stress on their own.

**Hand(s) to Mouth:**
Your baby brings his/her hand(s) up to his/her mouth and may suck on his/her fingers.

**Hands Together:**
Your baby may hold his/her hands together to make him/her feel more secure.

**Light Sleep:**
Your baby may fall into a light sleep in order to shut out sights and sounds that he/she finds upsetting.

**Snuggling:**
Your baby may snuggle into the corners of his/her bed to determine where the boundaries are.

The above information was adapted from Grenier, Bigsby, Vergara, & Lester (2003); Hussey-Gardner (1996).
Kangaroo Care

Kangaroo care originated in Columbia, South America as a way to keep infants warm when incubators were not available. The benefits of this type of care may include:

- Helping you bond with your baby
- Helping your baby to stay warm
- Helping your baby to stay calm
- Helping your baby to sleep better

How To Use Kangaroo Care

- First ask the staff in the NICU about their policy on the use of kangaroo care.
- You should wear loose clothing to allow your infant to fit inside your shirt.
- Dress your infant in a diaper and a hat with a light blanket for cover.
- Sit in a quiet and comfortable location
- Place your baby on your bare chest with skin to skin contact. Your baby’s head should be near your chin.
- Ask the NICU staff about the length of time that is appropriate for your baby to stay in this position.

The above information was adapted from http://www.marchofdimes.com
Infant Massage

Infant massage is a way to touch your baby in a gentle and positive manner. This technique is usually introduced close to discharge and requires special training. The benefits of this type of massage may include:

- Helping you bond with your baby
- Helping your baby to feel secure
- Helping your baby to stay calm
- Helping your baby to sleep better
- Helping your baby to gain weight

**How To Prepare for Infant Massage**

- First ask the staff in the NICU about their policy on the use of infant massage.
- Gather Supplies (unscented massage or oil, lotion, blanket, extra clothing, towels)
- Change your baby's diaper before beginning
- Find a warm and quiet area
- Relax yourself first
- Use slow and rhythmic movements
- Smile and make eye contact with your baby
- You can also talk or sing as you massage

**** Ask an occupational therapist or nurse about specific massage techniques.

The above information was adapted from http://laim.homestead.com
General Bonding Ideas

A few other ideas to help you bond with your new baby:

- **Participate in your baby's care**
  - You can get involved by helping with bathing, diapering, feeding, and dressing your baby. Ask the NICU staff how you can help.

- **Take pictures of your baby with you and your family**
  - You can share these images with family and friends who are not able to visit.

- **Decorate your baby's space**
  - You may be able to bring toys, clothes, or blankets from home to create a cozier environment for your baby. You may also want to put up pictures of your family to allow the staff to get to know you better.

- **Record yourself reading a story or singing a lullaby**
  - The sound of your voice can be soothing to your child.

- **Spend time watching your baby**
  - Watching your baby will help you understand how they are feeling and will help you meet their needs.

The above information was adapted from http://www.marchofdimes.com
Parenteral/Intravenous Feeding

This type of feeding is used when a baby’s digestive system is not quite ready to take food. Intravenous/parenteral feeding provides nutrition to your baby directly into his/her blood vessels. This type of feeding gives your baby a mixture of sugars, fats, proteins, minerals, and vitamins; all of the nutrients he/she needs to grow. This type of nutrition is sometimes called total parenteral nutrition (TPN) and it means that your baby gets all of his/her food intravenously.

Infusion /Intravenous Pump:
This machine delivers nutrients to your baby at a rate that is specific to your child. It will give him/her as much or as little food as he/she can tolerate at one time.

Intravenous Feeding can be provided through 3 types of lines/tubes:

1. Peripheral Line: This line goes into a vein in the baby’s arm, leg, foot, or hand and is close to the surface of the skin.

2. Umbilical Line: This line is placed in a blood vessel in the baby’s umbilical cord.

3. Central Line: This line is placed in a major blood vessel near the baby’s chest or groin area. This type of line requires surgery to be put in place.

The above information was adapted from Veraboa (1993); Hunter (2002). Photo courtesy of Atrub NICU.
Feeding

Enteral/Gastrointestinal Tube Feeding

This type of feeding is used temporarily until your baby is ready to nipple feed. This is typically the next step after intravenous feeding and this transition is gradual. At times your baby may be tube fed and intravenously fed. Babies who are tube fed are often given a pacifier to suck at the same time to help them learn to breathe, suck, and swallow in the right order. Breast or bottle feeding is usually the next step.

This is one type of tube used for feeding. It is called a nasogastric tube. It delivers food directly to the baby's stomach.

There are 4 types of tubes used:

1. **Nasogastric (NG):** This type of tube feeding is also called gavage feeding. The tube is placed up the baby's nose, down his/her throat, and into his/her stomach.

2. **Orogastric (OG):** This type of tube feeding is also called gavage. The tube is placed in the baby's mouth, down his/her throat, and into his/her stomach.

3. **Nasojejunal (NJ):** With this type of tube feeding the tube is placed up the baby's nose, down his/her throat, and through the stomach delivering food directly into the intestines.

4. **Gastrostomy:** This type of tube feeding is for baby's who will need to be fed this way long term. The tube is placed directly into the stomach and requires surgery for placement.

The above information was adapted from Veragro (1993); Hunter (2001).

Photo courtesy of Altuz NICU
Breast/Bottle Feeding

Breast or bottle feeding is the next step after tube feeding. The transition from tube feeding to breast/bottle feeding is also gradual and breast milk may be first introduced during tube feeding. Breast milk is the best for your baby as it provides the most nutrition and is the easiest to digest.

Breast or bottle feeding is also a good time for you to bond with your baby.

Oral feeding is not always easy but there are a number of ways to help your baby learn to feed by mouth.

The following suggestions may help make feeding easier:

* If you are breast feeding drink plenty of water; this will increase milk production.
* Hold your baby in the kangaroo position after feeding to help with digestion.
* Feed your baby when he/she is alert.
* Use a feeding position recommended by the NICU staff
* Encourage pacifier sucking to help build strength in the mouth muscles.
* Find a calm and quiet place with dimmed lighting.
* Change your baby's diaper before feeding.
* Feeding should be a quiet time so that your baby can focus on eating.
* Monitor your baby's sucking and breathing pattern.
* Document your baby's feeding with the help of the NICU staff; include time and length of feeding, amount eaten, as well as how you feel the feeding went.

The above information was adapted from Veragra (1993); Hunter (2001).
Positioning

When your baby is in the NICU he/she may be put into certain positions that will help him/her to feel more secure and will help promote growth and development. You might hear the staff in the NICU talking about different positions.

Positioning Definitions:

**Prone:** This means that your baby is laying on his/her stomach.

**Supine:** This means that your baby is laying on his/her back.

**Sidelying:** This means that your baby is laying on his/her side.

**Nested:** This means that your baby is surrounded by blankets and/or pads.

**Swaddled:** This means that your baby is wrapped snuggly and securely in a blanket.

**Flexion:** This means that your baby's arms and legs are close to his/her body. This is a preferred position for your baby because it helps them feel more secure.

**Extension:** This means that your baby's arms and legs are held away from his/her body. This position makes your baby feel less secure and can increase stress.

The above information was adapted from Hunter (2002); Vergara & Blissby (2004).
Positioning

**Equipment**

These are just a few pieces of equipment that may be used to keep your baby in a comfortable position that is appropriate for his/her development.

**Sheepskin or Gel Mattress:** These devices provide your baby with a soft surface to lay on and keeps his/her skin from getting sore.

**Bendy Bumper:** This is a brand name positioning device that is used to keep your baby in a flexed position. It can be bent in a variety of shapes to meet your baby's unique positioning needs. A rolled up towel also works well.

**Snuggle Up or Bunting:** These pieces of equipment help keep your baby in a flexed and nested position. These devices also allow your baby to be moved while in the positioning aid which decreases the stress associated with being moved.

**Wedges:** This type of device allows your baby to rest in an elevated position. This positioning aid is typically used for babies with gastroesophageal reflux (GER), apnea or respiratory problems.

The above information was adapted from Hunter (2002); Vergara & Bigsby (2004). The photos were obtained from http://childrensmedical.respironics.com/index.html
Tips for Parents

During this stressful time it is more important than ever to make sure you take good care of yourself. Here are some ideas to help you cope with the challenges of having a baby in the NICU.

- Keep in mind that emotional stress can have physical side effects such as headaches, aching muscles, and fatigue.
- Treat yourself well:
  - try to get enough sleep
  - eat healthy foods on a regular basis
  - exercise
- Accept help from family and friends. They can:
  - Baby sit your other children
  - run errands
  - clean house
- Make plans for a weekly family activity to touch base with your family and friends.
- Find time for yourself.
  - Take a relaxing bath
  - Go for a walk
  - Watch a movie
  - Get a massage
  - Read a book, or whatever you need to do to relax.

When you take care of yourself you will be better prepared to take care of your baby!

The above information was adapted from http://www.kidshealth.org
Having a baby that is sick can be hard for brothers and sisters to understand. Here are some ways that you can give your other children the attention they need and help them adjust to their new sibling.

- Talk to your children about how they feel.
- Maintain routines as much as possible
- Visit the NICU with siblings
- Take pictures or videos of your new baby to share with your other children and family.
- Find a doll or stuffed animal that is about the same size as your new baby to give your other children an idea of how big their new brother or sister is.
- Make an audio tape of your other children talking, singing, or reading to their new brother or sister to play for the baby.
- Arrange for alone time with your other children to give them your undivided attention.

* make sure to find out about your facilities rules and regulations regarding sibling visitation.

The above information was adapted from Munch & Levick (2001).
Going Home

Before your baby is ready to go home he/she has to meet certain guidelines. Each NICU will have its own set of criteria for discharge so ask your case manager or other NICU staff members what the criteria are for your baby.

The following are some of the most common guidelines that your baby should meet before going home:

- Your baby will be able to keep him/herself warm without the help of an incubator.
- Your baby will be able to breathe on his/her own (some babies are allowed to go home on oxygen).
- Your baby is able to breast feed or feed from a bottle (Some babies may still need some tube feedings).
- Your baby's medical condition is stable.
- Your baby weighs around 4 pounds, or more, and is gaining weight steadily.

If your baby requires tube feeding or is going home with other machines make sure you are comfortable with all of his/her equipment before leaving the NICU. Make sure to ask any questions you may have; the NICU staff is there to help you.

The above information was adapted from Hunter (2001); Vergara & Bigsby (2004); Verma, Sridhar, & Spitzer (2003).
Going Home
Parent’s Checklist

If we are
■ Comfortable giving our/my baby a bath.
■ Comfortable with taking care of his/her umbilical cord.
■ Comfortable feeding him/her.
■ Comfortable giving him/her medications.

If We Know...
■ How to mix formula if needed.
■ How much and how often to feed my/our baby.
■ How to take our/my baby’s temperature and
■ How to read the thermometer.
■ How to perform CPR if necessary.
■ How to use a car seat properly.
■ How to use all of the equipment my/our baby needs.
■ What to do in an emergency.
■ The name and number of someone we can call if we have questions.

# __________________________
Going Home

The Ride Home

Finally the day you have been waiting for! Your baby is ready to go home. But, before you get in the car there are a few things to consider.

Car Seat Tips:

- Always put your baby in a car seat when riding in a vehicle.
- The middle position of the back seat is the safest.
- Most standard car seats are too large for your baby; you may need an insert like the one pictured to the right.
- Avoid using heavy blankets or snowsuits under the harness straps. These make difficult to tighten the straps as much as is needed to keep your baby safe.
- Never leave an infant unattended in a car seat in a vehicle.
- Never remove an infant from a car seat when the vehicle is in motion. Pull the vehicle over to the side of the road if needed.
- The base of the care seat should sit flat on the seat not sloped with the vehicle (rolled towels or blankets can help level the seat).
- If you are unsure of how to use a car seat ask the NICU staff to help you.
- Some cities/hospitals offer car seat “clinics” where you can have your car seat inspected in your vehicle.

This information was adapted from Altru Health System car seat safety guidelines 2005.
Tips for Playing with your baby at home

• Repeat the sounds your baby makes
• Imitate your baby’s facial expressions
• Carry your baby face forward so he/she can see what is going on
• Establish routines so your baby knows what to expect
• Smile and use a soft voice when interacting with your baby
• React to vocalizations consistently and positively
• Always respond to a crying infant
• Change your babies room or crib decorations to encourage exploration
• Vary the sounds you make after imitating your baby’s sounds
• Exaggerate your facial expressions when talking to your baby
• Record the voices of familiar people to play for your baby
• Show your baby pictures of you and your family

Always make sure to pay attention to your baby’s cues. If your baby is getting overwhelmed stop and take a break.

The above information was adapted from Quick & O’Neal (1997).
Continuing Care

Taking your baby home can be scary. But you don't have to do it all alone. There are services in your community that are there to help you with your very special baby.

Your case manager and the rest of the NICU staff can help you find the services available in your community. One program available in most states is Early Intervention.

Early Intervention is...

- A government program that provides services to help your baby meet his/her developmental milestones. These programs typically employ:

  - Case Managers
  - Occupational Therapists
  - Physical Therapists
  - Speech Language Pathologists
  - Education specialists
  - and other developmental specialists

- These services are usually provided in your home but may also be provided in a daycare setting.

The above information was adapted from Vergara & Bigby (2004).
References


This Certificate is Awarded to:

I was __________ weeks old.

I weighed __________ grams, which is about __________ pounds and __________ ounces.

I was __________ inches long.

Date: ____________________

Authorized Signature
CHAPTER V

SUMMARY

The product developed throughout the course of this project was designed to be an easy to understand and family friendly guide that occupational therapists working in the NICU can provide to families. In this product, common sights, sounds, and staff are concisely defined allowing families to learn about the NICU and feel more comfortable taking part in their infant’s care. Another strength of this guide is that it presents basic information common to most NICUs, but it can be easily adapted to meet the unique needs and regulations of individual NICUs.

This product is limited by the minimal research regarding the efficacy of printed educational materials on familial adaptation to the NICU. Further research focused on the most appropriate time to introduce educational materials to families would be beneficial. This product also requires continual updates to assure that current and accurate information is being provided to families.

The successful implementation of this product into clinical practice would require a marketing plan to promote use of the product to NICU facilities and determination of alterations needed to suit each facility. Packaging and pricing for the product would also need to be determined in order to make it accessible to facilities and families. Prior to implementation, the authors recommend that photographs retrieved from websites be replaced with professional photographs to allow widespread distribution. Furthermore,
additional photographs would be beneficial to further illustrate concepts and facilitate understanding.

The authors would recommend that a pilot study be conducted to determine the efficacy of this product. In this pilot study a satisfaction survey would be provided to families following a NICU stay. Recommendations for a survey would include questions pertaining to the usefulness, ease of understanding, and value of the product in assisting families in adapting to the NICU environment. These surveys would also provide families with an opportunity to provide feedback and suggest areas of expansion. The results of these surveys can be used to enhance product development and research.
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