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Preterm infants with gastroesophageal reflux disorder: an intervention handbook for parents

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PRETERM INFANTS WITH GASTROESOPHAGEAL REFLUX DISORDER: AN INTERVENTION HANDBOOK FOR PARENTS

By

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Advisor: Gail Bass, Ph.D., 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

Master’s of Occupational Therapy

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This Scholarly Project Paper, submitted by Melissa Cramer, MOTS, 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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Degree Master's of Occupational Therapy

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Melissa Cramer, MOTS

Date

12-30-08
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ABSTRACT

One of the problems that health care workers practicing in the neonatal intensive care unit (NICU) face is providing care that is individualized to each infant and his/her family, being supportive to the infant during their development and to parental roles, and being sensitive to the needs of each infant and his/her parents and family (Lawhon, 2002). There is an additional challenge when the infant is also diagnosed with gastroesophageal reflux (GERD). Parents are often the primary caregivers and advocates for their infant in the NICU; for this reason, it is important that they understand and take part in their baby’s care. Therefore, by providing clear and easy to understand explanations of the equipment, technology, staff, and common procedures related to infants in the NICU and GERD parents are able to gain the confidence needed to care for their baby.

An extensive review of literature was completed; it included descriptions of the types of NICU staff, equipment and devices, diagnosis and treatment of GERD, the occupational therapist’s role, and parental involvement. This author also visited an area neonatal intensive care unit to gather information and examples of resources provided to parents while their child is in the NICU. It was concluded that families benefit from materials and education from the NICU staff that was clear and concise as well as user friendly. It was also determined that these materials and educational sessions would be used or implemented during the infants stay in the NICU.
An easy to understand resource manual was developed to be provided to parents of preterm infants with GERD. The manual is divided into sections that include information about: the NICU, equipment in the NICU, personnel in the NICU, an overview of GERD including diagnosis and symptoms, treatment options for GERD, other cares for the preterm infant, tips for parents and continuing care, as well as additional resources and a glossary of terms. Each section provides easy to read descriptions of the various topics and pictures are included to facilitate understanding of the material presented.
CHAPTER I

INTRODUCTION

Project Background

I initially developed an interest in the neonatal intensive care unit through my pediatric course work. I later developed an interest in gastroesophageal reflux (GERD) in preterm infants after completing a community experience and working with local professionals in the NICU. My interest was heightened by personal stories of parents of children with GERD. My interest in these two topics led me to seek out additional information on common practices in the NICU and treatment of GERD in preterm infants.

The neonatal intensive care unit is often a stressful and confusing environment for families and infants. It can be even more stressful when there is an additional medical concern or problem that the infant and the infant’s family has to cope with. In addition to learning about the NICU and how to adapt to the highly technical equipment, the parents also have to learn and understand more about the new diagnosis their infant has of GERD. Because families and parents are often the primary advocates and caregivers for infants, it is important that they understand and take part in their baby’s care. By providing clear and easy to understand explanations of equipment, technology, and diagnosis and treatment of GERD in preterm infants, professionals can help alleviate
parental stress and help the parents become more comfortable and promote involvement in their baby’s care.

The primary role of the occupational therapist practicing in the NICU is to educate the family on feeding positions, formula modifications, sleeping positions, and help to facilitate the parent-infant relationship. The occupational therapist may also teach the parents how to interpret their baby’s signs, educate them on Kangaroo care and infant massage, and proper handling techniques (AOTA, 2006; Caretto, et al., 2000).

Occupational therapists practicing in the NICU are uniquely qualified to help parents and families adapt to the NICU experience and cope with caring for an infant with GERD.

Model

The model used to guide the development of this scholarly project was Occupational Adaptation by Schultz and Schkade (2003, p. 220-223). This model has a number of assumptions that guide its use in occupational therapy. Some of these assumptions include: stressful life events can overwhelm an individual’s ability to adapt, the more stressful the life event the higher the demand for change or adaptation, and successful occupational performance relies on an individual’s ability to adapt to a new situation successfully.

This model is relevant to the experiences of parents and infants with GERD in the NICU as these individuals are faced with an unfamiliar environment and a stressful life event. The focus of Occupational Adaptation is on the interaction between the person and the occupational environment. When a person is in a stressful situation, he or she will seek to adapt their interactions to achieve a sense of mastery. The adaptation process of this theory is essential for engaging in occupations or activities that are satisfying and
provide meaning to the person (DeGrace, 2007). The success of the individual’s ability to adapt hinges on their ability to reflect on their adaptation skills and make adjustments or changes as needed (Schultz & Schkade, 2003). Because reflection is an important aspect of this model the product includes pages and forms that allow for parents to reflect on things such as going home checklist, infant feeding and overall cares. The product also facilitates parental adaptation in the NICU environment by presenting information on common equipment, staff descriptions, and the diagnosis and treatment of GERD in preterm infants.

By using resources such as this manual, parents in the NICU are able to improve their caregiving skills and their ability to adapt to their infant’s needs. Parents are also better able to interact with staff in the NICU in order to gain more knowledge and pursue the development of new skills they will need in order to take care of their new baby with GERD. Through these interactions and gain in knowledge, parents will be prepared for their role as primary caregivers and achieve the sense of mastery desired.

Summary

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

Introduction

Treatment of infants and toddlers with gastroesophageal reflux disorder (GERD) often begins at the time of birth and in many instances when these children are born prematurely. These infants will begin their extensive treatment in the neonatal intensive care unit at the hospital where they are born. This process involves a multidisciplinary approach, of which occupational therapists play a role. Research in this area has been sporadic and there are varying viewpoints regarding the treatment of gastroesophageal reflux in preterm infants.

The purpose of this scholarly project was to develop a manual for parents of preterm infants with gastroesophageal reflux disorder. The manual was designed to guide parents through the various interventions utilized to treat GERD and to describe the role that the occupational therapist has in their child’s care and treatment. The manual was also designed to assist parents with understanding the occupational therapy evaluation and treatment process. Current research and literature was used to develop the manual and to support the validity of the project. The following chapter is a review of that literature and research. It is divided into the following sections: neonatal intensive care units, gastroesophageal reflux disorder, role of the occupational therapist, and benefits of parental involvement.
Neonatal Intensive Care Units

The neonatal intensive care unit (NICU) is a unit of a hospital that is highly specialized in the care of prematurely born infants or those infants that require special care. These specialized care units for neonates are also classified according to the level or intensity of care they provide (Hunter, 2005). Hunter describes the different types of nurseries as either level I, level II, level III, or level IV. A level I nursery provides care for infants that are well and are born after uncomplicated pregnancies. Level I nurseries are often found in smaller community hospitals. A level II nursery will often have a neonatologist on staff and provides care that is a step above level I. This care includes special services to newborn infants with more medical needs such as phototherapy to treat jaundice, tube feedings, or intravenously (IV) administered antibiotics. A level II nursery or NICU does not always have the equipment or specialty trained staff, such as a pediatric surgeon or cardiologist, to treat and care for infants with medical emergencies or severe neonatal problems. These type of problems are often addressed at a level III NICU. These nurseries are staffed with specially trained personnel and have specialized equipment to provide treatment required for the variety of medical needs of each infant. Although not a recognized classification, "level IV" is often used to describe those nurseries that are prepared for neonatal rescue. A "level IV" NICU will have even more specialized equipment that might be needed should a newborn infant go into respiratory failure.

The infants that are usually cared for in the NICU present with different medical conditions; many of the infants in the NICU are born prematurely. Infants are considered premature if they are born before 37-38 weeks gestational age (GA). Gestational age is
often taken into account when predicting possible problems or complications with the infant such as respiratory distress. There is an increased risk for complications in infants that are born at 28 weeks or less (Hunter, 2005). Although these infants are the ones that need the most care, the majority of infants in the NICU are often attached to many different types of equipment to facilitate and monitor their care.

**Equipment**

Some of the equipment that is used in a NICU for the specialized care of neonates includes equipment to support thermoregulation, respiration, and nutrition as well as immune system supports. Often newborns and infants in the NICU need all the calories they can for growth and healing. Hunter (2005) notes that in order to reduce the amount of calories the infant uses in order to stay warm, thermoregulation equipment is used. Hunter (2005) and Neonatology on the Web (2002), both describe the radiant warmer and the incubator as thermoregulation equipment. Besides the thermoregulation equipment, NICUs are often equipped with a variety of oxygen therapy equipment including: bag and mask ventilation, continuous positive airway pressure (CPAP), mechanical ventilation, extracorporeal membrane oxygenation (ECMO), vapotherm, an oxygen hood, or a nasal canula (NC). Each of these is designed with a specific function in mind and are used in different situations depending on the infant’s needs (Hunter, 2005).

Other common pieces of equipment used in the NICU include intravenous tubes (IV) tubes and pumps for nutritional support and medication administration. Besides fluid pumps that supply nutrition and fluids, at times there are pumps attached to the infant to aid with secretion of wastes. There are also monitors to measure the various vital signs such cardiac and respiratory function. Two types of equipment used for this are the pulse
oximeter and the physiologic monitor. A defibrillator may also be used to shock the heart back into rhythm. Equipment used in the NICU for nutrition includes bottles with various sizes of NUK™ nipples with different flow rates for feeding and nasogastric (NG), or orogastric (OG) feeding tubes (Hunter, 2005 and Medline Plus, 2007). All of these pieces of equipment are further described in Table 2.1.

Table 2.1 Equipment in the NICU

<table>
<thead>
<tr>
<th>Piece of Equipment</th>
<th>Description</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Thermoregulation Equipment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiant warmer</td>
<td>Open bed with overhead source of heat</td>
<td>Often used during new admissions or for easy access to infants that are critically ill or have complicated medical care.</td>
</tr>
<tr>
<td>Incubator (Isolette)</td>
<td>A clear plastic box that encloses the mattress and infant and provides heat</td>
<td>Used for warmth and to provide a more quiet environment for infant; can be accessed from portholes or a door in the side or the top</td>
</tr>
<tr>
<td>Open crib</td>
<td>Bassinet-style bed</td>
<td>Used with more stable and larger infants</td>
</tr>
<tr>
<td><strong>Oxygen Therapy Equipment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bag and mask ventilation</td>
<td>A face mask with bag attached is squeezed rhythmically to provide oxygen and positive pressure</td>
<td>Used to resuscitate and infant at birth or during emergency, or to increase oxygen</td>
</tr>
<tr>
<td>CPAP</td>
<td>Steady stream of air provided by nasal mask, endotracheal tube, or nasopharyngeal tube. May or may not use supplemental oxygen</td>
<td>Positive pressure used to keep airways open in infants with breathing difficulty such as respiratory distress syndrome, pulmonary edema, or apnea</td>
</tr>
<tr>
<td>Mechanical ventilation</td>
<td>Breathing controlled by machine by inflating lungs</td>
<td>Infant is usually nasally or orally intubated and used for infants with decreased respiratory drive, pulmonary disease, or poor oxygenation</td>
</tr>
<tr>
<td>ECMO</td>
<td>A system of life support that uses modified heart-lung bypass to provide a near total rest of the lungs and decrease lung trauma</td>
<td>Used in infants with critical respiratory failure who are unresponsive to other methods</td>
</tr>
<tr>
<td>Vapotherm</td>
<td>Respiratory therapy that provides warm, moist air through a nasal canula at high flow rates</td>
<td>Allows for a higher flow rate of air/oxygen blends without drying nasal passages; improves gas exchange; decreases effort of breathing</td>
</tr>
<tr>
<td>Oxygen hood (oxyhood)</td>
<td>A plastic hood that is placed of infants head and provides flow of warm humidified oxygen</td>
<td>Used with infants who require greater than 21% of oxygen in room air; allows higher flow without drying of nasal passages</td>
</tr>
<tr>
<td>Nasal canula (NC)</td>
<td>Provides humidified oxygen through prongs that fit in the nostrils</td>
<td>Provides supplemental oxygen without use of hood; allows for easier handling of infant</td>
</tr>
<tr>
<td><strong>Nutrition Equipment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intravenous pump (IV pump)</td>
<td>A pump that regulates the flow of fluids and medications</td>
<td>Used to provide fluids and various medications and nutrition supplements.</td>
</tr>
<tr>
<td>Scale</td>
<td>A scale fitted with a clear plastic bin to hold infant</td>
<td>Used to measure the infants weight; typically measured in grams</td>
</tr>
<tr>
<td>NUK nipples</td>
<td>Bottle nipples that resemble the mother’s nipple; have higher flow rate</td>
<td>Used for intermittent bottle feeds of breastfeeding infants</td>
</tr>
<tr>
<td><strong>Cardiac &amp; Respiratory Equipment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Defibrillator</td>
<td>Machine that provides electric shock to the heart</td>
<td>Used rarely in the NICU as abnormal heart rhythms are unusual</td>
</tr>
<tr>
<td>Oximeter</td>
<td>Machine to monitor oxygen saturation of baby’s blood</td>
<td>Oxygen saturation is measure by a light from the machine shining through the baby’s skin and measuring the approximate oxygen present</td>
</tr>
<tr>
<td>Physiologic monitor</td>
<td>Sometimes called a cardiorespiratory monitor; a monitor attached to the various lines on the infant to measure vital signs</td>
<td>Alarms can be configured to alert when vital sings go below a certain limit; most record data for a period of time and can be printed.</td>
</tr>
</tbody>
</table>
Although there is a lot of equipment in the NICU, an even greater asset to the infants’ care is the medical staff and care team in the NICU. Some of the medical staff heavily involved in the care of infants in the NICU are: neonatologists, physician assistants, nurse practitioners, neonatal nurses, NICU case managers, social workers, nutritionists, respiratory therapists, occupational therapists, physical therapists, speech language pathologists, and clinical psychologists (Vergara & Bigsby, 2004). Table 2.2 includes a description of the roles of the professionals involved in neonatal care in the NICU.

Table 2.2 Professionals in the NICU

<table>
<thead>
<tr>
<th>Professional</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neonatologist</td>
<td>Doctor who has completed additional training to care for premature infants and newborns; typically responsible for the medical care of these infants</td>
</tr>
<tr>
<td>Physician Assistant</td>
<td>Professionals who work under a physician; trained to address symptoms and work with physician to choose treatment method</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>Registered nurse (RN) who has obtained additional training in a specialized area; supervised by a doctor; may prescribe medications and complete some procedures</td>
</tr>
<tr>
<td>Neonatal Nurse</td>
<td>Registered nurse (RN) or licensed practical nurse (LPN) responsible for daily care; one nurse assigned per shift; have most contact with infant</td>
</tr>
<tr>
<td>NICU Case Manager</td>
<td>Individuals with extensive experience in neonatal care and early intervention services; each infant is assigned a case manager; also helps with preparation for baby’s discharge to home</td>
</tr>
<tr>
<td>Social Worker</td>
<td>Individuals who have completed training in clinical social work and have experience working with families; help families cope and provide information and resources for infants care</td>
</tr>
<tr>
<td>Nutritionist</td>
<td>Registered diabetics often with additional training in pediatric and neonatal nutrition; assist doctors determine appropriate nutritional needs of infants and help address feeding problems</td>
</tr>
<tr>
<td>Respiratory Therapist</td>
<td>Individuals responsible for monitoring breathing and setting ventilation machines appropriately; may perform treatments to clear infant’s lungs</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>Therapists who have knowledge of pediatric development and completed additional training in NICU intervention; usually focus on feeding, positioning, and adapting environment to meet baby’s needs</td>
</tr>
<tr>
<td>Physical Therapist</td>
<td>Therapist who specializes in motor development and have special training in pediatrics and NICU interventions; may assist with positioning and healthy movement patterns</td>
</tr>
<tr>
<td>Speech Language Pathologist</td>
<td>Therapists who have completed training in speech development as well as pre-language skills that are needed to acquire speech; may assess baby’s ability to suck and swallow and recommend special feeding techniques</td>
</tr>
<tr>
<td>Clinical Psychologist</td>
<td>Professionals who have completed a Ph.D in psychology and have experience working with families in crisis situations; may provide counseling to individuals and families</td>
</tr>
</tbody>
</table>
Gastroesophageal Reflux Disorder

Definition

Within these special care units of the hospitals, the NICUs, there are many premature babies that are treated for a wide variety of conditions. One of these conditions is gastroesophageal reflux disorder (GERD). GERD is a common gastrointestinal (GI) disorder and is often described as the “reflux of gastric contents” and is associated with symptoms of discomfort (Eisen, 2001). Wolf and Glass (1992) further state that it is a “spontaneous return of gastric contents into the esophagus” (p. 336). Eisen (2001) also reported that a poll estimated that approximately 50% of adults in the United States indicate heartburn or symptoms of GERD each month. However, GERD is not just a condition or diagnosis that adults experience. According to Poets (2004), GERD is common in premature infants and can occur upwards of three to five times per hour. Most infants have gastroesophageal reflux to some degree during their first year of life and this often resolves on its own by thirteen to fourteen months (Young, Lyden, Ward, Vanderhoof, & DiBaise, 2007).

Diagnosis

According to Dhillon and Ewer (2004), 22% of infants admitted to the NICU are diagnosed with GERD. Although a majority of infants are diagnosed with GERD in the NICU, there are those who are diagnosed because the episodes of reflux do not resolve on their own within the first year of life. There are a variety of methods used for detection and diagnosis of GERD. Poets (2004) notes that detection cannot be completed with one test, but indicated that constant measurement is needed to detect and diagnose GERD. Therefore the “gold standard” for detection has become pH monitoring.
Poets (2004) indicated that this method has progressed and is easy to use. A pH
probe is inserted through the nasal passages and into the esophagus to monitor acid levels
(Case-Smith & Humphry, 2005). Poets (2004) noted that measurements can be taken at
various locations and include the stomach, esophagus, above the lower esophageal
sphincter, or at the pharyngeal level. According to Case-Smith and Humphry (2005), this
method has one advantage over other methods of testing. It is able to measure the
frequency of GERD over a period of 24 hours. The only disadvantage that is noted by
Poets (2004) is that pH monitoring relies heavily on gastric activity and GERD cannot be
detected when pH is >4. Many premature infants have gastric contents that are >4 for
90% of the time or more. Another problem that surfaces when attempting to diagnose and
detect GERD in premature infants is due to the frequent feedings that neutralize that
acidity of the stomach contents (Martin & Hibbs, 2006).

Due to the nature of this dilemma, Dhillon and Ewer (2004) pointed out that in
premature infants clinical features are more relevant for detection. Dhillon and Ewer
reported the most common symptoms as follows: regurgitation, vomiting, apnea,
bradycardia, and desaturation. Vandenplas and Hauser (2000) also looked at the common
clinical manifestations of GERD in infants and found that regurgitation is among the
most frequent and occurs on a daily basis in most 4-month old infants. However, they
also pointed out that regurgitation is normal during the first 6 months of life and that the
normal daily frequency of acid reflux is around 31 episodes per 24 hours.

Although pH monitoring remains the “gold standard” for GERD detection Eisen
(2001) states that “there remains no single test that can uniformly detect GERD” (p. S16).
Eisen also reported that other utilized forms of detection include endoscopy and barium
swallow. Case-Smith and Humphry (2005) also report that gastroesophageal scintigraphy is a method that can be utilized to determine the severity of GERD. This process involves the infant ingesting a radionuclide isotope. The movement of this isotope is recorded by a camera as it moves through the esophagus, stomach, and intestines. This extensive process allows for a more accurate diagnosis of GERD and records stomach emptying time. Case-Smith and Humphry (2005) indicated that this procedure is used when physicians are considering fundoplication, a surgery that tightens the gastroesophageal sphincter.

Poets (2004) also reported that another solution to the dilemma of diagnosing GERD in preterm infants is with the multiple intraluminal impedance (MII) technique. Instead of measuring pH, this technique measures electrical impedance during swallowing of a bolus. Poets (2004) stated that the principle behind this technique is “to record changes in impedance in the gastrointestinal lumen that are caused by the passage of a bolus...” (p. 129).

However, these are complex tests and require significant analysis and are time consuming. James and Ewer (1999) suggest a more practical approach for detecting of GERD in premature infants. They recommend that litmus testing for acid can be performed on oropharyngeal secretions. Their report indicates that two or more positive litmus tests are enough to begin positional treatment with these infants. Regardless of the method used for detection, it is important that GERD be detected in order to initiate proper treatment in premature infants in the NICU.
Prevalence in Preterm Infants

GERD is becoming a more common issue related to neonatal health and is being treated more often in the NICU. A study by James and Ewer (1999) found that 78% of the population of pre-term infants had significant GERD and that early diagnosis and treatment is necessary. Other studies also report similar results related to the incidence of GERD in preterm infants. A study by Dhillon & Ewer (2004) indicated that 22% or approximately one-fifth of babies born before 34 weeks gestational age who were admitted to NICUs were diagnosed with GERD. Although there are varying statistics in each study, these results are still significant and indicate that GERD is a problem that is often addressed in preterm infants during their care in an NICU.

Contributing Factors

There are many studies that report various factors that contribute to the presence of GERD in preterm infants. Some of these factors include position during sleep and while feeding and the method of feeding. The first factor that is often observed as a contributing factor is the effect of position. Ewer, James, and Tobin (1999) noted the relationship between position and its effect on GERD. They noted that those infants who spend the majority of their time in supine and lying flat are more susceptible to GERD and reflux symptoms. This is caused by the gastric contents settling in closer proximity to the gastroesophageal junction. They also found that an unsupported upright position can increase abdominal pressure and increase the severity of symptoms.

Although position and source of nutrients, whether formula or breast milk, are factors that have an impact on GERD; different methods for feeding have been shown to have an impact on GERD as well. Poets (2004) indicated that one of these factors is the
use of a feeding tube. Feeding tubes are often the primary means of providing nutrients to the preterm infants, but this study found that the frequency of GERD nearly doubled when the placement of the tube ended in the stomach rather than in the esophagus. Martin and Hibbs (2006) also pointed out that reflux tended to be more common during non-feeding times for those infants who were fed exclusively by nasogastric tubes. Although tube feedings were not the sole contributor to the frequency of reflux and GERD symptoms, this method of feeding has been found to have an influence.

_Potential Health Risks and Concerns_

Although GERD is a diagnosis that can be treated there are other health concerns and risks that have been associated with preterm infants and GERD. Some of these risks are outlined by Wolf and Glass (1992) in _Feeding and Swallowing Disorders in Infancy: Assessment and Management_. Failure to thrive, aspiration, apnea, and sudden infant death (SID) are just a few of the health problems that result due to GERD symptoms. Omari, et al. (2002), also reported irritability, vomiting, apnea, aspiration, pneumonia, and failure to thrive as some of the major health concerns associated with GERD. It becomes clear from these articles that besides the discomfort caused from GERD, there are other more serious and life threatening problems.

Each of these life threatening conditions should be addressed simultaneously with the GERD symptoms should they arise during the infants course of treatment in the NICU. The first and most obvious of the health concerns associate with GERD is failure to thrive. Crooks and Wavrek (2005) define failure to thrive as the “diagnosis given to children, frequently infants and young children, who fail to grow or gain weight” (p. 884). Mascarenhas and Dadhania (1995) also included “inadequate intake, excessive
losses, and gastrointestinal disease causing malabsorption” (p. 255) as other causes for failure to thrive and an infant not being able to meet his/her nutritional needs. The ability to gain weight and to grow is impaired in preterm infants who suffer from GERD since vomiting occurs more frequently in these infants (Dhillon and Ewer, 2004; Vandenplas and Hauser, 2000). Due to the lack of adequate nutrition, which is essential for healthy growth and development, failure to thrive becomes a primary concern with preterm infants. Poets (2004) found that infants with GERD had a 19 day longer stay in the NICU that those without. Although GERD is not the only contributing factor to failure to thrive, it plays a role in the ability of premature infants to receive sufficient nutrition and gain adequate weight in order to remain healthy.

Another concern that is associated with GERD is aspiration. Wolf and Glass (1992) noted it is hard to determine whether the aspirations are caused directly by the ascension of refluxed food or if the aspiration is brought about by descending food during swallowing. Despite the current difficulty in determining the source of aspiration, aspiration can lead to life threatening conditions, particularly aspiration pneumonia which is often fatal for infants in the NICU (Vergara and Bigsby, 2004, p. 220). In the article by Poets (2004), the author pointed out that there is noted retraction and stridor after a reflux episode which can contribute to the aspirations. For this reason, it is critical that infants who suffer from GERD symptoms be diagnosed and monitored closely.

In addition to the above described health concerns and risks related to GERD, another more serious yet controversial concern exists – sudden infant death (SID). SID is often associated with apnea as a result of the prone sleeping position that is often used for infants with GERD (Ewer, James, & Tobin, 1999; Vandenplas & Hauser, 2000.) Poets,
(2004) found that apnea is often found in conjunction with GERD and that the apneas were more likely to occur after an episode of GERD. However, there is still much research to be done in this controversial area of concern and there is still a great deal of debate regarding the positioning of preterm infants who are diagnosed with GERD.

Current Treatment Options

One of the advantages of GERD is that it is treatable in preterm infants and even later in life should it carry over into childhood and adulthood. However, Young, et al. (2007) emphasize that the type of treatment received during the first few months of life is “uniquely different” and often an inappropriate method of treatment is used. There are two methods of treatment currently recognized for infants – a medicinal approach and alternative methods such as positioning and various alterations to formulas and breast milk. The most drastic of treatments for GERD is surgery which is often a last resort.

The medicinal approach is just that – medications prescribed specifically for the treatment of GERD and symptoms associated with GERD. Of all infants discharged from the hospital that were born with extremely low birth weights 25% were placed on either promotility or antacid medications and at times both. In a study conducted by Booth, Heyland, and Paterson (2002), it was noted that promotility drugs such as cisapride, erythromycin, and metoclopramide had a positive effect on GERD and its symptoms. Cisapride specifically helps to reduce regurgitation and vomiting (Vandenplas & Hauser, 2000). Approximately two-thirds of the NICUs in the study conducted by Dhillon and Ewer (2004) reported that cisapride was used to treat GERD in preterm infants. As with all medications, there is controversy as to whether the use of cisapride and other
promotility drugs are truly effective in the treatment of GERD in infants (Dhillon & Ewer, 2004).

Besides medications, other alternative methods for the treatment of GERD in preterm infants have been used. These alternative approaches include formula and breast milk thickening and positioning techniques during and after feedings. Thickening of formula or breast milk whether through tube feedings or with a bottle was reported in 98% of NICUs caring for infants with GERD (Dhillon & Ewer, 2004). Often the formula or breast milk is thickened with rice cereal, and this has been shown to decrease the number of emesis. However it did not alter the frequency of reflux episodes, but infants were happier and showed a greater gain in weight due to the decrease in emesis (Wolf & Glass, 1992). Besides the thickened feedings, Wolf and Glass (1992) also recommend more frequent feedings of three to four ounces every three to four hours versus larger feedings further apart.

Although medications and manipulations to feedings have shown success, another area that is gaining recognition with respect to GERD treatment is positioning. Research that has been done indicates that certain body positions have a greater effect on gastroesophageal reflux than others treatments, and the position of the infant during feeding can impact GER. Dhillon and Ewer (2004) stated that keeping the infant positioned between either a 15 and 30 degree angle or a 30 to 45 degree angle with head up will help to reduce GER. This elevation is reported as the most effective when compared with supine, prone or the upright seated position. Infants can be placed on an incline more easily in some of the commercially available incubators that can be positioned at varying degrees of elevation. If this is not an option, the use of a foam
wedge angled at 30 degrees can also be implemented into the treatment. It is less expensive and still an effective method of maintaining the head-up position (Wolf & Glass, 1992). This head-up position can also be implemented during feedings to help reduce the occurrence of GERD episodes (Dhillon & Ewer, 2004). Wolf and Glass (1992) indicate that this same method can be used with bottle and breast feeding as well. The infant should be held at a minimum of a 45-degree angle and the flat, horizontal feeding positions should be avoided.

Besides the increase in head elevation, it has also been noted that prone and left-lateral side down positions may reduce the amount of GER in premature infants (Dhillon & Ewer, 2004; Poets, 2004; Ewer, James & Tobin, 1999). Khoury, Camacho-Lobat, Katz, Mohiuddin, and Castell (1999) in their study of adults and sleep position also came to the same conclusion that episodes of GERD were decreased in the left-lateral and prone sleeping positions. In comparison, the study by Ewer, James & Tobin (1999) showed that the supine position resulted in an increase in the severity of GER in preterm infants and the left-lateral position during feeding and sleeping led to a significant decrease in the episodes of GERD. In relation to SID, Vandenplas and Hauser (2000) found that SID is decreased in the supine position but that GERD symptoms increased. They argued that infants get quieter more restful sleep in the prone position which also reduces the number of GERD episodes experienced. Although not perfectly clear, it would appear that prone and left lateral side down positions are beneficial in reducing the severity of gastroesophageal reflux in preterm infants in the neonatal intensive care units and at home.
As a last resort and in severe cases only surgery is used to treat GERD. Surgery is only used for those patients who do not respond to other therapy options and are at risk for developing chronic lung disease or complications such as Barrett’s esophagus, strictures, life-threatening events, respiratory failure, recurrent aspiration, neuromuscular disabilities and chronic malnutrition that results in failure to thrive (Mascarenhas & Dadhana, 1995; Dhillon & Ewer, 2004). Of the types of surgeries performed in the treatment of GERD, the most common was the Nissen fundoplication (Mascarenhas & Dadhana, 1995; Dhillon & Ewer, 2004). The Nissen fundoplication involves the following essential components according to Hoffman and Ross (1995):

“…mobilization of the esophagus at the esophageal diaphragmatic hiatus for restoration of the intraabdominal esophagus, crural tighten, mobilization of the fundus of the stomach by division of the short gastric vessels and splentic attachments, and a 360° wrap of the fundus around the lower esophageal segment (pp. 287-288).”

This procedure is far from standard and is associated with many concerns such as gas-bloat and vomiting at an unpredictable capacity. There are also higher risks for complications involving the small intestine after surgery (Hoffman & Ross, 1995). Therefore, this surgery is reserved as a last resort for treatment in infants.

Role of the Occupational Therapist

The role of the occupational therapist in the NICU has a focus on promoting the health of the infant and their ability to achieve occupational competence. The American Occupational Therapy Association (2006) emphasizes the importance of the role of the occupational therapist in the effective treatment and care of infants in the NICU. Some of
the areas that therapists will need specialized skills and knowledge in include communication with other staff and families, cultural competency, infant assessment, sensory integration, neurodevelopmental interventions, parental and caregiver education, social interactions, and feeding interventions (AOTA, 2006; Caretto, et al., 2000). The occupational therapist’s role is clearly described as someone that is advanced in skills and knowledge in occupational therapy and working with infants in the NICU, and he or she should be able to work with the families in order to create the best environment in which the infant can grown and develop.

The OT should be familiar with all the areas of the NICU and know how to interact with families and other staff within the NICU. The needs of the infant and the families must be assessed, and the therapist should have an understanding of the occupations that are valued by the family. Another aspect of the role of the occupational therapist is to provide education to the family about factors that may interfere with their infant’s participation in these occupations. The therapist should respect and work with the family regarding various cultural values (AOTA, 2006). The therapist must also be able to communicate effectively with other staff in order to carry out the best treatment interventions without jeopardizing the health and stability of the infant.

The therapist must be able to assess the fragile infants and be able to discern the various signals that the infant displays with regards to readiness for engagement. These signals should then be taught to the family (Vergara & Bigsby, 2004). The OT should have the basic skills to assess and determine functional outcomes of the infant and be able to educate and work with the families to carry out the treatment plan. Treatment can include sensory integration and neurodevelopmental interventions; these approaches have
to fit within the infant’s “medical status, physiological homeostasis,” the infant’s developmental needs and the family needs (AOTA, 2006, p. 659).

The occupational therapist is going to be heavily involved in educating the family on the various occupations of infants and the signals they display as well as interventions to carry out with the infant. Vergara and Bigsby (2004) have divided the occupations of infants into two categories, learning occupations and apprenticeship occupations. The skills that are considered important by the adults in the child’s culture are learning occupations. An example of a learning occupation is exploration which is considered the most common learning occupation; this is also the primary manner in which infants learn. Newborns will explore and survey their environment by analyzing visual, auditory, oral, tactile, proprioceptive, and vestibular stimuli. This input helps the infant familiarize themselves with their surroundings. Apprenticeship occupations include the activities that aid the child in adapting to their culture. The authors use the example of procuring and feeding. Procuring, or solicitation of care, is the method in which infants are proactively interacting with their environment. Some of the behaviors identified with procuring are crying in response to hunger, blocking bright lights with their hands or arms, or turning their head away to indicate they need a break. Infants in the NICU are unable to solicit care through these behaviors and are often more dependent on external support (Vergara & Bigsby).

One area that infants in the NICU are dependent on others for is securing nourishment. Feeding is one of the apprenticeship occupations that Vergara and Bigsby (2004) defined; it is also one of the most natural and frequented occupations of infants. However, feeding is an area that occupational therapists often will address with parents of
preterm infants because this is an occupation that is often compromised by the infant’s fragile state (Hunter, 2005). Caretto, et al. (2000) found that most parents feel inadequate and are often concerned with feeding their infant after discharge from the NICU. The therapist will often work with and educate the parents and other potential caregivers on the proper positioning and handling techniques to use during feeding times whether it is through bottle or breast feedings. The occupational therapist will not be involved in education about tube feedings, but they are involved with the transition from tube feeding to oral feeding (Caretto, et al., 2000). The occupational therapist may educate parents and caregivers on the types of feeding interventions in the NICU. The therapist may help the parents understand and encourage pacifier sucking throughout hospitalization even if infant is tube or gavage fed to promote sucking patterns. The therapist may also teach the parents how to provide oral stimulation as a warm-up to feeding and advise parents to feed their infant in 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 the infant in an upright position to facilitate better swallowing and decrease the risk of aspiration are other aspects of feeding that the therapist may educate the parents about (Hunter, 2005; Case-Smith & Humphry, 2005).

Positioning during feeding is one area that is especially important to address with parents and caregivers when working with a preterm infant who is also diagnosed with GERD (Dhillon & Ewer, 2004; Wolf & Glass, 1992). Positioning the infant in a semi-upright position during feeding and keeping the infant in this position 15-30 minutes after feeding has been shown to keep feedings down and reduce GERD symptoms (Vergara & Bigsby, 2004). The prone position also has been noted to reduce the symptoms of GERD,
but Vergara and Bigsby also point out other benefits such as increase in quiet sleep time, neuromotor benefits such as better head control, physiologic benefits including fewer stress responses, and improved breathing, and lower use of energy. The occupational therapist will work with the parents and caregivers and educate them on the proper positioning techniques to use during feedings as well as what positions to place their infant in for sleep and rest in the incubator to facilitate the above mentioned benefits of positioning. Positioning techniques also taught to the parents and caregivers include recommended timelines for repositioning to reduce risks of pressure sores and misshapen heads, assuring proper diaper fit to decrease the risk of hip deformities, and gentle handling techniques during transfers and diaper changes (Hunter, 2005).

Another area that occupational therapists will address with the family and caregivers is that of social interaction which is another apprenticeship occupation identified. (Vergara & Bigsby, 2004). Social interaction is a critical component of successful establishment of caregiver and infant attachment. Infants in the NICU tend to be less responsive to social interaction as compared to their full-term counterparts. This is due to the difficulty preterm infants have maintaining alert states. Some ways to promote social interaction is through Kangaroo or skin-to-skin care, infant massage, feeding times, and through face-to-face contact and talking to the infant (Vergara & Bigsby, 2004; Hunter, 2005).

Kangaroo care involves placing the infant on the bare skin of the parent with the infants stomach resting on the parents stomach with the head of the infant on the parent’s chest. Some of the benefits of Kangaroo care include easier transitions in sleep states, positive effects on apnea, bradycardia, oxygen saturation, respiration, and heart rate,
helps the baby keep a more constant body temperature, and promotes weight gain.

Overall Kangaroo care has also shown to decrease the amount of time the infant spends in the hospital (Hunter, 2005; Vergara & Bigsby, 2004).

Infant massage is another method that the occupational therapist might teach to the parents. Infant massage provides a way for the parent and baby to interact and bond. The parent uses gentle massaging techniques to promote blood flow, simulate brain development, normalize muscle tone, and relax and calm the baby. The benefits for the parents include an increased confidence in care and handling of their baby (Infant Massage USA, 2006). Each of these interventions which promote social interaction can be taught to the caregivers by the occupational therapist.

Parental Involvement

Parents often anticipate and look forward to the birth of a full term, healthy infant. However, when their child is born prematurely, the parents must adapt the expectations to meet the medical needs of their infant. Often the birth of a preterm infant brings about various emotional and physical demands that parents are not prepared for; with the arrival of a medically frail and preterm infant the parents are unsure of what to expect and these demands often intensify. During what was to be a time of celebration involving family and friends, parents of premature infants can feel isolated due to the restrictions of the NICU environment. Parents are not able to focus on nurturing and spending quality time with their child, because their primary focus is often on health and survival which in turn can create feelings of uncertainty, confusion, fear, anxiety, or even anger. The parents of preterm infants are now sharing the responsibilities of caregiver and decision maker with
the multidisciplinary team and there becomes a lack of clear parental roles (Vergara & Bigsby, 2004; Lawhon 2002; Griffin, 2006.) Vergara and Bigsby (2004) stated:

The lack of parental involvement 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).

Dudek-Shriber (2004) found that the most stressful aspects of having a child in the NICU is this alteration of the parental role. Because of this concern, it is important for the occupational therapist to involve the family in as many aspects of the infants care while in the NICU and to encourage active participation from the parents.

Family-centered care, according to Griffin (2006), is “a philosophy of care that embraces a partnership between staff and families….Unrestricted parental presence in the NICU, parental involvement in infant caregiving, and open communication with parents are basic tenets of family-centered care” (p. 98). The idea of family-centered care is one that has historically been difficult to implement in the NICU, but it has been shown to be beneficial for the families and patients. Family-centered care also stresses the inclusion of parents during admissions, rounds, and even in emergency situations. It also requires that parents, especially the mother, are involved with the infants care. One way of including the mother in their mothering and nurturing role is through basic cares such as diaper changes and feedings. Griffin (2006) also suggests that mothers who breast feed and are involved with feeding feel that they are “making a difference” in the care of their infant.

In a study by Van Riper (2001), the involvement of parents was validated. One response
from one mother was “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).

As parents become more involved with their child’s care with the help of the occupational therapist and NICU team, they begin to bond with their infant and start to relax when taking part in the cares of their baby. The parents also become more comfortable in their roles as they gain confidence in their abilities to care for their child (Lawhon, 2002). This confidence in their abilities can facilitate more secure interactions with their infant which in turn can nurture the parent-infant relationship. The family-centered approach aids the family in being able to recognize and respond to their infant’s cues of stress or stability in an appropriate and effective manner. This approach also allows the parents to work with the NICU team to provide therapeutic positioning and developmentally supportive handling, regulate sensory input and provide positive touch. The parents are also able to facilitate functional oral feeding through bottle or breast feeding, and overall be able to meet the infant’s long-term developmental needs. Parents will also feel more attached and close to their infant, will focus less on technical care, and will also have decreased levels of stress making their time and stay in the NICU more enjoyable with their focus shifting to the relationship with their infant and not on their infants medical condition (Hunter, 2005).
Chapter Summary

The NICU can be an intimidating place for parents of pre-term infants, but it can be even more frightening when your infant is also being treated for other complications related to their premature birth. One of these conditions is GERD. From diagnosis to treatment, it can be a lengthy process and can cause fear and anxiety in parents about the health and well-being of their child. However, GERD is a treatable condition in preterm infants and the proper education and involvement of parents can help facilitate proper treatment of the disorder. The occupational therapist has an important role and can educate and guide the parents through the necessary interventions as well as help them develop stress management and coping skills.
CHAPTER III

METHODOLOGY

The topic of gastroesophageal reflux disorder and neonatal care became an area of interest to me after completing a 20 hour community experience and shadowing an occupational therapist in a neonatal intensive care unit as well as completing a three month internship in pediatrics which included NICU follow-up clinics. I noted that many children that were born pre-term experienced GERD as an infant. I determined that parents would benefit from a user friendly resource that would help them understand the NICU as well as GERD. The product of this scholarly project is a user-friendly resource manual for parents based on information in current literature and research and the information obtained from area NICU personnel.

An extensive review of literature was completed; it included: an overview of the NICU, equipment in the NICU, personnel in the NICU, a description of GERD and symptoms, diagnosis of GERD, treatment of GERD, role of the occupational therapist, and parental involvement. I obtained information and examples of materials given to parents about their child in the NICU. I also observed feeding evaluations conducted by an occupational therapist in the NICU and by a pediatric therapist in an outpatient pediatric clinic. The information was used to guide and direct the review of literature and the development of the final product. Lastly, I obtained permission to take photographs of equipment in the NICU at Altru Health System in Grand Forks, North Dakota.
A resource manual was developed based on the information obtained. It was developed to provide parents with an easy to understand guide to the basics of the NICU, equipment and personnel in the NICU, but primarily to address the needs of their premature baby diagnosed with GERD. The manual is divided into sections that include information about: the NICU, equipment in the NICU, personnel in the NICU, an overview of GERD including diagnosis and symptoms, treatment options for GERD, other cares for the preterm infant, tips for parents and continuing care, as well as additional resources and a glossary of terms. Each section provides easy to read descriptions of the various topics and pictures are included to facilitate understanding of the material presented.
CHAPTER IV
PRODUCT

The product developed as a result of this scholarly project was designed to be an easy to understand and family friendly guide that occupational therapists working in the NICU could provide to parents who have a preterm infant diagnosed with GERD. In this product, common equipment, terminology, descriptions of staff, and common treatments for GERD in preterm infants are concisely defined in order to allow parents to learn about the NICU and GERD and feel more comfortable participating in their infant’s care. This manual is formatted with easy to understand language and pictures to help support the written information and starts with an introduction to the NICU and staff, followed by descriptions of GERD and treatments used in the NICU. Tips for parents and resources are also included towards the conclusion of the manual. Pages for note taking are also available for the parents use during their time in the NICU or after discharge in the home setting.
PRETERM INFANTS WITH GASTROESOPHAGEAL REFLUX DISORDER: AN INTERVENTION HANDBOOK FOR PARENTS

Melissa Cramer, MOTS
&
Gail Bass, Ph.D., OTR/L
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Preface

I would like to extend a special thank you to Altru Health System for allowing me to access their neonatal intensive care unit and the opportunity to take photographs of their equipment.

Unless otherwise noted, other photographs were obtained from the following programs and/or websites:

MasterClips

* Indicates words defined in the glossary at the end of this manual.
Introduction

The purpose of this guide is to help you become more acquainted with the neonatal intensive care unit (NICU) and to understand more about the care of your baby who has been diagnosed with Gastroesophageal Reflux Disorder (GERD). The NICU can be overwhelming and a frightening place for new parents, especially for those whose newborn is also suffering from other medical complications. This guide will help you to understand the people in the NICU who are helping to care for your baby, the equipment you might see there, and various treatment options for GERD.

This guide will also give you some suggestions of ways to interact with your newborn in order to take part in his/her care and to aide in their treatment of GERD. You will also 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 understanding of the NICU and the care and treatment your baby will receive. It is NOT meant to take the place of the medical advice given to you by your baby's doctor and NICU staff. Please be sure to always ask the NICU staff and your baby's doctor if you are uncertain or have further questions.
Our New Baby

Name: ________________________________

Born: ___________ 20 ___ At: ____________am/pm

Month Day

Weight: _______________ Length: _______________

Parents: ___________________________________________________

Siblings: ___________________________________________________

Hospital: ___________________________________________________

Doctor: ___________________________________________________

First Visitors:

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________
Baby's First Picture
What is the NICU?

What is the NICU? And why is my baby there? These are questions that you might be asking as new parents.

The Neonatal Intensive Care Unit (NICU) is a unit of a hospital that is highly specialized in the care of prematurely born infants or those infants that require special care. The infants that are usually cared for in the NICU present with different medical conditions; many of the infants in the NICU are born prematurely. Infants are considered premature if they are born before 37-38 weeks gestational age* (GA).

Besides prematurity, infants in the NICU are also treated for other conditions such as respiratory and cardiac problems. Another condition that your baby might be treated for in the NICU is gastroesophageal reflux disorder (GERD).

The length of your baby's stay in the NICU depends on the severity of their condition. The following pages of this manual will help to familiarize you with the equipment and staff in the NICU; treatments that your baby with GERD may receive are also outlined for you.

The above information was adapted from Hunter, 2005.
Equipment in the NICU

When you walk into the NICU for the first time it can be very overwhelming with all the tubes, wires, and beeping sounds coming from the various machines. The different pieces of equipment and machines that your baby might be attached to are explained more in this portion of the handbook.

** Remember: Always wash and scrub according to your hospital’s NICU policies before entering the NICU as many infants are medically fragile and are more susceptible to infection.

The various types of equipment used in the NICU are explained more in the next few pages. The types of equipment include:

1. Temperature Regulation
2. Oxygen Therapy
3. Nutritional Therapy
Temperature Regulation

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

Isolette or Incubator:
This clear plastic box encloses the mattress and infant and provides heat. The side of the isolette opens for access to your baby. Some have portholes for your arms so you can interact with your infant.

Open Crib:
This is a bassinet-style bed with a mattress but no heat source. Your baby will be dressed and swaddled and placed in this type of bed when he/she is more stable.

The above information was adapted from Hunter, 2005; Neonatology on the Web 2002; Medline Plus, 2007. Photographs courtesy of Altru NICU.
Heart & Oxygen Therapy

**CPAP:** This steady stream of air provided by nasal mask, endotracheal tube, or nasopharyngeal tube helps with your baby's breathing. It may or may not use supplemental oxygen.

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

**Nasal Canula/Mask:**
This is a tube or mask provides humidified oxygen through prongs that fit in the nostrils. It makes handling of your baby easier when they need to be on oxygen.

The above information was adapted from Hunter, 2005; Neonatology on the Web 2002; Medline Plus, 2007. Photographs courtesy of Altru NICU.
Heart & Oxygen Therapy

**Oximeter:** This machine helps to monitor your baby's level of oxygen saturation. A light shines through your baby's skin to obtain an approximate level of oxygen found in their blood. The machine is connected to small finger pad that is attached to your baby like the one pictured.

**Physiologic Monitor:** This machine is used to monitor your baby's heart and breathing. Lines are connected to the machine and alarms can be set so that if their heart rate or breathing rate go below a certain limit, the alarms will beep.

The above information was adapted from Hunter, 2005; Neonatology on the Web 2002; and Medline Plus, 2007. Photographs courtesy of Altru NICU.
Nutritional Therapy

Scale: This scale is fitted with a clear plastic bin to hold your baby. Your baby is often weighed in grams to monitor growth, but your doctor and NICU nurses can also tell you what your baby weighs in pounds and ounces.

Intravenous (IV) Pump:
A pump that regulates the flow of fluids and medications and nutritional supplements to your baby.

NUK® Nipples: This are nipples that are used for bottle feedings in the NICU. They often have a faster flow rate and do not require as much suck from your baby. There are different sizes and rates of flow. Your doctor and NICU staff will help determine what is the best size and flow rate for your baby.

The above information was adapted from Hunter, 2005 and Medline Plus, 2007. Photographs courtesy of Altru NICU.
NICU Staff & Roles

There are many people that you may come in contact with while your baby is in the NICU. It is often hard to remember what each person's job is. The following descriptions will help you understand each of their roles when working with your baby.

**Neonatologist:** Doctor who has completed additional training to care for premature infants and newborns; typically responsible for the medical care of these infants

**Physician Assistant:** Professionals who work under a physician; trained to address symptoms and work with physician to choose treatment method

**Nurse Practitioner:** Registered nurse (RN) who has obtained additional training in a specialized area; supervised by a doctor; may prescribe medications and complete some procedures

**Neonatal Nurse:** Registered nurse (RN) or licensed practical nurse (LPN) responsible for daily care; one nurse assigned per shift; have most contact with infant

The above information was adapted from Vergara & Bigsby, 2004.
NICU Case Manager: Individuals with extensive experience in neonatal care and early intervention services; each infant is assigned a case manager; also helps with preparation for baby’s discharge to home.

Social Worker: Individuals who have completed training in clinical social work and have experience working with families; help families cope and provide information and resources for infant care.

Nutritionist: Registered dieticians with additional training in pediatric and neonatal nutrition; assist doctors determine your baby’s nutritional needs and help address feeding problems.

Respiratory Therapist: Individuals responsible for monitoring breathing and setting ventilation machines appropriately; may perform treatments to clear infant’s lungs.

The above information was adapted from Vergara & Bigsby, 2004.
**Occupational Therapist:** Therapists who have knowledge of pediatric development and completed additional training in NICU intervention; usually focus on feeding, positioning, and adapting environment to meet your baby's needs.

**Physical Therapist:** Therapist who specializes in motor development and has special training in pediatrics and NICU interventions; may assist with positioning and healthy movement patterns.

**Speech Language Pathologist:** Therapists who have completed training in speech development and pre-language skills that are needed to acquire speech; may assess baby's ability to suck and swallow and recommend special feeding techniques.

**Clinical Psychologist:** Professionals who have a Ph.D in psychology and have experience working with families in crisis situations; may provide counseling to individuals and families.

The above information was adapted from Vergara & Bigsby, 2004.
Gastroesophageal Reflux & Our Baby

What is Gastroesophageal Reflux?
Within the NICUs, there are many premature babies that are treated for a wide variety of conditions. One of these conditions is gastroesophageal reflux disorder (GERD). GERD is a common gastrointestinal (GI) disorder. It is described as the reflux of gastric contents and is associated with symptoms of discomfort due to a spontaneous return of gastric contents into the esophagus. GERD is common in premature infants and can occur upwards to three to five times per hour. Approximately one-fifth of babies born before 34 weeks gestational age who were admitted to NICUs were diagnosed with GERD.

Causes & Symptoms
Some of these factors include positioning in sleep and in feeding, and the method of feeding. The most common symptoms that your baby may experience are regurgitation*, vomiting*, apnea*, bradycardia*, and desaturation*.

The above information was adapted from Eisen, 2001; Poets, 2004: Wolf & Glass, 1992.
Diagnosis
Most infants have gastroesophageal reflux to some degree during their first year of life. Determining if your infant has GERD is something that your doctor will discuss with you and the method used is specific to your baby and their needs. Some of the methods used are described below.

pH* Detection
This has become known as the "gold standard" for detecting GERD. This method involves probes being placed in the esophagus, stomach, and at other levels of the GI tract. One advantage of pH monitoring is that the number of episodes in a 24 hour period can be determined.

Gastroesophageal Scintigraphy
This method is more extensive and allows for a better diagnosis of GERD. A radionuclide isotope* is ingested and then followed on camera as it moves through the digestive tract. The severity of GERD can be determined in this manner, but because it is such an intensive method it is not used as often.

Other Methods
Other methods that are used are endoscopy*, barium swallow*, and multiple intraluminal impedance technique*. These methods are not as common. Further information can be obtained on these methods from your baby's physician.

The above information was adapted from James & Ewer, 1999; Poets, 2004; Case-Smith & Humphry, 2005; Eisen, 2001; Vandenplas & Hauser, 2000; Dhillon & Ewer.
Treatment Options

The good news for you and your baby is that GERD is a condition that is treatable. There are various treatment options and include the following: medications, feeding and sleep positioning, and as a last resort, surgery.

Medications
Some of the prescription drugs that might be prescribed to you baby include promotility* drugs and antacids. Some of the promotility drugs include cisapride, erythromycin, and metoclopramide. These medications help reduce regurgitation and vomiting in your baby. These medications will most likely be in liquid form that are given to your baby through their feeding tube.

Surgery
This is a last resort and is often used only for those that do not respond to medications or feeding and sleep positioning which are described on the next two pages.

The above information was adapted from Mascarenhas & Dadhania, 1995; Dhillon & Ewer, 2004; Vandenplas & Hauser, 2000
Feeding Approaches

**Thickening of Formula/Breast Milk**
Feeding approaches include formula and breast milk thickening and positioning techniques during and after feedings that decrease the symptoms of GERD. Often the formula or breast milk is thickened with rice cereal and has been shown to decrease vomiting. Your baby will most likely be happier and gain weight due better. More frequent feedings of three to four ounces every three to four hours is also recommended. (A feeding schedule is included in the Additional Resources section of this manual.)

* Oral feedings are recommended when the infant can remain awake and aroused enough for the feeding.

**Feeding Positions**
Another technique used during feeding is the positioning of your baby while feeding whether by bottle or during breast feeding. The following pages outline and show pictures of the various positions that are recommended for bottle and breast feeding.

The above information was adapted from Dhillon & Ewer, 2004; Hunter, 2005; Wolf & Glass, 1992.
Whether your baby is bottle fed or breast fed is up to you and your doctor, but there are numerous benefits to breast feeding including improved health, less stress, and greater developmental outcomes whether the mother’s milk is fortified or not.

**Bottle Feeding Positions**

Bottle feeding often begins in the NICU. The position used the most is with your baby placed in front of you supported on your lap with one arm supporting their head and spine. You should hold your baby in an up-right position or at a minimum of 30 degree angle.

This position allows you to have eye-to-eye contact with your baby. This contact can contribute to the bonding process with your infant.

Be sure to ask your NICU staff about taking your baby out of their isolette and the placement of tubes during bottle feeding.

The above information was adapted from Dhillon & Ewer, 2004; Hunter, 2005; Wolf & Glass, 1992.
Breast Feeding Position

Find a comfortable position for you and baby. There are four main positions. Try each to find what works for you. It’s also a good idea to vary the positions.

- **Cradle hold**—sit with your arm bent across your lap. The baby’s head rests in your elbow and her or his body along your forearm and lap. The baby’s chest should be against your skin so he or she doesn’t have to turn his or her head to reach the nipple.

- **Cross-cradle hold**—sit with your arm bent across your lap. This time, the baby’s head is in your hand and his or her body extends toward your elbow. This is helpful in learning to get the baby latched on, as you can control his or her head better.

- **Football hold**—sit with your arm bent alongside your body. The baby’s head rests in your hand, with his or her head facing your breast and his or her body extended along your forearm next to your body. This position is more comfortable if you have engorged breasts, sore nipples, or plugged ducts. It is also good after a c-section, because the baby is not resting on your sensitive stomach. If you’re able to multitask, this is a good position for nursing twins.

The above information was adapted from Kassel, 2008.
Sleeping Positions

There are positions that you can place your baby in while they are sleeping or at rest to help reduce the symptoms of GERD.

**On the Tummy (Prone)**
This position is where your baby is sleeping or resting on their tummy. It helps to decrease the amount of GERD occurring in your baby.

**On the Left-Side**
Lying on the left side has been shown to decrease the amount of pressure on the gastrointestinal tract and reduces the amount of GERD episodes. A rolled blanket or a baby bumper may be used to keep your baby on their side.

**Inclined**
This position is the same as placing your baby on their tummy with the exception of the use of a wedge or elevation of the head of the incubator to around 30-45 degrees. This head up position and being placed on the tummy keeps the stomach contents down to help decrease GERD symptoms.

The above information was adapted from Dhillon & Ewer, 2004; Poets, 2004; Ewer, James & Tobin, 1999; Wolf & Glass, 1992.
Positioning Devices

Some of the devices used during sleep and rest positions are the bendies, positioning blocks, and reflux wedge.

**Bendies**
These positioning devices are made of soft foam with a flexible core to help keep your baby in a flexed or curled up position when laying on their tummy. It can also help to keep them on their side or from sliding down when they are elevated in the isolette. (If a bendy is not available, towels or blankets can be rolled and placed around your baby.)

**Positioning Blocks**
These are soft foam blocks that can be adjusted to fit your baby to help keep them on their side. These are used more for side-lying than the bendies.
Reflux Wedge

This positioning device is used specifically for infants with GERD and allows you to use this in a standard crib. The device helps to keep your baby at a 30-45 degree incline which has been found to decrease the symptoms of GERD. Your baby is placed in the sling to keep them on the wedge. These can be commercially ordered from Pedicraft in 6 different sizes and come in pink and blue. A blanket can be placed on the top of the dribble pad for extra protection, but the material is washable.

The above information was adapted from www.pedicraft.com.
Other Cares

Bonding
As a parent you can bond with you baby during feedings, diaper changes, having face-to-face interactions, and by talking to you infant. Your infant will respond to you in different ways during these interactions and you and your baby will bond together. Some ways to bond with your baby are through Kangaroo Care and Infant Massage.

Kangaroo Care
This method of bonding has been shown to have many other medical benefits. To do Kangaroo Care, place your baby who is wearing only a diaper, on your bare skin, tummy to tummy with their head on your chest. Some of these benefits are:

• Helps baby transition in sleep states
• Has a positive effect on apnea, bradycardia, oxygen saturation, respiration, & heart rate
• Helps baby keep a more constant body temperature
• Helps baby gain weight better and decreases time spent in the hospital

The above information was adapted from Hunter, 2005; Vergara & Begsby, 2004, and Larimer, 1999.
**Infant Massage**

Infant massage is just one way for you as parents to interact with your baby. You will provide a nurturing touch to your baby to various parts of your baby’s body as well as use different handling techniques. It also has many neurological benefits for your baby and also has benefits for you as parents.

- **Benefits for Baby**
  - Relaxes and calms your baby to promote growth and quiet time for development.
  - Normalizes muscle tone and increases blood circulation.
  - Stimulates brain development and improves sensory awareness.
  - Promotes bonding and attachment.

- **Benefits for Parents**
  - Feel more confident and comfortable in your baby’s care.
  - Learn to understand and respond to your baby’s cues.
  - Provides a time for bonding and develop ways to calm your baby.

The above information was adapted from [www.infantmassageusa.org](http://www.infantmassageusa.org)
Tips for Parents

This is a stressful time for you and your family. It is important to make sure that you take care of yourself so that you can take care of your new baby. 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 an affect on your physical health such as headaches, fatigue, and aching muscles.
- Treat yourself well:
  - Get enough sleep
  - Eat healthy foods
  - Exercise
- Accept help from family and friends:
  - They can help you:
    - Baby sit your other children
    - Run errands
    - Clean house
- Make time for yourself:
  - Take a bath
  - Go for a walk
  - Watch a movie
  - Get a massage
  - Read a book, or whatever activity you do that helps you relax

The above information was taken from
http://www.kidshealth.org
Going Home

Before your baby is ready to go home he/she needs to meet certain guidelines. Each NICU has their own set of guidelines and criteria for discharge. Be sure to ask your case manager or other NICU staff members what the criteria are for your baby.

The following are a few of the most common guidelines that your baby should meet before going home.

- Your baby is able to keep him/herself warm without the help of an incubator or other heat source.
- Your baby is 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 feedings or is going home on oxygen or other machines, please make sure you are comfortable with all of his/her equipment before leaving the NICU. Make sure you ask any questions you may have. Remember the NICU staff is there to help you.

The above information was adapted from Hunter, 2005; Vergara & Bigsby, 2004.
Going Home
Parent's Checklist

I am/We Are...

☐ Comfortable giving my/our baby a bath.
☐ Comfortable with feeding him/her.
☐ Comfortable with positioning him/her.
☐ Comfortable giving him/her medications.

I/We Know

☐ How to mix formula if needed.
☐ How much and how often to feed my/our baby.
☐ How to take my/our baby’s temperature.
☐ How to perform CPR if needed.
☐ 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**

The day has finally come for your baby to go home! But, before you put your baby in the car, consider the following:

**Car Seat Tips**

- Always put your baby in a car seat when riding in a vehicle.
- The middle of the back seat is the safest position for the car seat.
- Most standard car seats are too big for your baby; you may need to purchase an insert so that your baby fits properly.
- Avoid using heavy blankets or snowsuits under the harness straps. These make it hard to tighten the straps as much as is needed to keep your baby safe.
- Never leave your baby unattended in a car seat in a vehicle.
- Never take your baby out of their car seat when the vehicle is moving. Pull over to the side of the road if needed.
- The base of the car seat should sit flat on the seat. Towels or blankets can be used to level the car seat.

If you have questions, be sure to 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.

The above information was adapted from Altru Health System
Continuing Care

Taking your baby home can be scary, but you do not have to do it all alone. There are services in your community that are available to help you with your very special baby and their needs. Your case manager can the rest of the NICU staff including the occupational therapist can help you find the services that might be beneficial to you and your baby. One program that is available in most states is Early Intervention.

Early Intervention Is...

- A government program that offers services to help your baby meet his/her developmental needs. Early intervention often focuses on your baby’s development from 0-3 years of age. These programs typically employ:
  ~ Case Managers
  ~ Occupational Therapists
  ~ Physical Therapists
  ~ Speech Language Pathologists
  ~ Education Specialists
  ~ and other developmental specialists
- These services are often provided in your home but they may also be offered in a daycare setting or in clinic settings.

The above information was adapted from Stephens & Tauber, 2005, and Vergara & Bigsby, 2004.
Additional Resources for Parents

The following pages contain resources for you to use with your baby when you take him/her home.

Don’t forget to ask your occupational therapist, case manager, and other NICU staff about resources and handouts on areas that you might be concerned about.
## Infant Feeding Log

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Other Resources

These are additional resources that you as parents can access to help make caring for your preterm baby easier.

Preemie shopping

The Preemie Store and more
http://www.preemie.com/

For a Special Baby Preemie Clothes
http://www.preemie-clothes.com/

Reflux -- GERD

Pediatric/Adolescent Gastroesophageal Reflux Assoc. (PAGER) Reflux Information
http://www.reflux.org/

Gastroesophageal Reflux & Related Motility Disorders (GERD) Information re: Reflux/Medication/Testing

Post discharge

After the NICU: advice for when you finally bring baby home
http://home.san.rr.com/gtbangs/advice.htm

Premature Fathers

Yahoo Club for Dads of Premature Infants
http://clubs.yahoo.com/clubs/dadsofpreadterminfants
References


Glossary

**Apnea:** the absence of spontaneous breathing/respiration

**Barium Swallow:** an X-ray test used to define the anatomy of the upper digestive tract

**Bradycardia:** Excessive slowness in the action of the heart, usually with a heart rate below 60 beats per minute.

**Desaturation:** he process of converting a saturated compound to one that is unsaturated

**Endoscopy:** Endoscopic examination, therapy or surgery performed on interior parts of the body.

**Gestational age:** the total number of weeks the infant was in utero before birth

**Multiple intraluminal impedance technique:** technique measures electrical impedance during swallowing of a bolus

**pH:** a measure of acidity and alkalinity of a solution that is a number on a scale on which a value of 7 represents neutrality and lower numbers indicate increasing acidity and higher numbers increasing alkalinity

**Promotility:** an agent that speeds the process of digestion to decrease regurgitation and reflux

**Radionuclide isotope:** Radioactive substances are used in medicine as tracers for diagnosis

**Regurgitation:** to throw or put back; example: regurgitate of stomach contents back into the mouth

**Vomiting:** The forcible expulsion of the contents of the stomach through the mouth.

Terms adapted from:
Hunter, 2005; Poets, 2004

http://medical-dictionary.thefreedictionary.com/desaturation
heartburn.about.com/od/promotilityagents/Promotility_Agents
http://www.online-medical-dictionary.org
NOTES

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CHAPTER V
SUMMARY

The product developed as a result of this scholarly project was designed to be an easy to understand and family friendly guide that occupational therapists working in the NICU could provide to parents who have a preterm infant diagnosed with GERD. In this product, common equipment, terminology, descriptions of staff, and common treatments for GERD in preterm infants are concisely defined in order to allow parents to learn about the NICU and GERD and feel more comfortable participating in their infant’s care. Another strength of this guide is that it presents basic information about the NICU and GERD, but it can be easily and readily adapted to meet the needs and specifications of individual NICUs.

This product, however, is limited by minimal research regarding the use and efficacy of printed educational materials for parents’ adaptation to the NICU and for infants with GERD. The research was also limited on infants with GERD in the literature that was more up-to-date and current. A majority of the literature was fifteen years or more old. Further research which has a focus on appropriate times to introduce materials such as these would be beneficial. Continued research and updates would also need to be made to the current product to ensure that the most accurate information is provided to the parents.

The successful implementation of this product into clinical practice would require marketing and promotion of the product for use in NICU facilities. A needs analysis
would also be required to assess the types of adaptations needed to meet the needs and requirements of each individual facility. Packaging and pricing of the product would also need to be determined in order to make it accessible to the facilities and the parents. Prior to implementation, it is recommended that professional photographs be used in the product instead of photographs retrieved from websites. This would allow for the product to be distributed to more facilities. Furthermore, additional photographs would be beneficial to illustrate more of the concepts and facilitate better understanding.

One last recommendation is that a pilot study be conducted at a local NICU to determine the efficacy of this product. In this pilot study a satisfaction survey would be provided to the parents following an NICU stay. The survey form should include questions related to the usefulness of the manual, ease of understanding, and value of the product in aiding the parents in adapting to the NICU environment and to coping with caring for their infant who is diagnosed with GERD. The surveys would also provide the families with an opportunity to provide feedback and suggestions for improvement or expansion. The results of the surveys would then be used to increase the effectiveness of the product and further its development and research.
REFERENCES


When your baby is in the NICU. Retrieved on September 30, 20008 from http://www.kidshealth.org.
