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Infant morbidity and mortality continues to be a significant problem in the U. S. Preterm birth and/or low birth weight and congenital anomalies are primary causes of infant morbidity and mortality. Analysis of an existing study was done on data from a prospective longitudinal, case based, mixed-methods research study to examine learning needs of parents in the Neonatal Intensive Care Unit (NICU) whose infants were born with complex cardiac anomalies or born extremely premature. The principles of Knowles' Theory of Adult Learning were used to frame the study and findings. Systematic review of the parent and provider interview transcripts from six cases and nurse-kept Interdisciplinary Patient and Family Education Records was conducted to determine parent education needs and provider given information during and after the infant's hospitalization. Findings revealed the theme of parents wanting to answer the question, 'What is going on with my baby's care?' while information given by providers was classified under the theme 'Whose Team are you on?' Resources utilized to find information by parents were explained by the theme, 'Help me Learn'. Contextual variables of parents were also noted to impact learning needs of parents depending on whether the infant was hospitalized or discharged from the hospital and were grouped into themes of 'Issues Before the Infant's Birth' and 'Adjustment to Everyday Life'. Providers need to be aware of the learning needs of parents, potential factors that may influence this learning, and to consider these needs when giving infant care.

*Key words:* NICU, parent learning needs, provider communication, chronically ill infants

PARENT EDUCATION NEEDS OF INFANTS WITH COMPLEX  
LIFE-THREATENING ILLNESSES

by

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## DEDICATIONS

This dissertation is dedicated to the glory of God, my personal Lord and Savior. Without God's calling and strength, this journey would not have been started or finished. Throughout my nursing career, Philippians 4:13 has offered hope and inspiration, "I can do all things through Christ who strengthens me."

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APPROVAL PAGE

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## **CHAPTER I**

### **INTRODUCTION**

The United States (U.S.) continues to have a significant number of infants born prematurely and/or with low birth weight annually. As a result, these infants are likely to have critical life-threatening conditions, known as infant morbidities. Parents of infants with these long-term conditions need education from nurses during hospitalization in order to provide the infants with specialized care at home. Preterm and/or low birth weight infants can have individual needs requiring the parents to have specific education to care for these infants for the first several months to years of their lives. Parents of infants with critical illnesses need to have thorough, consistent educational materials, such as brochures or websites, in order to provide optimal care.

#### **Background**

In 2011, preliminary data indicated there were 3,953,593 babies born alive in the U.S. (Hamilton, B.E., Martin, J.A., Ventura, S J., 2012). Preliminary data also indicated that 6.05 infant deaths occurred per 1,000 live births in 2011 (Hoyert, D.L. & Xu, J., 2012). Approximately two-thirds of these deaths (4.04 deaths per 1,000 live births) occurred during the first 28 days of the infant's life, defined as neonatal death, and the remaining died between that point and their first birthday, defined as post-neonatal death. Two of the leading causes of infant death include prematurity and low birth weight (Hoyert, D.L. & Xu, J., 2012). Of the infants born prematurely or with low birth weight

who do survive to their first birthday, health problems may affect them throughout their lives. The most frequently occurring problems include retinopathy of prematurity, bronchopulmonary dysplasia, and intraventricular hemorrhage (Centers for Disease Control and Prevention, 2013). Having one of these co-morbidities increases an infant's risk of poor outcomes by 42%; two co-morbidities increase poor outcomes by 62%; and all three co-morbidities increase poor outcomes by 88% (Schmidt, 2003).

Since a nation's infant mortality is widely considered to be an important reflection of political, social, health care delivery, and medical outcomes in a geographic location (National Center for Health Statistics, 2013[a]), infant morbidity and mortality in the U.S. are undoubtedly significant health problems both to nursing and the future of America.

### **Prevalence of Infant Morbidity and Mortality in the U.S.**

International infant mortality rates indicate that the U.S. ranked 31 out of 34 ranked countries in the world in 2008 with a rate of 6.6 deaths per 1,000 live births (Heisler, 2012). This rate was an alarming three times higher than the country with the lowest infant mortality rate: Luxembourg, with 1.8 deaths per 1,000 live births (Heisler, 2012). A few years earlier, in 2004, the U.S. ranked 29th in the world in infant mortality (MacDorman & Mathews, 2008). Surprisingly, in 1990, the U.S. ranked 23rd and in 1960, 12th in world infant mortality (MacDorman & Mathews, 2008). Clearly, these U.S. infant mortality statistics reflect negatively on national health care delivery outcomes.

## **Infant Morbidity**

For the purposes of this study, infant morbidity is defined as any health condition present at birth which causes chronic life-threatening illnesses. The number of children with disabilities from prematurity continues to rise (Centers for Disease Control and Prevention, 2013). According to the March of Dimes Foundation (2009), prematurity is a key contributor to chronic respiratory problems, developmental delays, and hearing and vision problems. The odds of any major morbidity occurring are dramatically decreased by factors such as increased gestational age, higher birth weight, and female gender (Warner, Musial, Chenier, & Donovan, 2004). Even if a premature infant survives, there may be continual health problems throughout his/her entire life.

## **Prematurity and Low Birth Weight**

National Center for Health Statistics (2013[b]) data indicate that in North Carolina (N.C.) in 2010, 12.7% of all infants were preterm (born prior to 37 weeks gestation) and 8.1% of all infants had birth weights less than 2500 grams, which is the criterion for determining low birth weight. The majority of infants born prematurely or with low birth weight are admitted to an Intensive Care Unit (ICU) environment at birth for continuous care as the infant learns to breathe, feed, and regulate body temperature independently.

In the U.S. in 2010, 12.0% of all live births were preterm (National Center for Health Statistics (2013[c])). The N.C. premature birth rate is slightly worse at 12.7% of all live births. This statistic is about 10% above the *Healthy People 2020* targeted level of 11.4% for premature births (Hamilton, Martin, & Ventura, 2010). In 2010, 8.1% of all live births in the U.S. were classified as being low birth weight. The *Healthy People*

2020 goal calls for no more than 7.8% of all live births to be of low birth weight. In N.C., the rate was the same as that for low birth weight infants than the U.S. rate. Clearly the incidence of low birth weight and preterm births is a problem requiring interventions in both the U.S. and N.C. (Hamilton, Martin, & Ventura, 2010).

According to the most recent statistics, infant mortality due to prematurity and low birth weight in the U.S. in 2008 was 112 per 100,000 live births (National Center for Health Statistics (2013[d])). The N.C. rate is much higher at 163.9 per 100,000 live births in the same year (National Center for Health Statistics, 2013[e]). The lower an infant's birth weight and the younger an infant's gestational age, the higher the infant's chances of death, thus impacting infant mortality rates. For example, over 50% of all infant deaths in the U.S. occurred to the two percent of infants born at less than 32 weeks gestation in 2007 (Mathews & MacDorman, 2011).

### **Health Indicators**

*Healthy People 2020* was developed by the U.S. government as a series of targets to lead the nation toward health (U.S. Department of Health and Human Services, 2010). One of the overarching goals of *Healthy People 2020* is to realize health equity, eliminate disparities, and improve the health of all populations. Health disparities are defined by *Healthy People 2020* as a type of health difference closely linked with economic, social, or environmental disadvantage that adversely affects people's ability to achieve health (U.S. Department of Health and Human Services). Infants born preterm or with low birth weight are a population who experience health disparities due to their high mortality and health conditions that contribute to high morbidity rates.

One topic area in *Healthy People 2020* deals with maternal, infant, and child health. Health of the maternal, infant, and child population is an essential indicator of the health status of the nation and of future generations (U.S. Department of Health and Human Services, 2010). Maternal, infant, and child health includes not only the women who give birth to the infants and children, but also the families, friends, and caregivers of the women, infants, and children. The *Healthy People 2020* target for all infant deaths is 6.0 deaths per 1,000 births, a goal 10% below the 2006 statistic of 6.7 deaths per 1,000 births (Hamilton, Martin, & Ventura, 2010).

A state program, *Healthy Carolinians 2020*, has goals and objectives congruent with those of its national counterpart, *Healthy People 2020*. For example, one of its 13 focus areas is maternal and infant health. Specifically, North Carolina has set a goal to decrease infant mortality from 8.2 per 1,000 births documented in 2008 to a 10% improvement of 6.3 per 1,000 births by 2020 (North Carolina Department of Health and Human Services, 2011). While this 10 year target is ambitious, compared with the rest of the U.S., only six states have infant mortality rates worse than North Carolina: South Carolina, Arkansas, Tennessee, Alabama, Louisiana, and Mississippi (National Center for Health Statistics, 2009[a]).

### **Linking Maternal Knowledge and Infant Morbidity**

A solid link between a higher maternal education level and lower infant mortality was demonstrated through studies conducted over a two-decade period in Sweden, Finland, Norway, and Denmark (Arntzen, et al., 2007). Three of these four countries ranked in the top six countries for having the lowest infant mortality rates in the world

(Heisler, E.J., 2012). Another study conducted in Sweden over a seventeen-year period found that women with low education, defined as the minimum required by law, are at increased risk when compared with women having high levels of education, defined as having a college education, of having an infant die during the first year of life (Gisselmann, 2005). Women having lower education were at nearly twice the risk of having an infant born with low birth weight when compared to women of high education in the same study (Gisselmann, 2005). No such long-term retrospective studies have been conducted in the U.S.

The indicator of high maternal formal education level and lower infant mortality can be utilized to target information given to mothers. Increasing maternal education related to care of the infant after birth has the potential to lower infant mortality rates by increasing maternal education specific to prenatal care and infant care. Nurses should consistently provide information to all mothers of infants in the ICU environment, despite level of formal education. Topics such as feedings and keeping infants warm are universal to all infants and can help the mother be confident in her ability to care for the infant at home. Previous formal education of the mother can aid her in that she has used study skills and has a history of using prior knowledge to tie to new learning. Being aware of formal levels of education can assist nurses by allowing them to plan additional time and resources for teaching and evaluating mothers with lower levels of formal education as they may not have study skills or prior knowledge to link to new learning.

Educational offerings need not take long periods of time to be effective. A short 15 minute educational offering in small groups of less than ten in a Women, Infant, and

Children (WIC) office which informed parents of the recommendations of the American Academy of Pediatrics regarding the importance of placing infants on their backs to sleep was effective in educating parents on safe sleeping position for their infants and in changing their behavior (Moon, Oden, & Grady, 2004). In this study, education was given in a short period of time, providing parents information about the recommended sleep position for their infants. By completing a post-test, parents indicated their intent to place their infant on their backs to sleep. However, the amount of time required for parents of infants in the ICU to learn infant care has not been studied. Many researchers agree the situation surrounding the admission of an infant to the ICU environment decreases parental control and the health of the infant causes stress to parents (Cleveland, 2008; Feeley, Gottlieb, & Zelkowitz, 2007; Melnyk, et al., 2001; Olshtain-Mann & Auslander, 2008; Turan, Başbakkal, & Özbek, 2008). Because the ICU environment may result in greater stress and fewer opportunities for structured education, short offerings are likely to be beneficial. The first step in designing short educational offerings is determining factors that influence knowledge, such as delivery method, topic, and setting, in parents of infants admitted to the ICU. These issues have not been studied with parents of infants in the ICU specifically.

The results of another study demonstrate the importance and effectiveness of education to parents. Evaluation of the effectiveness of a community intervention, offered in the form of prenatal program services, on infant morbidity was the purpose of a study by a Healthy Start program in Florida (Salihu, Mbah, Jeffers, Alio, & Berry, 2009). Among the infant morbidities studied were prematurity and low birth weight outcomes

over a five-year period. Women were enrolled in the program while they were pregnant and followed until after delivery. A total of 536 mothers received program services, while 2,815 mothers did not. The mean age of those receiving services was 22 years, compared with 25 years on average for the control group. Over half of all mothers sampled completed high school. Women who received the services had a 30% lower risk for giving birth to infants born with low birth weight and of having a preterm birth, and a 20% reduced risk of infant morbidity than women who did not receive the services (Salihu, et al., 2009). Interventions such as this have the potential to impact infant morbidity statistics and need to be replicated.

### **Rationale for the Study**

Infants, who years ago would have died from certain illnesses, are now receiving therapies for these illnesses due to advancements in medicine and technology (Draper, Zeitlin, Field, Manktelow, & Truffert, 2007; Fields & Behrman, 2003; Holditch-Davis, 2007). This population is classified as having complex life-threatening conditions (CLTC) and their parents are learning to live day-to-day with their conditions. The majority of infants with this classification have one of the following diagnoses: complex cardiac anomalies, extreme prematurity, defined as less than 26 weeks gestation, or infants with genetic diagnoses requiring stem cell transplant (Brandon, Docherty, & Thorpe, 2007; Draper, et al., 2007; Fields & Behrman, 2003).

The significance of selecting these infants for the study is easily seen by the following statistics as noted in specific research studies. Preterm birth, defined as infants born less than 33 weeks gestation, account for over one-third of all infant deaths, though

infants born prematurely comprise only two percent of the infant population (Draper, Zeitlin, Field, Manktelow, & Truffert, 2007). Approximately 35,000 – 40,000 infants are born with congenital cardiac anomalies annually (Roth, Adatia, & Pearson, 2006). Preterm birth, congenital heart disease, and genetic diagnoses requiring a stem cell transplant accounted for three-fourths of all inpatient infant deaths (Brandon, Docherty, & Thorpe, 2007). The infants who survive often have morbidities including neurological and developmental problems (Brandon, Docherty, & Thorpe, 2007).

For parents to become active participants in their infant's care during the ICU hospitalization, they must be able to comprehend the health information provided by the health care team (Henson, 2000). Henson notes nurses should always perform a needs assessment to determine the parent's level of knowledge and to never make a judgment about what a parent may or may not already know based on the parent's occupation or education. Ascertaining a parent's level of knowledge allows the nurse to tailor the education presented to parents to their level, making the education better suited to meet their specific needs. Parents and family members are in a crisis state when their infant is admitted to the ICU. Additionally, parents need to grieve in order to accept what has and is occurring to their family (Henson, 2000). Both of these facts may impact parent's ability to learn.

Parents of CLTC infants often grieve the loss of their expected healthy newborn. As a result of the grieving process, parents may go through a series of negative emotions including anxiety, fear, denial, shock, and helplessness (Henson, 2000; Lam, Spence, & Halliday, 2007; Wigert, Johansson, Berg, & Hellström, 2006). Acknowledging parents'

needs is the key to developing rapport, which also assists in decreasing stress (Lam, et al., 2007). Decreasing stress can enhance a parent's ability to understand educational information needed to care for their infant in the NICU.

Parental stress does not end once the infant is discharged from the ICU (Cleveland, 2008; Feeley, et al., 2007; Olshtain-Mann & Auslander, 2008). Parents of infants born prematurely continue to experience stress at higher levels than parents of term infants far beyond the day of discharge. This fact is particularly true of parents with infants born with very low birth weight (Feeley, et al., 2007). Nurses providing education to parents of infants admitted to the NICU should plan to take into account their increased levels of stress.

Communication with parents during the admission of their infant to the ICU needs to be basic, clear, and in written form in their native language (Henson, 2000). This information must be reinforced and repeated on a routine basis in order for the parent to be able to recall it. If verbal communication by health care providers to parents is limited, parents need to have access to educational offerings such as videos and booklets to reinforce the information given by the health care providers (Henson, 2000). Another reason for having various forms of communication available is that establishing effective two-way communication between parents and nurses can be difficult, especially given the changing emotions of parents and the number of nurses caring for the infant (Henson, 2000). Therefore, having information available in more than one format, such as both written and audio may be beneficial.

The ICU is a foreign environment to most parents, often causing stress when their infant is admitted (Fidler & McGrath, 2010). Parents by nature are protective of their infant, while to nurses; patient safety is part of hospital policy and a conscientious choice, such as frequency of hand washing. Parents of infants in the ICU often do not have the information needed to evaluate proper care of their infant, nor do they feel they have the right to question the care the infant is receiving. Frequent and honest communication between parents and nurses is needed in order to reduce potential stress and provide infants in the NICU with optimal care (Fidler & McGrath, 2010).

Parents advocate for their infants, particularly when they require treatment in the ICU (Gooding, Cooper, Blaine, Franck, Howse, & Berns, 2011). Parents need education and collaboration in order to determine what is best for their infant. The Internet can provide resources and services to help parents in these situations, as it is always available. Websites such as that of the March of Dimes are designed with parent needs in mind with topics such as infant development, transition to home, and the ICU environment. Technology, such as videoconferencing, has also comforted parents when they cannot visit the infant or when they need to meet with a group of providers in a different location. Parents reportedly do not feel like a true parent to an infant in the ICU until they are able to do more than look at their infant. Educational opportunities, through which technology can assist, can offer parents the opportunity to support their infant in the ICU and potentially feel more like a parent (Gooding, Cooper, Blaine, Franck, Howse, & Berns, 2011).

Nurses have the responsibility of supporting the families of infants in the ICU and evaluating their comprehension of their infant's condition (Gephart & McGrath, 2012). Though the Internet plays an important role in parent education, it cannot replace the nurse's perception and intuition. The nurse is at the bedside with the infant to answer parent's specific questions, individualizing responses to parents and offering alternative explanations to or resources for information needs. Nonverbal communication can also be noted. Open communication between the nurse and the infant's parents with the focus remaining on the infant empowers parents to advocate for and assist in the care of their infant (Gephart & McGrath, 2012).

While their infants are hospitalized in the ICU, parents must learn to care for their premature and/or sick infant prior to discharge. Often skills such as feeding, suctioning, and administering medications must be taught to the parent, building on their pre-existing knowledge and adapted to their infant's specific needs (Hudson, Elek, & Fleck, 2001). Learning these skills through information, demonstration, and practice allows parents to perform them correctly at home, thus potentially improving infant outcomes. However, the parents' stress level affects their ability to recall knowledge and, therefore, to learn. Learning a skill involves following a prescribed procedure, which can eventually be fundamentally carried out without following a prescribed order (Sousa, 2001). Mastering a skill allows parents to perform it while communicating with and assessing their infant, which helps parents to consider several aspects of their infant's care at once. Henson (2000) notes parents should prepare gradually for their infant's discharge from the NICU

instead of receiving a wealth of knowledge and practice a day or two prior to discharge. However, as noted by Henson, discharge teaching typically begins just prior to discharge because staff frequently cannot predict exactly when the infant will be sent home.

After an infant is discharged from the ICU, phone calls have been an effective strategy in decreasing readmission rates to the hospital in Boston (Dutkiewicz, 2010). The nurse care coordinator of the ICU calls the family to ask a series of standard questions regarding the discharge procedure, home care needs, family support, medications, and follow-up care. The information obtained is entered into a database via drop down menus and an email is automatically generated which is sent to the infant's primary care physician, home health care providers, and other essential care givers. Results from these calls show that parents frequently do not completely understand discharge instructions due to being overwhelmed. Having all of their questions addressed decreases the likelihood of missing important instructions and, thus of having the infant readmitted due to preventable health problems (Dutkiewicz, 2010).

Parents of infants in the ICU are not only listening to what nurses are telling them about their infant, they are watching as well (Carrier, 2009). In a report of an intervention tested in a level II NICU, parents were informed to place infants on their backs to sleep as a measure to decrease the risk of sudden infant death syndrome (SIDS) via handouts and verbal education. When the behavior was modeled by the nurses and the infant was placed on his/her back to sleep prior to discharge from the NICU along with the education via handout and verbal session, parents were more apt to continue the practice at home. Unfortunately, nurses were also noted by parents to keep blankets,

diapers, wipes, and other supplies at the foot of the infant's bed, which is not per SIDS recommendations, thus modeling bad behaviors. These are behaviors which parents should not replicate at home. Parents may be more likely to mimic these bad behaviors demonstrated by the nurses in the hospital environment when at home instead of practicing the correct behaviors that they were verbally taught by the nurses. How nurses position infants and arrange their sleeping environments has a great impact on how parents will position the infant once discharged (Carrier, 2009). These results highlight the importance of the nurse not only as a provider of information, but also a role model of appropriate behavior.

### **Conceptual Framework**

Malcolm Knowles' Theory of Adult Learning (Knowles, Holton, & Swanson, 2011) became one of the most influential learning theories during the late 1970's and 1980's and outlined six principles, noted below. The Theory of Adult Learning asserts that by applying these principles, more learning will occur in adults than without consideration of the principles.

Historically, theories of adult learning have considered the learner's self-concept, readiness to learn, and internal motivation to learn as essential to learning (Knowles, Holton, & Swanson, 2011). Thus how the client views his/herself, the desire to learn, and the timing of the information presented all have an impact on how and what the client learns. For example, a parent may want to learn about the infant's wound care in order to expedite healing, however may still be too upset over the cause of the wound to retain information.

## **Principles**

The Theory of Adult Learning contains six principles. These principles can be used in many diverse settings and must be viewed as essential when considering learning for adults. However, their meanings, as defined by Knowles (Knowles, Holton, & Swanson, 2011), do not change.

Principle 1: Adults have a need to know why they should learn something.

Principle 2: Adults have a deep need to be self-directing.

Principle 3: Adults have a greater volume and different quality of experience than children.

Principle 4: Adults become ready to learn when they experience in their life situations a need to know or be able to do in order to perform more effectively and satisfyingly.

Principle 5: Adults enter into a learning experience with a task-centered (or problem- centered or life-centered) orientation to learning.

Principle 6: Adults are motivated to learn by both extrinsic and intrinsic motivators.

As one of the primary roles of the nurse is to educate, Knowles' Theory of Adult Learning can be utilized in a variety of ways.

### **Applications of Knowles' Adult Learning Theory in Nursing**

Knowles' theory has been used in health care as a framework for both staff education and patient education. An example of staff education is educating staff about methods of teaching patients, such as prior to discharge. The principles of Knowles'

Theory of Adult Learning were used in the development of staff educational materials for hemodialysis nurses. Understanding these principles and using them to guide the formatting of the information provided, allowed staff to implement their new education in a shorter amount of time to enable nurses to become competent in hemodialysis skills. The developed modules worked so well for the facility that designed them that several facilities across Canada have adopted their use as well (Ludlow, Gaudine, & Jacobs, 2007).

Hospitalized clients being transferred from the intensive care unit environment to a step down unit and their families need to be educated on this change in environment (Mitchell & Courtney, 2005). A hospital in Australia used principles of Knowles' Theory of Adult Learning to determine that the development of a brochure would meet their education needs. The theory was used to determine the method of presenting the needed information. Recognizing that adults have a need to be self-directed and autonomous, the brochure allows adults to read the information when they are ready and to ask questions, displaying their readiness to learn.

Knowles' theory has been used in planning education for parents of deaf children. Programs created for parents of deaf children must consider the hectic roles of these adult learners. Considering the principles of Knowles' Theory of Adult Learning, parent support groups for deaf children have been found to be a great resource for this

population as they allow parent's past experiences to help teach other parents (Bodner-Johnson, 2001). These examples show the utility of Knowles' theory in the assessment of learning needs and the design of learning activities for adults using a variety of strategies.

### **Summary**

Infant morbidity and mortality continues to be a significant problem in the U.S., despite attempts to lower these rates. Preterm birth and/or low birth weight are primary causes of infant morbidity and mortality. These infants are often admitted to the ICU for monitored growth, feeding, and temperature regulation. Researchers have shown links between high levels of maternal knowledge and low infant morbidity. Providing relevant education to mothers who have infants in the ICU may lead to lower infant morbidity rates. The principles of Knowles' Theory of Adult Learning may play a role in increasing maternal knowledge by allowing the nurse to individualize education according to the parent's needs.

The purpose of this study was to compare the parental information needs and sources of information for parents of infants with complex life-threatening illnesses while the infant is hospitalized and after the infant's discharge. Assessing information and learning needs of parents of infants in the NICU is an essential component of caring for preterm and/or low birth weight infants. Determining the information needs and learning preferences of parents of infants with life threatening conditions during the infant's hospitalization and after discharge could positively impact infant morbidity in this population.

### **Specific Aims and Research Questions of Study**

The specific aims and research questions for this study were as follows:

Specific Aim 1: To determine the information needs of parents of infants with life threatening conditions compared with information given by health care providers to the parents during their infant's hospitalization.

Research Question 1: What topics (categories) of information were sought by parents during their infant's hospitalization?

Research Question 2: What topics (categories) of information were discussed by health care providers with parents during their infant's hospitalization?

Research Question 3: From whom and from what outside resources did parents seek information during their infant's hospitalization?

Research Question 4: What contextual variables were present which may have influenced information needs of parents during their infant's hospitalization?

Specific Aim 2: To determine the information needs of parents of infants with life threatening conditions compared with information given by health care providers to the parents following their infant's discharge from the hospital.

Research Question 1: What topics (categories) of information were sought by parents following the infant's discharge from the hospital?

Research Question 2: What topics (categories) of information were discussed by health care providers with parents following their infant's discharge from the hospital?

Research Question 3: From whom and from what outside resources did parents seek information following their infant's discharge from the hospital?

Research Question 4: What contextual variables were present which may have influenced information needs of parents following their infant's discharge from the hospital?

Specific Aim 3: To compare the information needs of parents of infants with life threatening conditions compared with information given by health care providers to the parents over time from hospitalization (time 1) to after discharge (time 2).

Research Question 1: What topics (categories) of information were sought by parents during their infant's hospitalization compared to the information parents sought after discharge?

Research Question 2: What topics (categories) of information were discussed by health care providers with parents during their infant's hospitalization compared to information discussed by the health care provider after their infant's discharge from the hospital?

Research Question 3: From whom and from what outside resources did parents seek information during their infant's hospitalization compared to the information sought and outside resources used after their infant's discharge from the hospital?

Research Question 4: What contextual variables were present which may have influenced information needs of parents during their infant's hospitalization compared to the contextual variables present after their infant's discharge from the hospital?

## **CHAPTER II**

### **REVIEW OF THE LITERATURE**

Some infants are born requiring individualized attention after birth which exceeds the services offered in general nursery. For example, infants born preterm or with low birth weight or born term with congenital anomalies are often admitted to the neonatal intensive care unit (NICU). This review of literature explores parents' reactions to the ICU environment, parent/nurse relationships, and parent education. Parents of infants in the ICU experience stress and anxiety. Nurses who work in the ICU play an important role in meeting the needs of parents, primarily by decreasing the parent's stress and anxiety through education about the infant. Nurses also provide parents of infants in the ICU with education needed to care for their infant at home. Some methods of teaching include face-to-face teaching, information provided over the Internet, or blending of the two methods. Parents of infants in the ICU need to have their educational needs met.

#### **Parent Reaction to the NICU Environment**

The establishment of NICUs in the U.S. is documented as early as the mid-1960's (Kavanaugh, Moro, & Savage, 2010). At this time, infants requiring specialized care were treated with adult instruments and tools, such as ventilators and intravenous lines, only with smaller volumes. In the 1970's, issues related to thermoregulation and noise control had not been addressed. Clustering of care was not thought of as important (Holditch-Davis, 2007). Great advances in providing care to infants requiring specialized

treatment in the NICU were made during the 1980's and 1990's, greatly increasing survival rates in this population (Griffin & Abraham, 2006; Kavanaugh, et al., 2010; Monterosso, et al., 2005). Infants younger than 25 weeks gestation, born weighing about a pound, are surviving to discharge and beyond (Holditch-Davis, Cox, Miles, & Belyea, 2003). Since the 1990's, one area of research has focused on the ICU environment and how infants and their parents interact with the environment.

The ICU environment can be intimidating to parents visiting their infant due to highly technological surroundings (Olshtain-Mann & Auslander, 2008). Cardio-respiratory monitors, pulse-oximeters, ventilators, blood pressure cuffs, and numerous intravenous lines, tubings, and pumps, all with their own shapes and alarms can distort an infant's appearance (Turan, Başbakkal, & Özbek, 2008). Parents often express lack of confidence and self-doubt regarding infant care in the NICU as the setting imparts feelings of decreased parental control over their infants (Olshtain-Mann & Auslander, 2008).

Many researchers have measured the level of parental stress among parents of infants hospitalized in the NICU (Cleveland, 2008; Feeley, et al., 2007; Melnyk, et al., 2001; Olshtain- Mann & Auslander, 2008; Turan, et al., 2008). All agree that the situation involved with the ICU admission, the ICU environment, decreased parental control, and the health of their infants compounds, causing stress to parents. Stress can be a barrier to learning. As infants near term gestation parents begin to become more

autonomous with infant care and prepare for discharge (Olshtain-Mann & Auslander, 2008); therefore, it is important to understand how parents experience the stress of the NICU and how parents best learn, to prepare them to care for their infants at home.

### **Parental Barriers to Learning: Stress and Anxiety**

The increased level of stress of mothers with infants in the NICU negatively influences maternal competence when compared with maternal competence with term infants ( $p < 0.01$ ) (Olshtain-Mann & Auslander, 2008). Eighty sets of parents with term infants not requiring NICU care and eighty sets of parents with preterm infants requiring NICU care in Jerusalem participated in this longitudinal, mixed-methods study during admission and at two-month follow-up. The sampled mothers had an average age of 30 years, while the fathers' average age was 33 years. Mothers' mean level of education was 14 years while fathers had about 15 years. The hospitalized infants were approximately two months old when ready to be discharged from the NICU. Two instruments were used: Self-Perception of the Parental Role to measure parental competence, and an instrument using a Likert scale to measure parental stress. Follow-up interviews were conducted when all infants were ready for discharge. Mothers of infants who required NICU care expressed feeling less certain about their ability to parent their infant in their own home than mothers of term infants (Olshtain-Mann & Auslander, 2008).

Studies have been conducted in different countries which focus on the NICU environment and the level of stress and anxiety experienced by parents of infants in the NICU. Examination of anxiety levels of mothers with infants in the NICU was the focus

of a descriptive study in Turkey (Erdem, 2010). The NICU where the study was conducted admits 3000 infants annually. Infants had to weigh at least 2000 grams and have a minimum gestational age of 32 weeks in order for mothers to participate (N = 151). Seventy-two percent of the admissions in this study were preterm. More than half of mothers had at least a high school diploma. Mothers ranging from 20 – 34 years of age comprised 83% of the sample. Data were collected via face-to-face interview of the mothers while they were visiting their infant in the NICU, during which time the State-Trait Anxiety Inventory (STAI) was completed by the mothers. The results showed mothers had a moderate amount of state anxiety related to their infant's admission to the NICU. Nearly half of mothers with anxiety expressed particular concern about their infant's recovery. There was also a significant difference between anxiety levels, with mothers with a high level of income having less anxiety versus those with a low level of income having more anxiety ( $p < 0.05$ ). STAI scores were also found to increase along with the infant's length of stay. Interviews also indicated that approximately 70% of mothers received education from nurses about their infant during hospitalization. Researchers concluded that mothers were anxious regarding their infant's stay in the NICU. The level of anxiety increased proportionally as the infant remained hospitalized; therefore it is important to determine the best way to teach parents who are anxious (Erdem, 2010).

A longitudinal study was conducted in Canada to compare how parents adjusted to caring for very low birth weight (VLBW) infants (infants <1,500 grams at birth) at three and nine months of age (Feeley, et al., 2007). Sixty-one mothers and fathers

participated, each having a mean age of 33 years and an educational level of 14 years. The majority were married and first time parents. The following tools were administered: Support in Parenting (SIP), State-Trait Anxiety Inventory (STAI), and Nursing Child Assessment Teaching Scale (NCATS). Overall, fathers had a lower sense of confidence when caring for their infant than mothers, and it did not change over time. Anxiety levels were above the mean scores for the STAI and were similar and consistent for both mothers and fathers. Anxiety remained high, even after the VLBW infant was discharged from the hospital. Fathers reported receiving more support than mothers from outside sources such as colleagues and other social networks over time. The importance of identifying mothers and fathers with high levels of anxiety in order to encourage parents to discuss their concerns about their adjustment to caring for VLBW infants was noted (Feeley, et al., 2007).

A research study in Turkey compared the anxiety levels of parents in an experimental group (N=20) versus a control group (N=20) at 10 days after their infant had been admitted to the NICU (Turan, et al., 2008). The average age of both groups was 25 years. Eighty percent of the experimental group had completed high school as compared with 95% of the control group. For the experimental group, the nurses caring for newly admitted infants spoke with the parents one-on-one for about 30 minutes regarding topics such as the infant, the equipment in the unit, how the infant appeared, visitation policies, and parent participation in infant care, before the parents saw their infant. Nurses promoted sharing of feelings between mother and father during this time. This allowed parents to ask questions of the nurse and have some of their concerns

addressed very soon after the infant was admitted. The nurse then accompanied the parents to see their infant and remained with them, introducing them to what had been discussed and to personnel in the unit. The control group did not receive any standardized education prior to seeing their infant; however their questions were answered when they arrived in the NICU. This NICU typically had only two nurses working per shift, therefore presenting routine information was not a common practice. Due to issues surrounding communication, researchers were not contacted regarding a potential study participant until 1-2 days after admission. By the time informed consent for study participation was obtained and the intervention had been given, measurements were not taken until approximately 7-10 days after birth. Anxiety levels as measured by the State-Trait Anxiety Inventory given at 10 days after the infant's admission were significantly different ( $p < 0.05$ ) for both mothers and fathers between the experimental and control groups. The parents receiving information from the nurse one-on-one prior to entering the NICU reported feeling less anxiety regarding their infant's admission to the NICU than those having questions answered after arriving in the NICU for the first time. The researcher's results indicate a decreased level of parental anxiety following one-on-one teaching by a nurse (Turan, et al., 2008), however the researchers did not consider potential threats to internal validity to the study, such as other possible causes of parental stress.

Parents with infants in the NICU require specialized information and discharge teaching due to the reason their infant required care in the NICU. Numerous large research studies have been conducted in other countries to measure levels of stress using

the STAI (Erdem, 2010; Feeley, et al., 2007; Turan, et al., 2008), which all confirmed that parents feel stress and anxiety in the NICU environment. These studies have not been replicated in the U.S. One study included term infants, not those requiring care in the NICU. Though researchers agree that parents of infants in the NICU often experience a high level of anxiety, attempts to decrease parental anxiety or alternative methods to offer parent education to decrease the effects of this potential learning barrier have not been explored. Researchers have found that increased communication between health care providers and parents of infants in the NICU helps to meet information and educational needs of these parents. Topics or forms of communication have not been studied. A link between parental anxiety levels was found to be correlated with socioeconomic status in one study, however not confirmed by other studies. Determining the needs of parents with infants in the NICU regarding information and educational needs has not been extensively researched in the U.S.

### **Teaching-Learning: The Nurse-Parent Relationship**

The relationship between parents of an infant and nurses in the NICU is important in order to teach parents skills needed to care for their infant at home (Fegran, Fagermoen, & Helseth, 2008). Researchers in a qualitative study in Norway observed parents of infants in the NICU and the nurses who cared for them in order to investigate the relationships between the mothers (N=6), fathers (N=6), and nurses (N=6). Mothers had an average age of 31 years with the majority having a college education; fathers' average age was 36 years with the majority having less than a high school education; nurses' average age was 35 years with an average of six years experience in the NICU.

The convenience sample was observed for the length of stay (average 7 weeks) and interviewed when the infant was discharged from the NICU. Observers were registered nurses; however, they did not work in the NICU. The observer sat in the room with the parent and NICU nurse as they interacted. Feedings and infant care were the primary actions being observed. The observer also took field notes. The researchers found three separate phases of the parent-nurse relationship: the acute critical phase, the stabilization phase, and the discharge phase (Fegran, et al., 2008).

The acute critical phase began at the infant's birth and included the time period when the nurse served as the infant's main caregiver and the parents mostly watched their infant. Parents were encouraged to touch their infant, particularly through kangaroo care, and were informed of the infant's condition during this phase. The observers noted the importance of the nurse caring for their infant to have gained the parents' confidence as professional caregivers (Fegran, et al., 2008).

The stabilization phase was characterized by parents caring for their infants more and more as the infants' conditions improved while nurses simultaneously retained less and less of the infant care responsibilities while the parents were present. Nurses gradually handed over the infant's care to the parents, who became increasingly responsible for their infant. As nurses taught parents to care for their infant, parents were able to assume additional care of their infant in the NICU in preparation for discharge. Parents stated the importance of a trusting relationship with the nurse as this time can be challenging for parents (Fegran, et al., 2008).

Lastly, the discharge phase was characterized by parents becoming the infant's primary caregivers and the nurse serving as the supporter and encourager of care. Parents described this phase as exciting and joyful blended with feelings of trepidation about leaving the security of the NICU environment. Both parents and nurses expressed excitement at reaching this final stage. These results highlight the positive effects of communication and teaching, as well as parental autonomy systematically increasing in the NICU. Nurses are in the position and have the unique opportunity to help parents increase confidence in their abilities to care for their infant upon discharge from the NICU through education (Fegran, et al., 2008).

Feelings of stress and anxiety may be decreased when open lines of communication are established between parents of infants hospitalized in the NICU and nursing staff. A key ingredient to developing rapport between nurse and parent is being able to recognize the parent's needs (Lam, Spence, & Halliday, 2007). A pilot study in Australia aimed to examine the relationship between parental stress and the support parents received from the nursing staff in a NICU. The researchers hypothesized that the more support given to parents by nurses, the lower the parents' stress levels would be. Sixty-two parents of infants at risk for needing surgical interventions participated in this study. Over 70% were mothers and just over half were over the age of 30 years, which is above the average age of mothers with infants receiving care in the NICU. Approximately 60% had a high school education or less, while the remaining percentage had a college education. Over half (65%) were married. Two instruments were used, the Parental Stressor Scale (PSS:NICU), to measure parental stress coming from the NICU,

and the Nurse Parent Support Tool (NPST), which measures parents' feelings of nursing support during hospitalization of their infant. These self-report instruments were given to parents a few days prior to discharge. The study found a moderately negative correlation (0.59) between feelings of stress and nursing support. Overall, parents reported feeling less stress when they felt a part of the team caring for their infant compared with those parents who did not feel a part of the care team. As a part of the care team, parents were kept informed about the infant's condition and educated regarding care and care options (Lam, et al., 2007). The primary concern regarding the design of this pilot study was the fact the nurses caring for the infants gathered the data, acting in the researcher role as well, and therefore may have inadvertently influenced the responses of the parents.

Parent satisfaction with overall provider communication was improved when interventions targeted at the amount and quality of communication between health care providers and parents of infants in the NICU were initiated (Weiss, Goldlust, & Vaucher, 2009). Researchers in a level III NICU provided a standardized patient satisfaction survey (by Press Ganey Associates, Inc., <http://www.pressganey.com/index.aspx>) to a convenience sample of parents prior to the initiation of a communication intervention. The intervention consisted of education to the health care providers on communication skills; information given to parents about the various job titles and descriptions of health care personnel in the NICU; and displays of photos and names of health care providers posted at the entrance to the NICU. Once the intervention had been in place for two months, a different cohort of parents was surveyed using the same tool. The pre-intervention cohort of parents (N=50) and the post-intervention cohort of parents (N=34)

both had infants with an average gestational age of 32 weeks and were surveyed when their infant had been hospitalized approximately three weeks. The pre-intervention mothers had a mean age of 30 years while the post-intervention mothers had a mean age of 26 years. Approximately 70% of the pre-intervention mothers had at least a high school education, as did approximately 60% of the post-intervention mothers. Eighty percent of the pre-intervention mothers were either Hispanic or Caucasian as were two-thirds of the post-intervention mothers. The study results revealed a 34% increase in overall “very satisfied” parents after the intervention was initiated ( $p < 0.01$ ). The number of times parents selected the option “would like to speak with a health care provider more often” decreased to one-third of those surveyed after the intervention whereas two-thirds of parents chose this option before the intervention ( $p < 0.01$ ). Lastly, there was a 38% increase in parents reporting a health care provider was “always” available to speak with them after the intervention was implemented ( $p < 0.01$ ). Health care provider – parent communication could increase parent satisfaction in health care providers in the NICU, thus increasing the likelihood of parents asking questions about their infant (Weiss, et al., 2009).

Anxiety of mothers in the NICU may be decreased by nurses allowing mothers to actively participate in caring for their infant (Wigert, Johansson, Berg, & Hellström, 2006). A phenomenological hermeneutic study was conducted to examine mothers’ experiences of having their full term infant cared for in the NICU. Ten mothers, whose average age was 34 years, were interviewed in this Swedish study. Nine mothers lived with the infant’s father. Six of the ten were first-time mothers. Researchers identified

that the primary feeling mothers had was exclusion from involvement with care of their infant. Mothers expressed a need for trust in three areas: the infant's nurse, information, and communication. Mothers questioned their own ability to care for the infant if they perceived something was wrong, decreasing their confidence in their abilities as a mother. This study emphasizes the need for nurses to include mothers in infant care in the NICU. Mothers need to be active participants in their infant's care, which was found to decrease the mother's anxiety. When nurses support mothers on a routine basis by teaching and modeling infant care, the mother's anxiety level can be decreased (Wigert, et al., 2006).

A qualitative study examined mothers' experience of transitioning to motherhood while the infant was in the NICU (Heermann, Wilson, & Wilhelm, 2005). The NICU should be an environment which encourages mothers to proficiently understand their infant's abilities and behaviors. Researchers conducted interviews with 15 mothers of infants in the NICU and concluded that these mothers did not have the knowledge or the means to transition to motherhood without assistance. Through guided participation, the nurses mentored the mothers over time until they were able to take an active role in caring for their infants. Mothers described the nurse's guidance as more like teaching or coaching as the nurse was leading the mother toward the goal of caring for the infant independently (Heermann, et al., 2005). Mothers of infants in the NICU clearly have a need for this teaching and nurses play an active part in imparting this knowledge.

Researchers conducted a meta-synthesis focusing on mothers and mothering of preterm infants (Aagaard & Hall, 2008). The goal of the meta-synthesis, which examined 14 qualitative studies, was to use research to promote family centered care in the NICU.

Criteria for inclusion were: published in or after 2000; included key search terms mother, preterm, and NICU; found in one of the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, Web of Science or PsycINFO. The researchers discovered several central metaphors, showing that mothering an infant in the NICU is a process which is developed through the mother's relationships with her infant and the staff. Both giving birth prematurely and caring for an infant in the NICU cause stress to the families who experience it. Mothers often feel like outsiders in the NICU; however through the actions of nurses, such as providing updates and education about infant care, mothers develop into caregivers for their infants. Nurse awareness of maternal need for support, including her in discussions, and teaching her infant care may decrease maternal stress (Aagaard & Hall, 2008).

A research study identified nurse behaviors that help parents of infants born extremely prematurely make decisions before and after the infant's birth (Kavanaugh, Moro, & Savage, 2010). This longitudinal, descriptive, prospective study used a case study approach. Mothers were hospitalized at the time of recruitment and were between 21 and 25 weeks pregnant. Parents, mothers and fathers separately, and health care providers, including physicians and nurses, were interviewed at various time periods using semi-structured interview guides including prenatally; post-birth; if the infant was stillborn; and if the infant was born alive and later died. All parents and health care providers were interviewed prenatally and post-birth and contacted weekly for updates regarding the infant's condition and the need for decisions weekly for the first two months of the infant's life. Additional interviews were conducted as needed, such as

upon the infant's death or when a decision was made regarding the infant's treatment. Demographic data and chart reviews were also conducted. In total, 40 cases were recruited containing 203 interviews. The parents' mean age was 29 years with mean education being completion of high school. Over half of the parents were African-American, with the remaining of Hispanic and Caucasian ethnicities. Approximately one-third of the parents were married, one-third were single, and one-third lived together. Half of the parents reported an income of \$25,000 - \$70,000 annually. The researchers concluded the nurse-parent bond was important to provide information to parents about their infant, to answer questions about their infant, to explain their infant's care, and to provide education (Kavanaugh, et al., 2010). Nurses are at the bedside with the infant on a continual basis and interact with both the infant and parents on a routine basis. The nurse's knowledge of the individual infant and medical education places them in a position to advocate for the infant and for parents. Providing specific education to parents of infants in the NICU is an essential role of the nurse working in the NICU.

The nurse-parent relationship is important during an infant's stay in a NICU (Fegran, Fagermoen, & Helseth, 2008). Open communication and active participation with parents is essential to decreasing stress and anxiety associated with having an infant in the NICU (Aagaard & Hall, 2008; Heermann, Wilson, & Wilhelm, 2005; Lam, Spence, & Halliday, 2007; Weiss, Goldlust, & Vaucher, 2009; Wigert, Johansson, Berg, & Hellström, 2006). Keeping parents updated on the infant's status helps parents feel part of the team caring for their infant (Lam, Spence, & Halliday, 2007). Though the time and quality of provider information was noted as important, the content or delivery method

was not. Studies also noted the importance of determining parent's educational needs, but studies were not found regarding how to determine these educational needs. Nurses are in a position as continuous bedside caregivers to assist parents in advocating for their infant (Fegran, Fagermoen, & Helseth, 2008; Kavanaugh, Moro, & Savage, 2010). The qualitative study noting phases of the nurse-parent relationship was partially via observation, a subjective method. Verification of the finding has not been supported using any other research methodology. Potential flaws in the design of this pilot study were not discussed, nor was this pilot used as a basis for future studies. No such study has been conducted in the U.S., although research studies have noted these findings in other countries. Studies that interview both the parents and the nurse separately, particularly using longitudinal methods to verify findings, have not been performed.

### **Parent Educational Needs**

A systematic review of research published between 1998 and 2008 was conducted to determine what is known about parents with infants in the NICU regarding the parent's needs and behaviors (Cleveland, 2008). The search terms "parents or parenting" and "neonatal intensive care unit" were used together to retrieve 60 qualitative and quantitative articles. The purpose of the review was to answer the following questions: (1) What behaviors support parents with an infant in the neonatal intensive care unit?; and (2) What are the needs of parents who have infants in the neonatal intensive care unit? The reviewers found four nursing behaviors which support parents with an infant in the NICU: (1) parent education with opportunities for parents to practice skills; (2) maintenance of a welcoming NICU environment; (3) emotional support of parents by

nurses; and (4) parent empowerment. Six overall needs of parents with infants in the NICU were identified via the literature review: (1) a therapeutic relationship between parent and nurse in the NICU; (2) individualized infant care; (3) NICU staff being positive toward the presence of parents in the NICU; (4) parent – infant contact; (5) nurse protection of a parent’s infant in the NICU; and (6) nurses giving parents accurate information about and inclusion in their infant’s care. The researchers concluded that the bond between parents of infants in the NICU and the nurses caring for the infants needs to be supportive and trusting in order for parents to feel emotionally safe and for education to occur in a relaxed environment. Parents need education regarding their infant’s condition and care that is accurate and easy to understand. Nurses who care for infants in the NICU must teach parents to care for their infants using guidance and support whenever possible. Unit policies and nurse orientation in the NICU may need to be considered in light of these findings to better meet the needs and behaviors of parents (Cleveland, 2008).

Examination of the hierarchy of needs in a diverse population of mothers with infants in the NICU was the focus of a study in an American level III NICU (Sargent, 2009). Forty-six mothers, with an average age of 28 years, completed an inventory of statements, rating them on a five-point Likert scale according to the statement’s importance to them. The sample was almost 60% African-American and Hispanic; most (nearly 50%) had a high school diploma as their highest educational level. The average gestational age of the infants was 33 weeks with a mean length of stay in the NICU of 14 days. Mothers ranked having questions answered honestly about their infants as most

important followed by knowing how their infants were being treated medically. Researchers concluded that mothers needed to be reassured about their infants and educated about the care their infant is receiving. Nurses who work in the NICU are at the bedside with infants requiring specialized care and are trained to support and teach parents. The results of this study can help health care providers plan services for parents with infants in the NICU, such as specialized discharge education (Sargent, 2009).

A different study about the needs of parents with an infant in the NICU found comparable results (Mundy, 2010). A convenience sample of sixty parents of infants in a level III NICU participated in interviews either the week of the infant's admission or the week of the infant's discharge. The infant's mean gestational age was 32 weeks and had an average length of stay of 46 days. Mothers comprised three-fourths of the sample, with about 50% being first time mothers and 17% having a previous infant in the NICU. Roughly 50% of the participants were Caucasian with another 40% African-American. During the interviews, parents completed a tool rating their needs using a five-point Likert scale. Results showed parents need assurance first as shown by all parents expressing the desire to be called at home about changes in their infant's condition. Second, parents wanted to know why their infants required specific interventions. Third, parents indicated a need for information as indicated by parent's desire to be told specific facts about their infant. Nurses who care for infants in the NICU are in a unique position to assist parents in having all of these needs met through communication and education. Knowing the needs of parents with infants in the NICU can help health care providers incorporate parents' needs into the infant's plan of care (Mundy, 2010).

Determining when an infant is in pain can be difficult, particularly to a parent of an infant in the NICU setting (Franck, Oulton, & Bruce, 2012). Researchers in four London NICUs looked at parental involvement in infant pain management. Parents in both the intervention (N = 84) and control (N = 85) groups received two visits, lasting about 45 minutes each, from a researcher to provide information. The intervention group also was given a booklet containing information about pain and comforting in the NICU, which was evidence-based. These parents were encouraged to ask questions of their infant's nurse related to pain. The control group received the visits only. All parents completed the Parent Attitudes about Neonatal Pain (PAIN) survey within 3 to 7 days of admission before any intervention or meetings had occurred, after the second visit by the researcher (about 7 days later), and again three months after the infant's discharge. The majority of parents regardless of group assignment saw their role in pain management as vital and wanted to be a part of this aspect of care. After participation in the intervention, parents knew how to become involved in pain management as indicated by their ability to discuss potential interventions, while parents in the control group did not know how to become involved and saw their role more as being informed by the nurses and not actively participating in intervention. Both groups of parents stated apprehension about assisting with infant comfort and pain management while their infant was undergoing a procedure known to be painful, such as an intravenous line start. The researchers concluded that parent education is essential, particularly in the area of pain management, when parents are to become actively involved in their infant's care in the NICU so parents can be advocates for their infants (Franck, Oulton, & Bruce, 2012).

When infants are discharged from the NICU to the home environment, parents become the primary caregivers for the first time (Raines & Brustad, 2012). Discharge teaching is individualized to each parent based on the needs of the infant and parent dyad, yet all discharge teaching is completed within the stressful NICU environment. Parents are expected to be able to perform all care for the infant and anticipate the infant's needs after the discharge teaching has occurred. Even if the parents have an older child, taking home an infant who has required NICU care can cause anxiety (Raines & Brustad, 2012). Researchers used a descriptive study to assess parent's levels of confidence regarding being placed in the primary caregiver role upon discharge and after their first day at home, using a researcher developed, self-report tool. Inclusion criteria were parents of at least 18 years of age with an infant to be discharged home into their care for whom they would assume primary care responsibilities. The infant had to have been hospitalized in a NICU for at least 10 days. Completed parent tools were evaluated, all of which were completed by the infant's mother. The mean participant age was 27.5 years with the infant's gestational age ranging from 25 to 36 weeks gestation. Length of NICU stay was 12 to 73 days. For almost half of the mothers, this infant was their first. At the time of the infants' discharge, mothers were least confident about these three areas: administering medications to the infant, use of home monitoring equipment, and noticing changes in the infant's status. Mothers' levels of confidence continued to decrease in these same areas after the infant had been home for one day. Typically, these infant care responsibilities

are not assumed by the parent in the NICU until just prior to discharge (Raines & Brustad, 2012). Allowing parents to practice these roles earlier in the infant's stay may increase the parent's confidence with these skills after discharge.

### **Face-to-Face Education**

Education needed by parents includes how to position infants, particularly when sleeping. The purpose of a study in the U.S. was to inform parents about the risk of Sudden Infant Death Syndrome (SIDS) and back to sleep (BTS) guidelines recommended by the American Academy of Pediatrics (Moon, Oden, & Grady, 2004). Face-to-face educational sessions were presented to 310 mothers and primary caregivers in groups of three to ten prior to receiving Women, Infant, and Children (WIC) vouchers. Participants had an average age of 26 years and approximately 75% had graduated from high school. For half of those surveyed, this was their first infant. Questionnaires about infant sleeping positions were given to participants immediately after the educational sessions, giving parents no time between education and evaluation. The control group of 113 mothers and primary caregivers, coming from WIC offices in the area, received no education. Both groups were surveyed when their infant was six months old. After the intervention, 28% more caregivers planned to follow BTS guidelines, which instructed them to place infants on their backs to sleep, than before the intervention ( $p < 0.0001$ ). Overall, the study found that mothers or primary caregivers with at least a high school education were more likely to follow BTS rules ( $p = 0.03$ ). Caregivers who believed prone positioning increased the risk of SIDS were more likely to place their infant supine to sleep ( $p = 0.0013$ ) as compared with the control group, who received no education on

infant positioning. Caregivers with previous knowledge of BTS were also more likely to follow BTS guidelines ( $p = 0.007$ ) than those in the control group. This short, small group, face-to-face educational offering was found effective in informing caregivers about BTS guidelines (Moon, et al., 2004). While the population focus was mothers and caregivers of infants, the infants did not require specialized care such as those in the NICU. All infants however should follow BTS guidelines upon discharge. The mothers studied here, though not exposed to the NICU environment, represent the typical age and characteristics of learners in the NICU. A short educational session was found effective.

The efficacy of an educational and behavioral intervention program was the focus of a randomized, controlled trial conducted in two NICUs in the northeastern U.S. (Melnyk, et al., 2001). Two-hundred sixty families were randomly assigned to either the study or control group and all participants completed demographic and baseline tools: the STAI, Beck Depression Inventory, Parental Stressor Scale-Neonatal Intensive Care, Index of Parental Behavior in the NICU, and Parental Belief Scale-NICU. Inclusion criteria were infants with a gestational age of 26 to 34 weeks, birth weight less than 2500 grams, anticipated survival, no severe handicapping conditions, singleton birth, and born at the study site. The experimental group consisted of 147 families, compared with the control group of 113 families. Mothers had a mean age of 28 years with fathers mean age of 31 years. Caucasians made up the majority of both groups at approximately 60-70% while African-Americans comprised 20-30% of the group. About 82% of all participants completed high school. Infants had an average gestational age of 31 weeks and birth weight of 1650 grams. Average infant length of stay was 35 days (Melnyk, et al., 2001).

The experimental group received the Creating Opportunities for Parent Empowerment (COPE) program, which was a four-phase behavioral-educational intervention. Parents were given information in the forms of audiotape and writing in all phases of the study related to their infant's behavior, appearance, and activities as preterm infants and the information was delivered at set times during the infant's stay: phase one, 2 – 4 days after admission; phase two, 2 – 4 days after the first intervention; phase three, 1 – 4 days before discharge; and phase four, one week after discharge. After the information was received and reviewed, parents were taught specific examples from the material at the bedside during the infant's hospitalization to reinforce their learning. Each of the baseline tools was completed at all phases of the intervention and at the infant's two-month corrected age, for a total of six times. The control and experimental groups all received information packaged the same way as to be indistinguishable from the outside of the package. The control group received audiotaped and written information regarding hospital services, discharge information, and infant immunizations. No reinforcement of this material was provided for the control group parents. Participants were randomized in rotating 30 day blocks to minimize conversations between experimental and control group families (Melnyk, et al., 2001). Mothers in the experimental group had significantly less overall parental stress ( $p = 0.05$ ) than mothers in the control group. Both mothers and fathers in the experimental group had higher parental confidence about their role as parents ( $p = 0.002$ ) and what behaviors and characteristics to expect from the preterm infants as learned from the COPE materials ( $p < 0.001$ ) when compared to mothers and fathers in the control group. The average length of stay for the experimental

group was about 4 days shorter than that of the control group. The researchers concluded that mothers and fathers in the COPE program reported stronger confidence in their ability to understand their preterm infant's behaviors and characteristics compared to those parents who did not participate in the program, therefore COPE program participants were found more likely to interact with their preterm infants differently, such as in a more developmentally appropriate manner (Melnyk, et al., 2001). Parents who receive specific information about their infant requiring specialized care in the NICU were noted to be more involved with direct care of their infant and felt more comfortable doing so as noted by the tools administered over the longitudinal study. Parents in the intervention group had decreased stress levels compared with parents who did not receive information in the COPE program. Individualized education of parents with infants in the NICU is essential to increase parent participation in their infant's care, which as this study found, may lead to earlier infant discharge.

Face-to-face education allows for individualization of understanding to parents regarding their infant's needs. While short educational sessions have proven effective for parents of healthy infants in low income settings, their effectiveness has not been shown in parents of infants requiring NICU intervention or in other socioeconomic settings. Audio and reading materials reinforced by demonstrations at the infant's bedside in the NICU were effective in increasing parents' confidence in caring for their infant, yet audio and reading material interventions were not studied separately to determine if partial intervention was just as effective. Education outside the NICU environment was also not studied.

## **Internet Education**

While not focusing on parent education specifically, patient's perceptions of Internet use for health information was the focus of a large study (N = 1783) in Finland (Välimäki, Nenonen, Koivunen, & Suhonen, 2007). Upon patient discharge, a researcher-made questionnaire was distributed regarding opportunities to use the Internet and access to health information online. The mean age of respondents was 52 years (SD = 16 years). No participant had more than a vocational school education. Forty-five percent of respondents were between the ages of 18-44 years and over half were female. Nearly three-fourths of the respondents thought it was important or very important to use the Internet to deliver health information. Less than half, however, thought electronic mail was a useful tool for this purpose. The majority of patients wanted to receive health information, such as discharge teaching, in a face-to-face manner via verbal contact with medical staff. The Internet was found to be less preferred than the face-to-face format when patients were seeking health information (Välimäki, et al.,2007). Few studies have been completed on patient education via the Internet. Although this study did not target parents of infants in the NICU, all the participants were adults and half of the respondents were females of childbearing age. Studies are needed about the use of the Internet for patient education in specific populations, such as parents of infants receiving NICU care.

Reasons for and patterns of Internet use for health information by pregnant women and new mothers was the focus of an Internet-based study (Lagan, Sinclair, & Kernohan, 2010). Numerous general pregnancy information websites were used to recruit pregnant women and mothers of infants less than 12 months of age to participate

in this self-report survey. Of the 613 respondents, 60% were currently in their 5<sup>th</sup> or 6<sup>th</sup> month of pregnancy. Almost 100% of the participants had Internet access in their homes and 61% had access in their place of employment. Ninety-eight percent of the respondents were from North America, Europe, or Australia and just over half were primiparous. The mean age of the participants was 29 years with approximately half having completed high school or a technical degree and the remaining half with an undergraduate or postgraduate degree. Women searched the Internet most often during pregnancy to discover facts on pregnancy and childbirth (99%) and to find additional information about something their health care provider had given to them (94%). Additional reasons were to check for information about symptoms (89%) and to have more control over decisions made during their pregnancy (83%). Before searching the Internet for information, women most often asked their health care provider or their families and friends for information first. Women aged 17 – 25 years reported the information found on the Internet helped them prepare for conversations with their health care provider during antenatal visits ( $p = 0.004$ ). During pregnancy and in the year following, women used the Internet to access information regarding their pregnancy, which could lead to accessing information about their infants and children in the future (Lagan, et al., 2010). While women use the Internet for education when pregnant and new mothers use the Internet during the first year postpartum, studies have not been conducted to note if the Internet is a viable source of information for mothers of infants in the NICU. Topics researched by mothers were not noted within the study, just Internet use. Websites are available which demonstrate care of infants with specialized needs,

such as those found in the NICU, and with information for parents of infants in the NICU (<http://www.marchofdimes.com/>; <http://www.premature-infant.com/>). However, the use and effectiveness of these websites has not been studied. Parents used the Internet as a supplement to discharge education, however did not find the Internet an acceptable method alone for discharge information. This study was not replicated on women over the age of 25 for comparison to note if these findings hold true.

### **Face-to-Face Education with Internet Education Supplement**

The effects of newborn-care education via the Internet to supplement traditional methods of education provided during first-time mothers' third trimester of pregnancy was the focus of a study in Taiwan (Kuo, Chen, Lin, Lee, & Hsu, 2009). A control group of 57 mothers, average age 31 years, was compared with 61 mothers, average age 30 years, in the experimental group. The control group received traditional methods of education while the experimental group received traditional methods of education plus newborn-care education via the Internet as a supplement. Approximately 15% of the women had a high school education, while 85% had an associate's or bachelor's degree or higher. Both groups were administered self-report tools in the form of Newborn-care Knowledge scale and Maternal Confidence scale to measure maternal knowledge and confidence. Women in the experimental group knew more infant care ( $p < 0.001$ ) and were more confident in their abilities to provide care for their infant ( $p < 0.001$ ) than the control group. Almost half of the first-time mothers continued to use the Internet as a means of health education for guidance after the neonatal period, signifying the usefulness of newborn-care education via the Internet to supplement traditional methods

of education provided by health care providers during the mother's third trimester of pregnancy (Kuo, et al., 2009). While studies have shown parents prefer face-to-face education as opposed to Internet education alone, combining face-to-face education with supplemental education of Internet resources may be more beneficial than either method alone. The combined method of education was studied in healthy infants not requiring specialized nursing care, however has not been studied in the NICU environment. While this study displays significance in blending educational methods, it has not been replicated.

Researchers have studied parent education in a variety of forms, yet do not agree on the best method to utilize. Short, face-to-face educational sessions have been found effective, however a study by Raines and Brustad (2010) focused on term infants of mothers with low socioeconomic status. Parents of infants in the NICU want to be included in their infant's care and need to communicate closely with the infant's nurse in order to feel a part of the infant's care and need to practice skills needed at home (Raines & Brustad, 2012). How nurses are to support parents and guide them during their NICU stay has not been studied. Creating a relaxing NICU environment was also found to be important; however ways to create this environment were not addressed. The degree to which the Internet is used as a supplement to patient education and the form of communication with nurses and/or the health care team who care for infants in the NICU has not been studied in the U.S. Parent education in the NICU on specific topics allows parents to understand their infant's care and thus advocate for their infant, instilling a sense of control (Franck, Oulton, & Bruce, 2012). Which topics are the most important

to address with parents to allow them to understand their infant's care were not determined. Research has not shown whether parent education conducted outside of the stressful NICU environment would increase parent confidence in their abilities prior to discharge or once transitioned into the home environment.

### **Synthesis**

The NICU environment is different from that of the general nursery. Parents often respond to the NICU environment by reporting increased stress and anxiety levels. The STAI was used in several studies to measure anxiety (Erdem, 2010; Feeley, et al., 2007; Melnyk, et al., 2001; Turan, et al., 2008). Each of these studies reported an above the mean, moderate level of anxiety when compared with a parent whose infant was not in the NICU. Melnyk, et al. (2001) concluded that interaction between mothers and infants and nurses in the NICU was facilitated when the mother's anxiety was low.

The relationship which develops between the parent of an infant in the NICU and the nurse caring for that infant is important (Fegran, Fagermoen, & Helseth, 2008; Kavanaugh, Moro, & Savage, 2010). Phases of the parent-nurse relationship have been recognized (Fegran, et al., 2008; Lam, et al., 2007). The nurse gets close enough to the parent that the nurse often is able to see needs of the parent which the parent may not have identified for his/herself. Open communication between the nurse and the parent helps to decrease the amount of stress (Lam, et al., 2007; Weiss, et al., 2009) and anxiety (Wigert, et al., 2006) reported by the parent as this open communication often allows the nurse to impart knowledge regarding the infant to the parents during these interactions (Aagaard & Hall, 2008). The more a parent knows about the infant's condition and is

able to provide direct care for the infant, the less stress a mother reports and the closer to the infant the parent reports feeling (Aagaard & Hall, 2008; Wigert, et al., 2006). Parent interaction with nurses in the NICU who provide care for their infant is essential to meeting the parent's needs. However, the parent-nurse relationship after discharge from the NICU has not been the focus of research studies.

As parents of infants in the NICU adjust to parenthood, they often require guidance and teaching to learn about their infant's specific needs (Heermann, Wilson, & Wilhelm, 2005). Since parents often form a bond with the infant's nurse, the nurse often provides this education (Kavanaugh, et al., 2010). Parents also need support and information about treatments the infant is receiving and they need teaching to be individualized to their infant (Cleveland, 2008; Mundy, 2010; Sargent, 2009). While these facts are known, information regarding specific teaching has not been conducted. For example, there is not a standardized parent teaching list for parents of infants in the NICU which can be modified for individualized teaching. The individual educational needs of parents with infants born with various diagnoses, such as extreme prematurity or complex cardiac anomalies, have not been studied. The infant's diagnosis may require alteration in parent education depending on the infant's maturation, complications, or long-term chronic illnesses. Pain management teaching has been studied and shown to increase parent confidence in advocating for their infant during hospitalization in the NICU (Franck, Oulton, & Bruce, 2012). Additional topics have not been studied in this manner. If parent confidence in infant care is not instilled in the NICU, it is not gained

once the infant is discharged (Raines & Brustad, 2012). Studies have not replicated these findings. Parent education outside the NICU environment was also not studied to examine the effectiveness of education in lower stress environments.

Researchers have shown that mothers of healthy infants learned via a short, face-to-face educational session (Moon, et al., 2004). These mothers were of similar age and characteristics to mothers who have infants requiring specialized care in a NICU. The effect of the NICU environment on these mothers during education was not studied, however. In a study by Melnyk, et al. (2001), parents of infants in the NICU were given educational materials followed by face-to-face reinforcement of the material. The outcome was decreased parental stress and increased learning of the educational materials. Research has not been conducted related to the providing of these materials or their reinforcement via the Internet. Therefore studies are needed to confirm the effectiveness of teaching methods whereby the parent is introduced to the material, such as via a website, prior to a face-to-face educational session.

Patient discharge education was preferred face-to-face instead of via the Internet by women of childbearing age (Välimäki, et al., 2007). The women in the study choosing face-to-face education over Internet education were similar in age to women in their childbearing years and had the needs of adult learners as outlined in Knowles' Principles of Adult Learning. The women were also receiving education regarding patient care; however the teaching was not about their infant in the NICU. Therefore research is needed to specifically note the educational preferences of parents with infants in the NICU. Pregnant women in their third trimester and mothers during the first year

postpartum were asked questions regarding their use of the Internet to seek information regarding their pregnancy (Lagan, et al., 2010). These mothers noted the Internet as a useful source of information; however their infants were healthy and did not require specialized care in the NICU. Studies are needed to determine if this prior finding also holds true for parents of infants requiring specialized care in the NICU. Parents of healthy infants were also studied in a combined approach of face-to-face teaching along with Internet education supplementation (Kuo, et al., 2009). Parents were taught how to care for their newborn infants via traditional face-to-face approaches and given a website to reinforce their learning. Parents responded positively to this combination of methodologies. Studies comparing giving parents of infants in the NICU education via just face-to-face or Internet approaches or a blending of the two methods are needed.

### **Need for Study**

The purpose of the study was to compare the parental information needs and sources of information for parents of infants with complex life-threatening illnesses while the infant is hospitalized with their information needs and sources of information after the infant's discharge. Education provided and requested from time of diagnosis throughout hospitalization was compared to that after discharge throughout the first year of enrollment. Information needs and sources of information for parents of infants in the NICU have not previously been studied.

## **Adult Learning Theories**

Psychologists have considered how adults learn from the beginning of recorded education by studying the teachings of Plato and Socrates. As the centuries passed, theories of learning emerged and became more formal in the mid-twentieth century.

### **History of Adult Learning Theories**

Psychologists did much of the initial work in adult learning. John Dewey's and Eduard Lindeman's work in the 1920's were foundational (Lindeman, 1989). Adults regard their life experiences as highly important. Learning needs to be linked to an adult's life experiences, not to someone else's knowledge or situations. Dewey and Lindeman saw learning as a static concept whereby adults become aware of significant experiences. Lindeman summarized assumptions about adult learners (Lindeman, 1989):

1. Motivation to learn comes when an adult has a need or interest that learning will meet.
2. To an adult, learning is life-centered.
3. The most valuable resource for adult learners is experience.
4. Adults have an inner requirement to be self-directed.
5. Adults are individuals whose differences increase with age.

Maslow felt learning was an internal struggle between the safety of the already known and the desire to grow toward a goal. Tolman's work was the end of psychologists considering specific elements and the beginning of thinking about

relationships between the elements to form the first learning models. Robert Gagné, who challenged the view that learning is a singular process, defined five domains of the learning process, each with their own approach (Gagné, 1985):

1. Intellectual Skills: require prior learning of prerequisite skills
2. Motor Skills: developed through practice
3. Verbal Information: main requirement of learning; must be presented in an organized, meaningful format
4. Cognitive Strategies: presentation of repeated challenges to thinking
5. Attitudes: learned through human models and spontaneous reinforcement

Carl Rogers felt learning had to consider the human and not just the process itself (Rogers & Freiberg, 1994). Rogers posited the elements of important to human learning were:

1. The whole person is involved in the learning event, including the person's mind and emotions, known as personal involvement.
2. Even when the stimulus to learn is extrinsic, the person must have intrinsic motivation to learn, or self-initiation.
3. Learning alters the attitudes, behaviors, and, to a certain extent, the personality, of the person, known as pervasiveness.
4. Learning is evaluated by the person as the person measures the learning by personal standards, such as personal need for the learning.
5. Learning has meaning to the person as meaning is the foundation of the experience (Knowles, et al., 2011).

Theorists in England, France, Venezuela, and Canada began to use the term andragogy to represent the teaching and learning of adults and pedagogy to represent the teaching and learning of children (Knowles, et al., 2011). Entire courses and programs of study started to revolve around these definitions. Fields of study adopting this way of thinking include social work, human development, religion, and business (Knowles, et al., 2011).

Pedagogy gives control over course content, delivery, timing, and evaluation to the instructor (Knowles, et al., 2011). The learner needs to only follow the instructor's directions to learn. Pedagogy is based on the following assumptions:

1. Learners need to know the information in order to pass the class or grade.
2. The learner's self-concept is dependent or based on the instructor.
3. The instructor's experiences are more valuable than the learner's experiences.
4. The learner is ready to learn when the instructor is ready to teach.
5. Learning is subject-centered or organized according to required subjects.
6. Motivation comes from grades and other external pressures (Knowles, et al.).

The term adult has several definitions. The one recognized for the purposes of this paper is the one used by psychologists: a person who has arrived at a self-concept of being self-directing, responsible for his/her own life. The assumptions or principles of andragogy are presented below.

Once pedagogy and andragogy were defined and accepted, pedagogy was used with children and andragogy was used with adults (Knowles, et al., 2011). As psychologists began to better develop and understand learning in general, they realized

the instructor should have the ability to evaluate the learner and determine which strategies were appropriate in the given situation. This allows instructors to remove the learner's age from the equation and to provide instruction the best way for the learner (Knowles, et al., 2011). For example, a learner aged 18-21, though chronologically an adult by many standards may not have the life experiences necessary to be taught using andragogy (McGrath, 2009).

### **Knowles' Theory of Adult Learning**

Psychologists such as Dewey, Maslow, and Rogers paved the way for and strongly influenced the work of Malcolm Knowles. Knowles' Theory of Adult Learning became one of the most influential learning theories during the late 1970's and 1980's and outlined six principles, noted below. The Theory of Adult Learning asserts that by applying these principles, more learning will occur in adults than without consideration of the principles.

#### **Principles**

The Theory of Adult Learning contains six principles. These principles can be used in many diverse settings. However, their meanings, as defined by Knowles, do not change.

1. Principle 1: Adults have a need to know why they should learn something. Adults need to understand for themselves why they must learn something. The importance or relevance to the adult cannot be told or implied. Even if an adult is threatened with a consequence or punishment if they do not learn something, the adult will still take the time to explore why they should learn it.

2. Principle 2: Adults have a deep need to be self-directing. Being an adult is defined as being in control or in charge of your own life; being responsible for making your own decisions and consequences. Self-directed learning puts adults in charge of their own learning, including the pace of the learning, and when, where, and how they learn. Adult learners need to be seen as being capable of taking responsibility for themselves, and thus, their learning.
3. Principle 3: Adults have a greater volume and different quality of experience than children. Adults have life experiences that serve as resources upon which they attach new learning. These life experiences are a large source of an adult's self-identity. When adults relate new learning to a past experience, the new learning is given meaning and is solidified. The deeper the adult's past experience is linked to the new learning, the more permanent the new learning will be, such as via discussion and reflection with other adults.
4. Principle 4: Adults become ready to learn when they experience in their life situations a need to know or be able to do in order to perform more effectively and satisfyingly. This principle is an extension of Principle 1. Not only must an adult understand the need for the learning, but the timing of the learning must also be right for the adult. If the adult is not ready in their work, their home life, or their setting, new learning will not occur. Just as in Principle 1, this principle cannot be forced on the adult either.
5. Principle 5: Adults enter into a learning experience with a task-centered (or problem-centered or life-centered) orientation to learning. Adults, since they

have life experience, develop a centered approach to learning. If adults are taught around this center, they will see how to apply the new learning. This way of learning is very different from the way children are taught, based on subject orientation and fact-focusing to pass tests.

6. Principle 6: Adults are motivated to learn by both extrinsic and intrinsic motivators. This principle is also an extension of Principle 1. Extrinsic factors work for adults to a certain point and are needed. Intrinsic factors work better and are essential to the adult to increase self-esteem and to measure true achievement. Extrinsic factors can be imposed upon the adult, such as the adult being told the learning must take place before a promotion is given. If the adult does not have the intrinsic motivation of wanting the promotion, however, the learning will not take place. Both motivators are needed.

These principles of the Theory of Adult Learning must be viewed as essential when considering learning for adults.

### **Application**

The principles of the Theory of Adult Learning need to be applied to each adult learning situation, from single activities to total programs of study (Cyr, 1999). Adults, who are self-directed learners, are pro-active in their own learning. When the above principles are applied, adults become life-long learners (Cyr, 1999). Seven applications of Knowles' Theory of Adult Learning principles are suggested as a process:

1. Establishment of a climate conducive to adult learning: As adult-learning characteristics continued to be studied, the environment was noted to be of

importance as well (Cyr, 1999; Knowles, et al., 2011). Adults learn best in comfortable, informal, nonthreatening, flexible settings. The instructor should provide the learner with respect, care, and trust. When possible, the learner should have a choice of learning methods and resources and should share in the evaluation method (Knowles, et al., 2011).

2. Creation of an organizational structure for participative planning: When adults assist in the planning process, they tend to be dedicated to carrying out the process (Cyr, 1999; Knowles, 1980). When instructors plan learning activities and impose them on adults, the adults often express resentment, apathy, and can withdraw from learning. Knowles suggests that by involving small groups of students in planning (30 or fewer), the group will remain engaged and become successful in learning.
3. Diagnosis of needs for learning: Adults should play a role in determining their learning needs (Cyr, 1999; Knowles, 1980). Input into labeling the target competencies and where the adult is along the path to meeting these competencies is important to the adult. This perceived gap between the set goal and actual ability motivates the adult learner (Knowles, 1980).
4. Formulation of directions for learning (objectives): Setting objectives and learning outcomes should be a joint effort between the adult and the instructor (Cyr, 1999; Knowles, 1980). The objectives should be dependent upon the adult's current level of knowledge.

5. Development of a design of activities: The self-directed, adult learner sees the instructor as a resource person who is joining the learners on a path to learning (Cyr, 1999; Knowles, 1980). Andragogy views the instructor as someone who assists in learning, not someone who forces learning upon adults.
6. Operation of the activities: Since adults direct their own learning, the instructor is the adult's guide in discovering new knowledge. Thus, the instructor is not expected to have all the knowledge, but to lead the group in learning together (Knowles; McGrath, 2009).
7. Re-diagnosis of needs for learning (evaluation): Adults should be given the opportunity to evaluate their own learning based on the competencies they helped create at the beginning of the learning (Knowles, 1980). When adults are assigned a grade, their evaluation is completed by another adult, which can be seen as humiliating. When adults must receive a grade, such as when learning toward a program of study, the adult must be allowed to evaluate the course in order to provide their opinions related to the course and the instructor (McGrath, 2009). Adults must be open to constructive criticism when they are allowed to self-evaluate. When learning is self-evaluated and constructively criticized by the instructor, adults can be motivated by any deficits agreed upon and learning continues (Knowles, 1980).

The application of Knowles' Theory of Adult Learning in many ways mirrors the nursing process. Nurses use a series of steps in a cyclical manner to determine client needs and carry out nursing care. Upon evaluation if the client's initial problem was not

solved, the process begins again by re-considering the client's needs. The steps of the nursing process are listed below. Beside each step is the principle of Knowles' Theory of Adult Learning that is comparable.

1. Assessment of the client, including subjective and objective data. (This is similar to Knowles' creation of an organizational structure for participative planning.)
2. Formulation of the nursing diagnosis. (This is similar to Knowles' diagnosis of needs for learning.)
3. Planning of nursing interventions. (This is similar to Knowles' formulation of directions for learning and development of a design of activities.)
4. Carrying out planned nursing interventions. (This is similar to Knowles' operation of activities.)
5. Evaluating the client, or re-assessment. (This is similar to Knowles' re-diagnosis of needs for learning.)

As noted, the nursing process is similar to Knowles' theory. As nurses utilize the nursing process numerous times while providing hands-on care, the principles of Knowles' theory may be memorable and easy to incorporate when educating clients. While Knowles' Theory of Adult Learning is not a nursing theory, it applies to the role of the nurse as educator.

### **Applications of Learning in Nursing**

Nursing borrows various aspects of the concept of learning from psychology when assisting clients to learn skills which may be needed for self-care. According to Sousa (2001), an individual uses the motor cortex and frontal lobe of the brain to learn

physical skills. Once learned, these skills are then stored in the cerebellum (Sousa, 2001). Sousa further states that learning a skill involves following a prescribed procedure, which can be carried out fundamentally without conscious awareness. This allows clients to learn procedures and carry them out while interacting with and functioning in their environment. Learning as noted here takes time as teaching a skill once without reinforcement would not allow the learner enough exposure to the skill to be able to perform it without conscious awareness.

Sousa (2001) further explains that if a learner, or in this case a client, practices a skill improperly, unlearning and relearning the skill can be complex. Being successful with unlearning and relearning depends on the following: age of the student (the younger the easier to unlearn and relearn); amount of time spent practicing the skill incorrectly (the shorter the amount of time the more attainable the change); and the degree of motivation to unlearn and relearn (the larger the desire the less difficult the change) (Sousa, 2001). For example, according to Sousa, even a young student who has only practiced the skill incorrectly a short amount of time will have a hard time with unlearning and relearning the proficiency the proper way, if they lack the drive to do so.

Drive to learn is also noted by Hermansen (2005) as an essential component to any learning. Each individual's amount of enthusiasm to learn varies, as does what increases or decreases this level of motivation (Hermansen). These factors all play a role in a person's ability to unlearn and relearn. In part, it is the responsibility of the educator to be involved with encouraging each student to learn. This may be accomplished by using reinforcement. According to Biley and Smith (1998), the role of the teacher is to

facilitate or guide the student's learning, not to simply impart knowledge. When learning to become nurses, students must be able to apply their learning toward caring for each patient entrusted to them. This style of teaching, giving encouragement and motivation, assists the student to transition to the bedside (Biley & Smith, 1998). Other principles of teaching and learning are also used with nursing students both in the classroom and clinical settings. Since recalled knowledge is relearned by the brain, teachers must provide activities for students to frequently use information they already have. By using information learned previously, students strengthen the bonds of the knowledge and expand that knowledge to different contexts and uses.

### **Applications of Adult Learning in Health Care Disciplines**

Adult learning principles have been used in the education of health care professionals, including nurses, and also by nurses when educating patients. Adult learning principles have been used with residents, interns, occupational therapists, and phlebotomists (Brownstein, Rettie, & George, 1998; Dubouloz, King, Ashe, Paterson, Chevrier, & Moldoveanu, 2010; Fernandez & Delaney, 2004; Hartzell, Veerappan, Posley, Shumway, & Durning, 2009). Medical residents found the theory useful when organizing a journal club of their peers, and found the club to be both beneficial and interesting (Hartzell, et al., 2009). Chiropractic interns used adult learning principles when developing a questionnaire for clients (Fernandez & Delaney, 2004). Significant life experiences were used by occupational therapists to link new learning related to chronic health conditions in clients in rehabilitation (Dubouloz, et al., 2010).

Phlebotomists used the Theory of Adult Learning principles when creating modules for phlebotomy students (Brownstein, et al., 1998). Members of various health care disciplines have utilized adult learning theories to educate themselves and their clients.

### **Using Knowles' Theory of Adult Learning in Nursing**

A hemodialysis orientation program based on Knowles' Theory of Adult Learning was developed to increase the competency of nurses in providing care to their clients (Ludlow, Gaudine, & Jacobs, 2007). The program was designed in modules, allowing nurses to practice necessary skills and discuss past experiences after reviewing needed materials on their own, at their own pace, instead of in a classroom setting. Spending more time in group situations allowed the nurses to focus their time on skills they needed and to link the learning to their past experiences rather than sitting in a classroom where information they may already know is being presented to them. Using Knowles' Theory of Adult Learning has decreased the time for nurses to become competent in hemodialysis skills. The modules are being used in several facilities across Canada (Ludlow, et al., 2007).

Hospitalized clients transferring from the intensive care unit environment to a step down unit and their families need to be educated on this change in environment (Mitchell & Courtney, 2005). A hospital in Australia used principles of Knowles' Theory of Adult Learning to develop a brochure for this purpose. Nurses from the intensive care unit and step down areas worked with family members of clients in both units to determine what to include in the brochure. Topics included changes in the environments and the recovery process along with questions other families frequently asked a day or two after the

transfer. Knowles' Theory of Adult Learning was used so each client and their family would consider information when they needed it and had an available resource when needed (Mitchell & Courtney, 2005).

Knowles' Theory of Adult Learning emphasizes the importance of past experiences upon which to link new learning. Marienau and Segal (2006) explored this idea with regard to parents and continuous learning. Parents need to reflect on their past experiences through an objective lens in order to improve their abilities. Challenges are presented to parents over time as they frequently operate on lack of sleep and find conflict as their children mature. If parents see themselves as adult learners through the process of parenting, reflection will help them learn (Marienau & Segal, 2006). Thus, Knowles' Theory of Adult Learning can assist parents by bringing forward past experiences on which to build the knowledge to provide care to chronically ill infants.

#### **Use of Knowles' Theory of Adult Learning in this Study**

Infants with life threatening conditions often require concentrated care during the first several months to years of their life. Once their conditions are stable, the infants are sent home; however specialized care is often still necessary. Parents must learn to meet the needs of their infant with life threatening conditions prior to the infant's discharge. Examples of care requirements include oxygen administration, home cardiac and respiratory monitoring and maintenance, mechanical suctioning, and medication administration. Some parents are able to learn these skills in a matter of days, while others take weeks.

Parents may be classified as pedagogical or andragogical learners, depending on factors such as chronological age and past experiences. According to Knowles' Theory of Adult Learning, the adult, or in this case the parent, must be evaluated to determine the proper method of instruction. If the parent is to be instructed as an adult, he or she must be assessed to determine current level of knowledge about the topic. Learning methods must then be agreed upon between the parent and nurse. Once learning has taken place, the parent and nurse must evaluate the parent's level of knowledge again. If the correct principles are not followed the parent is less likely to be successful in learning. An important role of the nurse in parent teaching is determining the correct method of instruction through surveying the parent prior to providing education.

Parents of infants with life threatening illnesses may have other children. They may have experience with changing diapers, using a bulb syringe, and even administering medications. , However, they have not performed these skills on an infant with life threatening illnesses. This is where unlearning and relearning needs to be considered. The basis of these skills is the same, but the skill as a whole is different. Parents can refer to the past procedure, which can increase their learning by linking to past experience.

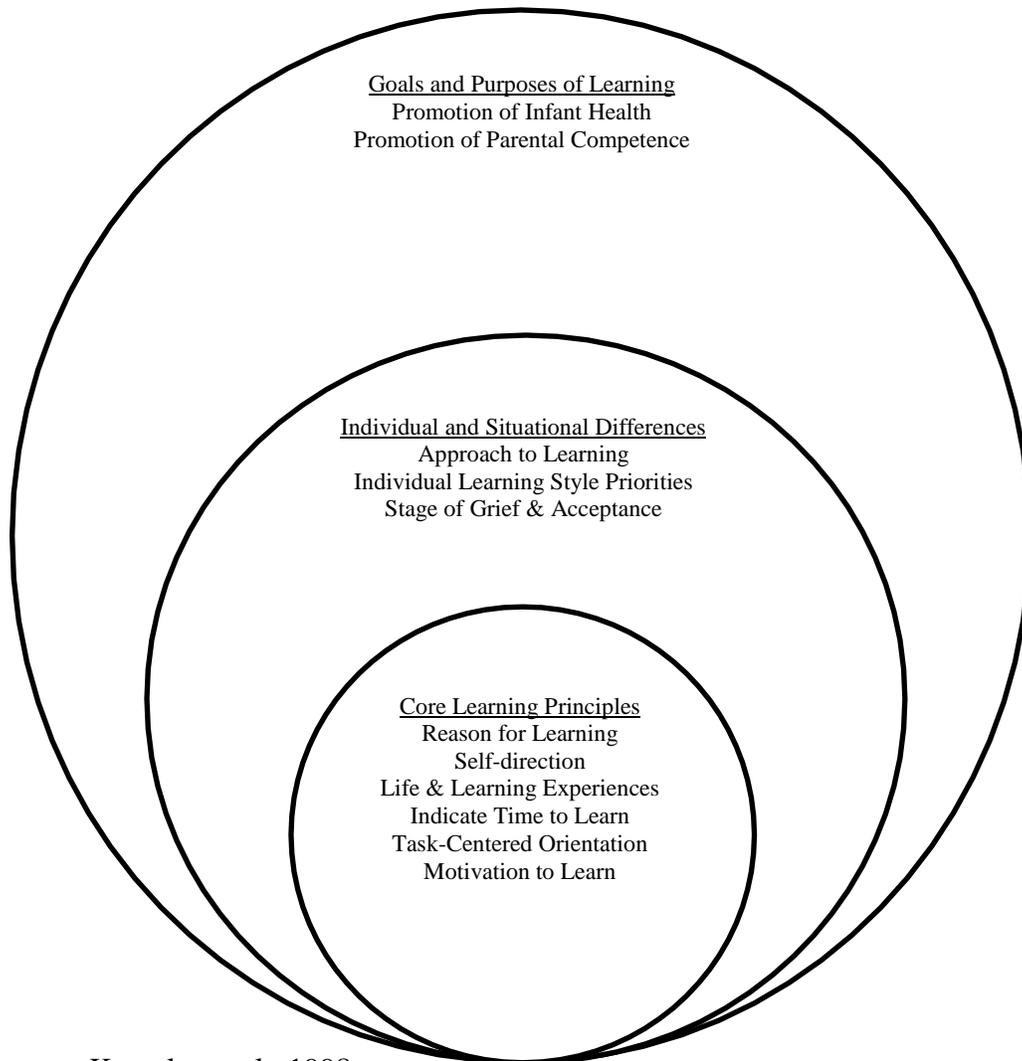
Instruction about home care for infants with life threatening illnesses must be done while the infant is still hospitalized. Due to this fact, nurses must predict what education parents will need prior to discharge of the infant. Once the parents are at home with the infant, the parents may discover additional information they need in order to care for their infant. Using Knowles' Theory of Adult Learning, the information parents received and the nurse's method of instruction during hospitalization were reviewed and

compared against the parent's information needs and preferred method of instruction after the infant was discharged. Information gained by this comparison will assist nurses to better instruct parents of infants with life threatening conditions in the future, both while the infant is hospitalized and after discharge.

### **Applying Theory to Study**

According to the Theory of Adult Learning, there are three zones of adult learning to consider when planning teaching: core adult learning principles, personal and situational differences, and the purpose and goal of learning. All three zones must be considered with the core adult learning principles at the center. Considering these zones of learning the Theory of Adult Learning is an appropriate framework for the study. See Figure 1 for a diagram of how these three zones pertain to the study.

Figure 1. Knowles' Theory of Adult Learning as applied to study



At the center of Adult Learning Theory are six principles. As Knowles describes, the core learning principles must guide all teaching activities, as pictorially depicted as the innermost ring of Figure 1. In the study, elements of these principles were looked for within the parent and provider interviews and examined for patterns. For instance, examples of how parents demonstrated readiness to learn and their self-directedness were

sought. It was noted if parents seemed to desire similar educational topics or requested information from the same or similar sources. These elements are demonstration of readiness to learn and self-directed behavior, both of which are principles of Knowles' Adult Learning Theory.

The middle ring of the diagram shows how the personal and situational differences can affect adult learning. While individual and situational differences for learning will by definition vary, they typically encompass items shown in the middle ring of Figure 1. They are: how parents view learning, such as with confidence or trepidation; how they best learn, such as by visual, auditory, or tactile means; what they think is most important for them to learn; and their ability to accept the infant's illnesses.

The outermost ring of the diagram considers the parent's purpose and goal for learning. The populations considered in this study are parents of infants born prematurely or with congenital heart disease and they likely have similar goals or purposes in learning to care for their infant. These goals and purposes are noted in the outer most ring of Figure 1 and include promotion of infant health and promotion of their competency to care for their infant (Hudson, Elek, & Fleck, 2001).

## **CHAPTER III**

### **METHODOLOGY**

The specific aims and research questions for the study were as follows:

Specific Aim 1: To determine the information needs of parents of infants with life threatening conditions compared with information given by health care providers to the parents during their infant's hospitalization.

Research Question 1: What topics (categories) of information were sought by parents during their infant's hospitalization?

Research Question 2: What topics (categories) of information were discussed by health care providers with parents during their infant's hospitalization?

Research Question 3: From whom and from what outside resources did parents seek information during their infant's hospitalization?

Research Question 4: What contextual variables were present which may have influenced information needs of parents during their infant's hospitalization?

Specific Aim 2: To determine the information needs of parents of infants with life threatening conditions compared with information given by health care providers to the parents following their infant's discharge from the hospital.

Research Question 1: What topics (categories) of information were sought by parents following the infant's discharge from the hospital?

Research Question 2: What topics (categories) of information were discussed by health care providers with parents following their infant's discharge from the hospital?

Research Question 3: From whom and from what outside resources did parents seek information following their infant's discharge from the hospital?

Research Question 4: What contextual variables were present which may have influenced information needs of parents following their infant's discharge from the hospital?

Specific Aim 3: To compare the information needs of parents of infants with life threatening conditions compared with information given by health care providers to the parents over time from hospitalization (time 1) to after discharge (time 2).

Research Question 1: What topics (categories) of information were sought by parents during their infant's hospitalization compared to the information parents sought after discharge?

Research Question 2: What topics (categories) of information were discussed by health care providers with parents during their infant's hospitalization compared to information discussed by the health care provider after their infant's discharge from the hospital?

Research Question 3: From whom and from what outside resources did parents seek information during their infant's hospitalization compared to the information sought and outside resources used after their infant's discharge from the hospital?

Research Question 4: What contextual variables were present which may have influenced information needs of parents during their infant's hospitalization compared to the contextual variables present after their infant's discharge from the hospital?

This study was descriptive in nature using data from a prospective longitudinal, case based, mixed-method research study. Analysis of existing data was chosen, as the data to address the specific aims had previously been collected as part of *Decision Making for Infants with Complex Life-Threatening Illnesses* (CLTC) (1 RO1 NR010548); however parent education of infants with complex life-threatening illnesses had not been the focus of examination in that study. Systematic review of the parent and provider interview transcripts from six cases and nurse-kept parent education logs was conducted to determine parent education needs and provider given information during and after the infant's hospitalization. A comparison of data collected regarding parent needs and provider given information during hospitalization and during follow-up after infant hospital discharge was also done.

### **The Original Study: Decision Making for Infants with Complex Life-Threatening Illnesses**

The following is a description of the original study, (*Decision Making for Infants with Complex Life-Threatening Illnesses*) in which the data for the current study were collected.

### **Purpose of CTLC Study**

The purpose of the CLTC (1 RO1 NR010548) was to study the trajectory of decisions made for infants with complex life-threatening conditions, with the ultimate goal to develop and test interventions to facilitate decision-making. As the infants' illnesses changed over time and as decisions were made regarding critically ill infants across time, the decisions themselves impacted those individuals who cared for the infants such as parents, nurses, doctors, and social workers. The parents' involvement in decision making was of particular interest. As the condition of an infant changed, particularly for the worse, the infant's medical team including doctors, nurses, and social workers met with the infant's parents. These conferences were to discuss the infant and all options available for treatment. While the physician typically made a recommendation, the ultimate decision, especially when a Do Not Resuscitate (DNR) order or withdrawal of a treatment was recommended, was up to the parents. The CTLC's ultimate goal was to generate hypotheses for both parents and providers of critically ill infants regarding the decision making process.

### **CTLC Setting and Sample**

Duke University Health System (DUHS) was the setting for the CTLC study. DUHS is an academic facility with 144 pediatric inpatient beds. All infants were recruited from either the Intensive Care Nursery (ICN) containing 64 beds, where premature infants are admitted; the Pediatric Cardiac Intensive Care Unit (PCICU) containing 13 beds, where infants with cardiac anomalies are cared for; or the Pediatric Bone Marrow Transplant (PBMT) ward containing 16 beds. If an infant was transferred

between units, the infant and parents were followed to the other units. Specialty outpatient clinics at DUHS were used to follow patients after hospital discharge, using such methods as face-to-face interviews during appointments or telephone calls to current locations or review of updated medical records after treatments.

The original study has a total of 33 cases containing 35 infants as two cases are sets of twins. While the ultimate goal was 40 infants enrolled, heterogeneity of infant characteristics was desired over total number. Variability of cases was of particular interest for the original study; and goals of the original study were met with 35 infants.

### **Inclusion Criteria**

Cases included the index infant, who was less than or equal to 24 months at the time of enrollment, one or both parents, physicians, nurses, and other health care providers and care coordinators. Parents were defined as either married; biological mother and father; a single biological parent; or a biological parent and his/her male or female significant other. When both parents were enrolled, data were collected separately so to get individual viewpoints. The diagnoses of focus for CTLC were complex cardiac anomalies, extreme prematurity (defined as born prior or equal to 26 weeks gestation), and genetic diagnoses requiring a stem cell transplant. These diagnoses were chosen because they require numerous treatment decisions, are highly complex, and have above average mortality rates. All infants were born with these disorders, though parents may not have been aware of the diagnosis at the time of birth. Variables of interest within the three diagnostic groups included infants across socioeconomic status, race, prenatal diagnosis, and twin births. This approach was selected to maximize

heterogeneity of the sample and allowed comparing and contrasting of decision-making of the different infant illnesses types. The thirty-three cases were as evenly distributed as possible, approximately 11 in each of the three diagnostic categories, enrolled and followed over a one year period, beginning with birth, diagnosis, or decision to treat. For the current study, six of these thirty-three cases were chosen. These selected cases were all from parents who participated in the study for one full year and were stratified to include various socioeconomic and ethnic backgrounds.

Health care providers and coordinators include the infant's attending physician, fellowship physician, principal nurse practitioner, principal staff nurse, and social worker. Providers and coordinators of care may change for an infant, such as when an infant is transferred to another unit or readmitted. This adds to the total number of providers and coordinators in that infant's case.

### **Exclusion Criteria**

Exclusion criteria for the study were: non-English speaking families; families in which either parent was under 18-years-old; non-biological parents; multiple gestations greater than twins, and parents present in the United States for the purpose of medical treatment only.

In order to determine if an infant met criteria to participate in the CTLC study, the research nurse coordinator screened all admissions to the ICN, PBMT, and PCICU units at least three times per week. A maximum of four cases were initiated over any 2 month period.

### **Available Data from CTLC**

CLTC consists of 35 infants from 33 case studies, including two sets of twins, with the infant serving as the index. Of the 35 infants enrolled, 23 infants completed a full year in the study and 12 infants died prior to completing a full year in the study. Each infant's chart was reviewed at least three times per week for infant health data such as medications, intravenous fluids, feeding type and method, and changes in the infant's respiratory status. Also at this time data were collected on the environment of the infant; narrative interviews were conducted, for example with a parent or coordinator of care; and instruments were completed by parents and providers, without influence or guidance from the interviewer, at the time of each interview. See Appendix A for each tool administered along with description and purpose. Electronic charting is used in the units of interest; therefore the majority of the medical record is always accessible to the research team, even before discharge. The portions of the medical record which remain paper or hard copy are scanned at discharge and incorporated into the existing electronic medical record.

Cases consist of numerous parent interviews, often including both parents interviewed separately, lasting approximately thirty minutes each. Interviews were conducted by trained researchers using structured interview guides specific to each reason for the interviews. Reasons for interview included: enrollment of the infant, when the infant had a life-threatening event, monthly, upon discharge, and at one year after enrollment. Semi-structured interview guides for each type of parent interview can be viewed in Appendices B-F. Interviews were conducted face- to-face when possible;

however telephone interviews were conducted when necessary, particularly after discharge. Recordings of interviews were transcribed and proofread for accuracy. Once accuracy was confirmed, a summary was written by the person confirming accuracy. During interviews with parents, standardized tools were administered according to the type of interview (See Appendix A).

During hospitalization, formal education plans and logs were kept by the nurses. See Appendix G for a copy of the Interdisciplinary Patient and Family Education Record. These logs note standard, as well as added and requested teaching materials given to the parents. After discharge, DUHS routinely scans and electronically saves these logs as they remain kept in hard copy form during the infant's stay. Thus they were available for analysis.

Additionally, provider interviews were conducted by the same trained interviewers who conducted the parent interviews. See Appendices H-K for the semi-structured interview guides for each type of provider interview available for these cases. Reasons for provider interviews include: upon enrollment of the infant, after a life-threatening event had occurred to the infant, after the infant was discharged, and one year after the infant's enrollment in the study. Providers also completed many of the same tools as the parents, at the time of each interview, as indicated in Appendix A.

### **Human Subjects Protection**

Approval for this study has been granted by the DUHS IRB, see Appendix L. The research nurse coordinator for the study screened all admissions to the PCICU, ICN, and PBMT at least three times per week screening for eligible infants. Once an infant

meeting inclusion criteria was identified, the infant's attending physician was asked for permission to speak with the parents. In most cases, a member of the health care team introduced the study to the parents and gave them a brochure containing an overview of the study. If a member of the health care team was not available, the research nurse coordinator approached the parents regarding the study. If parents expressed interest in participating, the research nurse coordinator met with the parents to provide additional information and obtain written consent.

To maintain confidentiality, all research team members were trained and retrained from time to time in all aspects of confidentiality for the study. Each infant was assigned a letter and number sequence instead of using the infant's name or medical record number. A list matching codes to mother's names is located electronically in a password protected file on the Duke University School of Nursing on-site file server, which is firewalled. Parents were given a \$20.00 gift card for each interview completed, while providers were given a \$50.00 gift card for each case for which they were interviewed.

### **The Current Study: Parent Education Needs of Infants with Complex Life-Threatening Illnesses**

#### **Purpose**

The purpose of this study was to compare the parental information needs and provider- given information to parents of infants with complex life-threatening illnesses while the infant was hospitalized to the needs after the infant's discharge. Education provided and requested from time of diagnosis throughout hospitalization was compared

to that after discharge throughout the first year of enrollment. Additionally, sources of information were noted during both these times. An analysis of CTLC parent and provider interviews was conducted to answer specific aims and research questions.

### **Design**

Analysis of existing data of a longitudinal study was appropriate because the data necessary to speak to the specific aims and research questions of the study examined if changes exist over time (Shadish, Cook, & Campbell, 2002). The original study was prospective in nature as it followed subjects forward in time, providing rich data for analysis for the aims of this study (Vogt, 2005). This study examined the parent's educational and informational needs during hospitalization as well as after discharge.

A longitudinal, case-study based method was appropriate to answer the research questions for the study due to the nature of the questions themselves. In order to determine knowledge deficits, time must pass, giving parents an opportunity to consider their educational needs. Gathering large amounts of data from the same population increases reliability, therefore, a case study approach is best.

The case study approach is appropriate for a study when the researcher wants to examine complex situations from multiple points of view (Eisenhardt & Graebner, 2007; Payne, 2007). Other advantages of the case study approach include the ability to keep the research in line with clinical practice and to keep actual life context key in the research (Eisenhardt & Graebner, 2007; Payne, 2007). All of these benefits are essential when studying complex life-threatening illnesses (Eisenhardt & Graebner, 2007; Payne, 2007).

Table 1. Numbers of Provider and Coordinator Interviews for each Infant’s Case Study

<b>Infant</b>	<b>Attending Physician</b>	<b>Cardiologist</b>	<b>Fellowship Physician</b>	<b>Nurse Practitioner</b>	<b>Primary Nurse</b>	<b>Social Worker</b>
P09	2		1	2	2	2
C22	1			1		1
C24	1			1	2	1
P25	4			4	4	2
P26	3			1	1	2
C27	2	1	1	1	2	2
Total = 47	13	1	2	10	11	10

### **Sample**

Six cases, three from extremely premature infant and three from complex cardiac anomaly infant categories, drawn from surviving infants from CLTC served as the sample. See Table 2 for the variability of these cases. These cases were purposefully chosen for their richness of data and complexity of the case. There were six mothers, five fathers, and 47 providers, including medical doctors, nurses, and social workers. A total of 175 parent and provider interviews were contained within these six completed cases, approximately 72 mother interviews and 56 father interviews. A breakdown of number of interviews by provider type can be seen in Table 1. Completed cases only from the CTLC database were used as data for this study because interview guide questions and parent and provider responses specific to the 12-month post-infant enrollment interview were key to Specific Aim 2, and incomplete cases would not contain all these data. Additionally, data saturation was expected to, and did, occur within these six cases. However, if upon analysis it was found that saturation did not occur, additional

completed cases were available to be assessed as they became available from the original study data set. Each of the six cases chosen were enrolled during or prior to the infant's first week of life.

The exclusion criteria placed on this study was the infants who died between the time of enrollment and completion of an entire year in the study. The reason for this exclusion was to have all cases with Parent and Provider Interview Post Discharge and Year 1 Interviews complete. This information was needed to answer Specific Aims 2 and 3. Additionally, infants who were born with genetic conditions requiring stem cell transplant were excluded as the parental learning needs of this population was thought to be different from the learning needs of parents of infants born extremely premature or born with complex cardiac anomalies. Parents of infants born with genetic conditions requiring stem cell transplant did not necessarily know of the condition prior to or immediately after birth. Enrollment of these infants was not conducted until the condition was determined, sometimes even up to a year or more after birth. The parents of infants born with complex cardiac anomalies or born extremely premature knew of their condition either prior to birth or immediately after birth and were enrolled within the first week of life. Therefore, the learning needs for parents of infants born with genetic conditions requiring stem cell transplant likely focused more on the condition itself rather than basic care of the infant.

Table 2. Study Sample Demographics and Interview Numbers

<b>Infant</b>	<b>Parent(s)</b>	<b>Age of: Mom; Dad</b>	<b>Years of Education Completed: Mom; Dad</b>	<b>Marital Status</b>	<b>Number of Providers</b>	<b>Race</b>	<b>Interviews</b>
P09	mom and dad	28; 25	16; 16	Married	5	Cauc.	13 mom and 10 dad
C22	mom and dad	22; 27	12; 11	Married	3	Native Am.	13 mom and 13 dad
C24	mom and dad	35; 38	18; 20	Married	5	Cauc.	10 mom and 9 dad
P25	mom and dad	25; 28	14; 12	Married	14	African Am.	14 mom and 13 dad
P26	mom	21; NA	7; NA	Single	7	Cauc.	11 mom
C27	mom and dad	31; 36	16; 12	Single	9	African Am.	11 mom and 11 dad
<b>N = 6</b>	<b>Mom = 6; Dad = 5</b>	<b>Average Mom = 27; Average Dad = 30.5</b>	<b>Average Mom = 13.8; Average Dad = 14.2</b>	<b>Married = 4; Single = 2</b>	<b>Average Number Providers = 7.2</b>	<b>African Am. = 2; Cauc. = 3; Native Am. = 1</b>	<b>mom interviews and dad interviews = 128 total</b>

Key:

C = cardiac; infants with complex congenital heart disease

P = extremely preterm; infants born between 23-26 weeks gestation

African Am. = African American

Native Am. = Native American

Cauc. = Caucasian

NA = not applicable

The six cases chosen for this study included infants from both the extremely premature and complex cardiac anomalies diagnostic groups. Infants with genetic disorders requiring stem cell transplant were not studied as this group was thought to have considerably different needs from the extremely premature and complex cardiac anomalies groups. See Table 2 for the demographics detailing the six completed cases

from the CTLC study. There were six mothers and five fathers, with the average age of mothers 27 years and fathers 30.5 years. African- American, Caucasian, and Native American races were represented.

### **Key Variables**

The following terms were defined for the purposes of this study:

1. Learning Needs = Information needed by a parent of an infant with a complex life- threatening illnesses as determined by the parent. Examples of this information may include definition and course of diagnosis, purpose and effects of medications, and/or alterations to the environment necessary at home for infant discharge. Each parent's learning needs vary.

2. Learning Preferences = The person from whom or the format in which the parent wants information. A parent's learning preferences may vary depending on the topic or skill to be learned. Learning preferences were identified on the Interdisciplinary Patient and Family Education Record and in the parent interviews. See Appendix G for options available on the Interdisciplinary Patient and Family Education Record.

3. Categories of Information = Areas or topics of information taught to parents of infants with complex life-threatening illnesses during hospitalization and follow-up care. Topics of information could include the infant's nutrition, testing or procedures and developmental care. Areas of information are individualized to each infant's parents. Categories of information were identified on the Interdisciplinary Patient and Family Education Record and in the parent interviews.

4. Dependable sources of information = Reliable knowledge or education regarding any aspect of an infant with a complex life-threatening condition. Examples of dependable sources of information include persons such as physicians, nurses, respiratory therapists; books; pamphlets; websites; or other research based education. Sources of information were identified on the Interdisciplinary Patient and Family Education Record (see Appendix G) and in the parent interviews.

5. Educational Needs = Provider identified needs as determined on the Interdisciplinary Patient and Family Education Record and in the parent interviews. These needs must be shared with the parents and met prior to discharge in order for them to care for the infant, either during or after hospitalization.

6. Outside Resources = Sources of information found outside of the hospital sought out by the parents of infants with complex life-threatening conditions. These sources may or may not be reliable, such as websites, podcasts, or blogs. Parents sought or requested information from outside sources as noted on the Interdisciplinary Patient and Family Education Record or in the parent interviews.

7. Time 1 = Period of time during which an infant with complex life-threatening conditions is initially hospitalized.

8. Time 2 = Period of time after which an infant with complex life-threatening conditions is discharged from hospitalization for the first time.

### **Data Access and Human Subjects Protection**

The researcher was added to the Duke University Hospital System Institutional Review Board (IRB) for the CTLC study approval and had access electronically to all

data needed to complete the research study. This study was also found exempt by the IRB at The University of North Carolina at Greensboro. Confidentiality was maintained throughout the study process. Each infant was assigned a label instead of using the infant's name or patient identification number. A list matching codes to mother's names was located electronically in a password protected file at Duke University to which the researcher had no access.

In order to access needed data, the researcher logged onto the Duke Cisco AnyConnect Virtual Private Network (VPN) to which a user unique identifier and password are required. Once this link was established, the researcher entered the database at Duke where the CTLC data are stored. The researcher was able to open all files associated with the CTLC study.

Parent interviews were located in a file labeled 'Decision Making Study' on the Duke University School of Nursing's file server located on-site. The server is firewall protected and only persons who are approved for the CTLC study by the Duke IRB have access to this file via username and password. When information is backed-up, the transfer is completed via secure File Transfer Protocol. All infants were given codes on all forms and pseudonyms in all transcripts, de-identifying them. Additionally, any file containing identifiable data is password protected. The on-site file servers are only physically accessible in locked rooms by Duke University School of Nursing network support specialists. The parent interviews used for the study remained in their current location as the researcher had access to them via the Duke Cisco AnyConnect VPN and physically at Duke on the hard drive.

Once interviews were coded and entered into Atlas TI, the researcher had a separate folder on the shared hard drive within the Decision Making Study file labeled specifically for the study to keep all ongoing and completed study analysis in a central location. Parent Interview Data Sheets were maintained on the shared hard drive as well. Each member of the CTLC study approved by the Duke IRB has access to the passwords to the de-identified data. All files with any identifiable materials are password protected. The researcher did not have access to any part of the infant's medical record without de-identification by a fellow member of the CTLC research team who is also an employee of DUHS. The only part of the medical record needed for the analysis of the study was the Interdisciplinary Patient and Family Education Records for each infant completed during hospitalization. All of the Interdisciplinary Patient and Family Education Records were pulled and saved electronically in a separate folder and made available to the researcher by a member of the research team who is also a DUHS employee. The electronic folder was on the DUHS School of Nursing hard drive and password protected as is the remainder of the information.

### **Data Analysis**

In order to answer Specific Aim 1, parent and provider interviews and Interdisciplinary Patient and Family Education Records collected during each infant's hospitalization were read for parents' information needs and information given by providers and then coded. Specific Aim 2 responses are in parent and provider interviews conducted after the infant was discharged from the hospital. These interviews were analyzed in the same way as those for Specific Aim 1. For Specific Aim 3, a comparison

was made of differences between parents' information needs and information given by providers during the infant's hospitalization and after discharge to see if differences existed. See Appendix M for an overview of how each research question was answered with the data available from the original CTLC study. A member of the dissertation committee checked the researcher's coding on a random sample of interviews to validate reliability.

Interdisciplinary Patient and Family Education Records were analyzed to obtain information given to parents as part of routine and/or by request. See Appendix G for a copy of the Interdisciplinary Patient and Family Education Record, used in the ICN, Infant Transitional Care Unit (TCN), and Special Care Nursery areas. The entire tool uses a detailed key of numbers and letters. The educator, typically a nurse, selects a topic of education, such as about the infant's diagnosis soon after admission or testing. Assessment of readiness to learn and barriers to learning of whoever is being taught, such as mother, father, or grandparents, follows. Methods of instruction, such as audio/visual or demonstration, were selected followed by learning outcomes and evaluation.

While the ultimate purpose of the Interdisciplinary Patient and Family Education Record is discharge preparation, there is room in all areas for 'Other', allowing information to be added as needed and space for comments and notes. An example of how to complete the tool is available on the front of the tool. The researcher was interested in requested information or education provided by 'Other' means as this likely designated information requested. Any information found on the Interdisciplinary Patient

and Family Education Record falling into any of the ‘Other’ categories was noted and placed on the researcher-developed tool, Interdisciplinary Patient and Family Education Record Summary Sheet, Table 3, for further examination. The data found were used in the analysis of Specific Aim 1 questions.

Table 3. Interdisciplinary Patient and Family Education Record Summary Sheet - Researcher Created Tool for Study

Case & Date	‘Other’ Category	Information Given	Comment/Note Provided

The researcher had been immersed in the larger study since the end of the study’s first year, however had not been involved with any specific cases. Prior to data analysis, the researcher had read the overview summary for all six cases. The number of interviews available for each case as well as the parent demographics for each case was also known. A brief review of the Interdisciplinary Patient and Family Education Records for the six cases had also been done prior to the beginning of any coding. Blank interviews without any coding were utilized by the researcher and the interviews were coded de novo. The interviews were available in the form of Microsoft Word documents, transcribed verbatim. Data were analyzed using qualitative content analysis (Neuendorf, 2002).

To begin data analysis, a mother interview, a father interview, and a provider interview from both complex condition groups and from the same time period, such as interviews completed at time of enrollment, were selected at random. Each interview was read word for word and areas in the text which mention the issues surrounding the key variables for the research questions were highlighted. These highlighted statements were reviewed and descriptive codes were assigned. The descriptive codes were then examined for parent comments related to their information needs and learning preferences. Principles of Stake's Multiple Case Study Analysis approach were utilized (Stake, 2006).

According to Stake (2006), the research questions should guide the multiple case analysis. Each case was analyzed individually and then for meaning along with the other cases. All findings were considered within the context from which they came (Stake, 2006).

After reading several interviews word for word, the researcher developed tool, Notes While Reading Parent Interview, found in Table 4 was filled with general information. Basically, each form was a one page overview of the interview, containing information such as Research Questions it helped answer, any unique information it held, general information noted with other interviews, and a summary. Since the form had an area for 'Uniqueness Among Other Cases', this form was not able to be completed until after the first several cases had been read, as the researcher did not have other cases for comparison to. Stake is careful to state that each sheet does not take the place of notes

written in the margin or highlighting throughout each interview by the researcher, but instead is a summary to remind the researcher of the salient points in the interview.

Table 4. Notes While Reading Parent Interview - Researcher Created Tool for Study

Infant Code:	Mother or Father:	Today's Date:
Reason for Interview: <hr/> <hr/> <hr/>		
Uniqueness Among Other Cases: <hr/> <hr/> <hr/>		
Which Research Questions are Addressed: <hr/> <hr/> <hr/>		
Possible Quotes for Multicase Analysis: <hr/> <hr/> <hr/>		
Summary of the Interview: <hr/> <hr/> <hr/> <hr/>		

(Stake, 2006)

When the six interviews (a mother interview, a father interview, and a provider interview from both complex condition groups and from the same time period) were coded, the codes were examined for similarities and collapsed as appropriate. At this point, two persons experienced in qualitative research on the dissertation committee reviewed samples of the text and the list of codes generated. Any disagreements were discussed and resolved. Then, the remaining interviews were read as described above, and the existing codes were assigned to appropriate text in these interviews. If ideas not reflected in the existing codes were discovered, new codes were generated to address these ideas. Every ten to fifteen interviews, the researcher stopped and reviewed the codes for possible combination, regrouping, or need for new codes and the aforementioned two committee members examined the work again. The sheet was used when considering the across case responses to each Specific Aim and to assist in remembering where more specific comments and notes are located (Stake, 2006).

From the data recorded on the individual sheets, patterns emerged, and codes were created which best described these patterns and similarities. Codes were examined for within and across case differences (Stake, 2006). Codes were grouped into categories as they related to each other. This process assured all data relevant to the research questions were noted for analysis from the parent interviews. Having parent quotes regarding key categories assisted with noting similar information needs and preferences in order to establish codes and for validation of the codes.

Specific questions on each interview guide were targeted as potential keys to each research question, as noted in Appendix M. While each interview was read in total and access to the audio files was available, these parent responses to the targeted questions were of particular interest.

### **Reliability and Validity**

Reliability was enhanced by the fact each audio taped interview was transcribed as accurately as possible and double checked for precision. This was done by research assistants reading the transcripts while listening to the audio tapes. Also, notes written by the person checking transcripts for accuracy were read and considered to determine if they held any important context or emotion within which to interpret the interview.

To improve validity of the findings, Dr. Lynne Lewallen, who is experienced in content analysis, and Dr. Debra Brandon, co-principal investigator of the CTLC study, reviewed the researcher's initial data analysis for one case and reviewed established codes periodically, following the process discussed earlier and further discussed in Chapter Four. Approximately 90% agreement was desired with differences in coding being discussed for rationale and consensus reached. Face-to-face meetings were held to discuss coding agreement among researchers.

### **Limitations**

Limitations to CLTC include the fact that the study was conducted at one facility. Though some infants were transferred from other tertiary facilities, this restricted the available sampled population. The same interviewer was not necessarily available to

collect all data with an individual on a case study. Rapport, or lack thereof, may have compromised willingness to divulge all information from providers and parents.

Drawbacks to case study methodology include the large amount of data which comes from following one case (Payne, 2007). For example, after the parent gets to know the researcher, the parent may decide to give only the data he/she knows the researcher is looking for versus the entire story. This method also is only generalizable to similar populations in geographically similar locations and facilities (Payne, 2007). Having large amounts of data can also be seen as a positive, as noted by Sandelowski (2011). The richness of data provided by parents can lead the researcher to explore paths not hypothesized (Sandelowski, 2011).

Lastly, the fact that analysis of existing data was used limited the researcher to previously collected data. The researcher was not able to ask additional questions of the parents as the chosen samples were of completed cases.

### **Summary**

Existing data of the longitudinal, case study, mixed-method research study *Decision Making for Infants with Complex Life-Threatening Illnesses* (CLTC) (1 RO1 NR010548) were used to answer questions regarding parent information needs and sources of information accessed. Two time periods in each infant's life were reviewed and compared, during hospitalization and after hospitalization. This content analysis documented differences and can improve education to parents of infants with life threatening illnesses in the future.

## **CHAPTER IV**

### **RESULTS**

The purpose of this study was to compare the parental information needs and sources of information for parents of infants with complex life-threatening illnesses while the infant is hospitalized and after the infant's discharge. Assessing information and learning needs of parents of infants in the Intensive Care Unit is an essential component of caring for preterm and/or low birth weight infants. Determining the information needs and learning preferences of parents of infants with life threatening conditions during the infant's hospitalization and after discharge could positively impact infant morbidity in this population. This chapter will present the findings of the study.

The study centered on the following Specific 1 Aims and Research Questions:

Specific Aim 1: To determine the information needs of parents of infants with life threatening conditions compared with information given by health care providers to the parents during their infant's hospitalization.

Research Question 1: What topics (categories) of information were sought by parents during their infant's hospitalization?

Research Question 2: What topics (categories) of information were discussed by health care providers with parents during their infant's hospitalization?

Research Question 3: From whom and from what outside resources did parents seek information during their infant's hospitalization?

Research Question 4: What contextual variables were present which may have influenced information needs of parents during their infant's hospitalization?

Specific Aim 2: To determine the information needs of parents of infants with life threatening conditions compared with information given by health care providers to the parents following their infant's discharge from the hospital.

Research Question 1: What topics (categories) of information were sought by parents following the infant's discharge from the hospital?

Research Question 2: What topics (categories) of information were discussed by health care providers with parents following their infant's discharge from the hospital?

Research Question 3: From whom and from what outside resources did parents seek information following their infant's discharge from the hospital?

Research Question 4: What contextual variables were present which may have influenced information needs of parents following their infant's discharge from the hospital?

Specific Aim 3: To compare the information needs of parents of infants with life threatening conditions compared with information given by health care providers to the parents over time from hospitalization (time 1) to after discharge (time 2).

Research Question 1: What topics (categories) of information were sought by parents during their infant's hospitalization compared to the information parents sought after discharge?

Research Question 2: What topics (categories) of information were discussed by health care providers with parents during their infant's hospitalization compared to information discussed by the health care provider after their infant's discharge from the hospital?

Research Question 3: From whom and from what outside resources did parents seek information during their infant's hospitalization compared to the information sought and outside resources used after their infant's discharge from the hospital?

Research Question 4: What contextual variables were present which may have influenced information needs of parents during their infant's hospitalization compared to the contextual variables present after their infant's discharge from the hospital?

This study was descriptive in nature using data from a prospective longitudinal, case based, mixed-method research study. The researcher was offered the opportunity to analyze data previously collected as part of *Decision Making for Infants with Complex Life-Threatening Illnesses* (CLTC) (1 RO1 NR010548). Since parent education was not the focus of the CLTC study, it was appropriate to do a secondary analysis of the CLTC data to answer these questions. Systematic review of the parent and provider interview transcripts from six cases and nurse-kept Interdisciplinary Patient and Family Education

Records related to these cases was conducted to answer the research questions. Since the Interdisciplinary Patient and Family Education Records were kept during hospitalization, no such information is available for the infants after their discharge from the hospital.

An overview of the sample demographics is presented below. Within case analysis offers insight into the participants during their year-long involvement in the original study. Across case analysis was also performed to look at issues specific to infants born extremely premature or born with complex cardiac anomalies. The specific aims and research questions follow with study findings.

### **Demographic Summary of Cases**

Included in the six cases were three extremely premature infants and three infants with complex cardiac anomalies. The premature infants were all born at 23-24 weeks gestation, on the cusp of viability. Two of the infants with complex cardiac anomalies experienced multiple cardiac surgeries for repair, while one received a cardiac transplant. Eleven parents, six mothers and five fathers, participated in the study for a full year or more. There were 72 mother and 56 father interviews available for review for a total of 128 parent interviews among the six cases. Numerous providers were interviewed in the cases for a total of sixteen physicians, ten nurse practitioners, eleven nurses, and ten social workers, or 47 interviews. Some providers participated in more than one case. All actual names have been replaced with pseudonyms.

### **Sample Cases**

Each infant enrolled in the study was assigned a code depending on the type of complex life threatening condition: extremely premature (P) or complex cardiac anomaly

(C), along with the chronological order of the case. For example, if the first infant recruited was an extremely premature infant, the assigned code would be P01. These codes allowed participants in each case to maintain confidentiality while providing a common reference for those utilizing the data in each case. While the infant's diagnosis, either born with complex cardiac anomalies or born extremely prematurity, was kept; all letters, numbers, and infant's names, and in some cases genders, have been changed from the pseudonyms given during the CTLC study. Provided is an overview of each case.

**'Aaron'**

'Aaron' was a male born extremely premature at 24 weeks gestation to a Caucasian couple in their mid to late twenties. This infant was the couple's first child. The family lived more than an hour away from the facility at which the infant was hospitalized. The mother worked in the home while the father was in the military, providing them with a middle level income. The parents had a post-secondary education. Both mother and father participated in the study for a full year, however due to scheduling of interviews, this took 451 days for the mother and 408 days for the father. Also interviewed were attending physicians, one fellow, one nurse practitioner, nurses, and a social worker. A total of twenty-three parent interviews and nine provider interviews were available for this case.

The father in this case asked to be contacted for updates before the mother, as the father felt the mother would have anxiety from new information. The providers noted this mother as hyper-vigilant with regards to the infant, even after discharge. The parents visited often and were noted advocates for their son.

This infant had many complications and procedures during his hospital stay including being ventilated for the first month of life, necrotizing enterocolitis requiring surgery with an ostomy, retinopathy of prematurity requiring surgery, and subsequent abdominal surgery for reanastomosis. The infant was discharged at approximately six months of life to the mother while the father was deployed overseas.

After hospitalization, this infant continued to have complications, some likely related to his prematurity. The infant had surgery to repair his overlapping metopic suture, an orchiopexy for undescended testes, and a procedure to release his frenulum. The father had returned from deployment prior to these procedures.

### **‘Bethany’**

‘Bethany’, a female infant, was prenatally diagnosed with several complex cardiac anomalies including hypoplastic left heart, ventricular septal defect, and malposition of the great arteries connected to the right ventricle. The parents had a toddler at home and had a previous infant die while hospitalized after several days of life. Both parents were of Native American descent and had a high school education. The mother worked in retail and the father worked in a manual labor position, providing them a low socioeconomic status. The parents lived more than an hour away from the facility where the infant was receiving care. Reportedly these parents had a good support system and were excited and optimistic about the birth of this child, despite having lost an infant previously. The parents gave examples of how the infant was like her older sister, but did not compare the infant to her sibling who died. Both parents spent much time caring for their daughter prior to discharge and stated they felt very comfortable taking her home.

The mother and father participated for one full year in the study, however due to scheduling of the interviews, this took 415 days. Also interviewed for this case were an attending physician, nurse, and social worker. The parents provided twenty-six interviews and the providers gave three interviews for this case.

During hospitalization, this infant required several invasive cardiac procedures. Surgeries were needed to create an atrial septostomy, patent ductus arteriosus ligation, pulmonary angioplasty banding, and correction of episodes of supraventricular tachycardia requiring cardioversion. A sternal wound infection was a complication. The infant was discharged at one month of age.

Surgeries were also required after the infant's initial discharge. A bidirectional Glenn procedure and pulmonary angioplasty were needed when the infant was approximately four months of age. The infant reportedly has had no further interventions required.

### **'Caroline'**

'Caroline' was a Caucasian female born to parents who knew of her complex cardiac anomalies prior to her birth. Birth issues included heterotaxy syndrome, intestinal malrotation, and numerous cardiac defects such as unbalanced atrioventricular canal defect, double outlet right ventricle, and pulmonary atresia. Her parents were married and in their mid to late thirties. The mother worked in the home and had a master's degree and the father was a professional, providing them a high level of income. The family lived between thirty minutes and one hour from the facility where the infant was hospitalized. The parents had one daughter who was three years old. 'Caroline's'

parents had many concerns during the study. Primary issues were related to the infant's feeding as the infant had extensive cardiac issues and was therefore managed by a cardiology specialist who did not manage gastroenterology issues. A second opinion from another hospital known for care of infants with gastroenterology problems was sought. The parents spoke frequently about a lack of coordination between the doctors caring for the infant. They were concerned the infant would have developmental delays due to numerous surgical interventions and hospitalizations. The parents admitted that even though they knew the infant had heterotaxy before birth, they did not know how rare the disorder remains. At the end of the interview with the parents, they were attending marriage counseling. The infant's sister was also receiving counseling related to issues with adjustment to the change of having a chronically ill child in their family.

Both parents remained in the study for a full year, however due to scheduling of the interviews, 407 days of participation were noted. The parents offered nineteen interviews. An attending physician, nurse practitioner, nurse, and social worker also were interviewed related to this case. The providers offered five additional interviews, totaling twenty-four interviews for this case.

During the course of this infant's hospitalization, she had an aortic pulmonary shunt to assist with blood flow and an exploratory laparotomy for malrotation of her bowel with an appendectomy. There were complications following the cardiac surgery which required additional exploratory surgery. The infant was discharged at approximately five weeks of life.

Since discharge, the infant has required additional surgical procedures due to cardiac issues. A Glenn procedure was performed to aid her tricuspid atresia. Persistent vomiting and issues related to feeding created the need for jejunostomy placement. The infant continued to have problems with feeding and vomiting.

**‘Daniel’**

‘Daniel’ was born to African American parents extremely premature at 23 weeks gestation. Both the mother and father each had a child from a previous relationship and the couple had lost an infant together previously at 22 weeks gestation. The mother and father had a high school education and worked in retail, offering them a low level of income. The family lived approximately thirty minutes from the facility where the infant was hospitalized. These parents met with physicians, nurses, social workers, and other providers many times during their stay and called family conferences, as did other families who participated in the study. These parents were noted to have consistent, frequent family meetings throughout the infant’s stay, whereas other parents were not noted as having family meetings as often. Physicians also met without the parents to discuss the infant’s case. The purpose of each meeting was to increase consistency of care to the infant, to increase family understanding of the infant’s needs and potential outcomes, and to include the family in decision making. Typically the parent requests these meetings, though a physician or any member of the care team can call one also. At least seven family conferences were held for this infant during initial hospitalization.

The mother and father completed a full year in the study, however due to scheduling of the interviews this took 380 days, supplying twenty-seven interviews.

Providers, including attending physicians, nurse practitioners, nurses, and a social worker, offered fourteen interviews for this case. In total, there were forty-one interviews available for this case.

While in the hospital, the infant experienced complications related to being born extremely premature. The infant had abdominal surgery related to necrotizing enterocolitis twice and surgical placement of a central line for intravenous access and a ventricular reservoir for hydrocephalus, with subsequent surgical removal of the reservoir for infection. Further invasive interventions included laser eye surgery for retinopathy of prematurity, abdominal surgery for reanastomosis and gastrostomy feeding tube placement, exploratory abdominal surgery for bowel obstruction, and another ventricular shunt placement for hydrocephaly. The infant was placed on contact isolation at two months of life for methicillin-resistant staphylococcus aureus. Discharge occurred at around eight and a half months of life.

After discharge, the infant was slow to gain weight and was readmitted to the hospital for failure to thrive. The infant's gastrostomy feeding tube was leaking and was replaced with a smaller lumen access. No further information of significance was noted regarding the infant prior to the end of study participation.

### **'Eileen'**

'Eileen', an infant girl, was born extremely premature at 24 weeks gestation to a Caucasian mother and Hispanic father. The father spoke primarily Spanish, therefore the mother was enrolled in the study, but not the father. The infant was born of an abdominal pregnancy creating the need for early delivery. The mother was in her early twenties and

had less than a high school education. The infant had two siblings who lived with the family more than an hour away from the site at which the infant received care. The father worked sporadically while the mother worked in a plant providing the family with a low level of income. The Spanish speaking only father was this infant's primary care giver. Providers were unaware at first that the father did not speak English because he would nod and indicate non-verbal understanding of information provided. Discharge teaching was reported to be difficult due to the language barrier. The mother worked outside the home with a noted change in job or working hours three times during the study. Transportation also was an issue for this family as they only had one vehicle, which was not in reliable repair.

The mother was interviewed eleven times during the study with participation noted for 417 days. Providers included three attending physicians, one nurse practitioner, one nurse, and two social workers for this case. In total, eighteen interviews were available for this case.

During this infant's nearly five months of hospitalization, she was treated for gastroesophageal reflux, congenital limb deficiency, abnormal posture and movement, hypotonia, and altered neurological status. Due to the fact the infant was the product of an abdominal pregnancy, there was no amniotic fluid to support the infant. This caused the bulk of the infant's problems such as muscle weakness and issues with arm and leg movements since the infant was compressed within the mother's abdomen.

After discharge the infant required a gastrostomy tube for poor feeding. The infant experienced slow growth during the first year, also having problems eating solid foods. Continued neurological deficits and delayed motor development were also noted.

**‘Fiona’**

‘Fiona’ is an African-American infant female who was born with numerous complex cardiac anomalies. Though the parents knew prior to the infant’s birth that cardiac anomalies were present, they did not know the extent of the anomalies until after the infant’s birth. Primary cardiac issues included restrictive cardiomyopathy, enlargement of both atria, pulmonary hypertension, hypoplastic aortic valve and arch, and multiple small apical muscular ventricular septal defects. The infant’s parents lived together though they were unmarried. The mother had two previous children and the father had six previous children, all from earlier relationships. The father had a high school education and worked as a transporter, while the mother completed college and worked in a factory. The family was provided a high level of income. The couple lived within fifteen minutes of the facility where the infant received care. Discharge education was provided to several family members of this infant, including learning to give enteral feedings and medications. While having more than one person prepared to care for the infant at home is recommended, staff was concerned about the potential for lack of consistency in care giving, leading to increased chance of feeding or medication error. The father worked nights and cared for the infant during the day, also causing concern for error. The father created a medication chart and system of feeding the infant to assist with decreasing potential errors which was used by the family to assist in consistent care.

Both parents completed 502 days in the study, providing twenty-two interviews. Two attending physicians, including a cardiac surgeon; one fellow; two nurse practitioners, including a transplant coordinator; one nurse, and two social workers were interviewed for this case for a total of nine provider interviews. In total thirty-one interviews were available for this case.

During the infant's five and a half month hospitalization, she received a heart transplant. Care primarily took place in a step-down unit awaiting transplant. A gastrostomy tube was placed after the transplant, prior to discharge to assist with feedings. Once discharged, the infant required cardiac biopsies at least every three months to check for potential complications, including organ rejection. At nearly one year of age, the infant's gastrostomy tube was removed. No further issues were noted when the parents completed the study.

### **Data Analysis**

Data were analyzed using qualitative content analysis (Neuendorf, 2002). Principles of Stake's Multiple Case Study Analysis approach were utilized (Stake, 2006). Each case was analyzed individually and then for meaning along with the other cases. All findings were considered within the context from which they came (Stake, 2006). Each interview was already transcribed into a Microsoft Word document. The researcher transferred the 175 interviews from each infant's parents and providers into Atlas.ti (Version 6.2. [Computer software] (2011) Berlin, Scientific Software Development) for analysis.

An Excel spreadsheet of available interviews was created by the researcher for each interview participant: mother, father, attending, fellow, nurse practitioner, nurse, and social worker. This made knowing which cases had interviews available at which time frames clearer. Recall that reasons for interview included: enrollment of the infant, when the infant had a life-threatening event, monthly, upon discharge, and at one year after enrollment. Examples of an event were decline in respiratory status or need for unplanned surgery. Also, some transcripts included data focused on more than one reason for the interview. For example, if an infant had an event and the next monthly interview was already scheduled, the interview would include information about the event and the monthly update in the same interview. Therefore, one interview could have more than one purpose, counting in more than one area on the spreadsheets. Selection of an initial set of transcripts to code was randomly made by the researcher to include a variety of participants and reasons for interview. While reading the initial interviews, quotes noted to potentially answer a specific aim or research question (content analysis) were highlighted within Atlas.ti and given preliminary codes for quick recall.

Eight of the initial eleven interviews analyzed were from four fathers and four mothers evenly divided between infants born extremely premature and infants born with complex cardiac anomaly. Interviews were conducted from study entry to one year of participation, including one event. Provider interviews were from an attending, a neonatal nurse practitioner, and a social worker, and all of the extremely premature infant cases included a study entry, one event, and a discharge. After reading these eleven interviews, the researcher met face-to-face with Dr. Debra Brandon, co-principal

investigator of the CLTC study and a member of the dissertation committee. The purpose of the meeting was to discuss process, quotes, and wording of initial codes. These initial codes and the specific aims and research questions were reviewed. During the meeting, the pair saw patterns in the preliminary codes and placed them into rough categories to streamline coding. Also, Dr. Brandon offered guidance and suggestions on the coding process to refine the preliminary codes into more formal codes with definitions. Each preliminary code was compressed into a more concise code and given a definition for consistency and clarification. The first eleven interviews were then re-coded based on the revised codes. Dr. Lynne Lewallen, chair of the dissertation committee, met with the researcher via telephone to discuss the process and reviewed the preliminary and revised code list and definitions.

After another thirteen interviews were read and assigned codes, the researcher met again with Dr. Brandon face-to-face. The revised codes and definitions were reviewed and the need for more clear and thorough definitions was noted. Newly added codes were also discussed and given definitions relative to the context of the interview to assure the appropriateness of quotes chosen to represent specific aims and research questions.

Next, the researcher met with both Dr. Lewallen and Dr. Brandon face-to-face to discuss consistency and unity regarding selection of interviews, quotes, and codes. By this time, another ten interviews had been read and the researcher was beginning to feel comfortable with the process. The researcher was unclear how to handle issues related to context of care, such as parental visitation and lodging during hospitalization. While not

a direct link to the intended outcome of the study, these issues could potentially reflect on the interviewee's responses and point of view. The group decided that issues related to context of care would be noted in researcher field notes for a richer meaning of the care, but would not be coded.

Another face-to-face meeting with both Dr. Lewallen and Dr. Brandon took place a few weeks later. Dr. Lewallen and the researcher coded one interview together prior to the Dr. Lewallen's independent review. Five interviews were randomly selected to be the first ones reviewed by Dr. Lewallen for comparison with the researcher.

Once Dr. Lewallen had reviewed the agreed upon interviews and their assigned codes, emails were exchanged regarding agreement to increase validity. A concern was raised regarding the lack of assigned codes related to the format of information exchange, such as via telephone or family conference. From this interaction, an additional group of codes and definitions were created to assist with clarification of format issues. New codes were created and all previously coded interviews were re-coded for consistency. The initial categories determined early in the coding process remained appropriate even after additional codes were added throughout the coding process. A complete list of categories, codes, and definitions is found in Table 5.

Table 5. Final List of Categories, Codes, and Definitions

Categories	Codes	Definition
Exchange	Information provided	Information given to parent
	Information received	Information heard by parent
	Information seeking	Information sought (requested) by parent
Characteristics	Alternative	Another path or option; break from the normal course of treatment
	Comfort	Information resulting in reassurance of the parent
	Consistency/Inconsistency	Same information from more than one source
	Fact	Research based information
	Lay terms	Common language known by the majority
	Options	Information presented to make a decision; choices offered
	Understanding	Comprehension of information
Format	Book or magazine	Sought, found, or given resource
	Email: discharged	Electronic mail exchange after infant's discharge from hospital
	Family conference	Scheduled meeting of providers and parents
	Internet	Information found on the world wide web
Actors	Medical doctor	Attending, fellow, surgeon, cardiologist, specialist
	Nurse practitioner	Advanced practice nurse caring for the infant
	Parents	Mother and/or father of infant
	Primary nurse	Nurse who cares for the infant during each shift possible
	Provider	When more than one medical provider is included or discussed
	Sibling	Brother or sister of infant
	Social worker	Hospital provided coordinator of infant's care
	Support system	Relatives and friends who provide encouragement and backing

When the first fifty transcripts had been read and coded, the researcher stopped and completed the self-developed Notes While Reading Parent Interview, found in Table 4, on each interview. The purpose of the form was to summarize the salient points of each transcript for easier analysis, in such a way as to keep the quote in context, as

Stake's method requires (2006). While re-reading the first interviews coded for the summary, the researcher noted that several coded quotes no longer matched the updated definitions of the codes. Thus the first fourteen interviews were re-coded to provide consistency with later coded transcripts. Transcripts were also reviewed for the need of a formatting code, as discussed earlier. These codes were added as appropriate.

New transcripts were read and coded until at least two interviews from each time period, while hospitalized and after discharge, one from an extremely premature infant and one from an infant with complex cardiac anomalies, and each type of interviewee (mother, father, attending, fellow, nurse practitioner, nurse, and social worker) had been reviewed. Due to the fact not every participant was interviewed at every appropriate time interval, this thoroughness was not always possible. For example, if a month 6 interview was appropriate for a father, yet the father did not respond to attempted contact by the interviewers, this time frame was skipped, and thus, not available. The researcher then looked at the number of transcripts read per case and selected interviews from cases least numerically represented. A total of 72 interviews, for 117 different reasons, had been coded at this time. All six cases were ultimately represented as were all mothers, fathers, and provider types.

The researcher met face-to-face with Dr. Brandon to determine how to proceed. Dr. Brandon recommended beginning to consider how the coded information might be combined to answer specific aims and research questions. She suggested using matrices to link contextual data to thematic data from the interviews. Emails were exchanged with Dr. Lewallen to maintain consistency among researchers.

Three additional interviews, one mother, one father, and one social worker, were selected for Dr. Lewallen to code for validity comparison. Questions remained as to the need for an information exchange format code with each quote. Dr. Lewallen agreed with the researcher to not force a code when one was not obvious as long as the specific aims and research questions were answered.

Each case was summarized for within case analysis. Information included demographic data, an overview of the infant's hospitalization, information obtained after discharge, and unique facts noted about each case by both the parents and providers. These summaries laid the foundation to begin across case summary and analysis. Salient quotes from each interview were placed on the summary sheets (Table 4) and then placed together with like quotes from other cases and grouped to answer each research question.

A face-to-face meeting was held with Dr. Lewallen to discuss the compiled information and to determine the next steps in the analysis. Quotes were needed to support research question summaries. In order to pull these, an Excel table of case information was needed for combination with information in Atlas.ti. We also discussed the fact that certain codes, such as 'consistency', were written to mark quotes showing the continuum of both consistency and inconsistency. This fact was essential to keep in mind during analysis.

The researcher next recorded the number of times each code was used and began to explore the evolving definitions of each code. Codes with similar definitions and uses were grouped together for the purpose of potentially combining codes. A few codes,

either not used or used minimally, were marked for potential omission or combinations, such as created codes that were not used or codes whose definitions were very similar to others.

Codes, definitions, and analysis were discussed at a face-to-face meeting with Dr. Lewallen. The rationale for combining or omitting codes was discussed and agreed upon. Determining which codes were most often used to answer each research question was considered an important next step. The researcher felt saturation had been reached as the need for no new codes was found in the last twenty-two interviews. While formulating the answers to each research question, the themes emerged from the codes that were frequently paired together and quotes with noted similarity of topic.

### **Study Findings**

Results for each specific aim and research question are below. Table 7 lists all codes used in responses to Specific Aim 1 along with the Research Question those codes were used to answer, the code's definition, and a salient quote. Overall themes were developed for each research question, and subthemes were developed from these which are used as headings under each Research Question in the discussion below.

#### **Specific Aim 1**

To determine the information needs of parents of infants with life threatening conditions compared with information given by health care providers to the parents during their infant's hospitalization.

As interviews were analyzed to answer research questions for Specific Aim 1, codes were assigned. The specific codes used to answer research questions, along with their definition and a salient quote are in Table 6. This information focuses the codes to the research question answers.

Table 6. Specific Aim 1- Codes Used Along with Definitions and Quotes

<b>Codes Used</b>	<b>Research Question</b>	<b>Definition</b>	<b>Quote</b>
Information sought	1	Information sought (requested) by parent	“And to us it was like they was just telling us anything to get us out of their face or just to put us at ease. And we told them, when first got here, that forget our feelings, we can get over our feelings but we want to know what’s happening...” (The mother of an infant with complex cardiac anomalies, during her one month interview.)
Information received	1	Information heard by parent	“they [providers] called us earlier during the day that they had gave us and was like they weren’t going to do it [procedure], because one of her cultures...came up bad.” (The father of an infant with extreme prematurity remembers during his eight month interview.)
Consistency/ Inconsistency	1, 2	Same information from more than one source	“Everybody wasn’t on the same page. So talking to ‘Sherry’ [social worker], she’s trying to get it together so we can come together to be on the same page.” (The mother of an infant with complex cardiac anomalies, during her one month interview.)
Family conference	1	Scheduled meeting of providers and parents	“Well they had a conference with all the doctors first then they had the conference [with] me and ‘Kamilla’ [infant’s mother] after they had to figure out what they was wanting to do...” (The father of an infant with a complex cardiac anomaly, stated during his initial interview.)

<b>Codes Used</b>	<b>Research Question</b>	<b>Definition</b>	<b>Quote</b>
Lay terms	1	Common language known by the majority	“But um, I basically after they tell me in layman’s terms why I can’t understand it, I pretty much get it after they tell me.” (The mother of an infant with extreme prematurity, stated during her initial interview.)
Understanding	1, 2	Comprehension of information	“Um...if I don’t understand something they try to get the...nurse practitioner – the nurse practitioner on call uh on duty to talk to me so I can understand it.” (The mother of an infant with extreme prematurity, stated during her initial interview.)
Internet	1, 3	Information found on the world wide web	“...when we did our research as far as WebMD® and talked to different doctors from different hospitals it [the information] was the same information here that was at another... their information was the same, it matched.” (The mother of an infant with complex cardiac anomaly, during her first month interview.)
Information provided	2	Information given to parent	“I feel like it’s the physician’s responsibility to educate the parents enough that they can make their own decision about things.” (A fellow physician of an infant born extremely premature stated during the initial interview.)
Alternative	2	Another path or option; break from the normal course of treatment	“...we’re going to go meet with the acupuncturist just because we know people who have had good luck with acupuncture and decreasing all sorts of things.” (The father of an infant born with complex cardiac anomalies, during the six month interview.)
Fact	2	Standardized practice	“Um basically, basically they came and told us what they needed to do. They were like, if it was fine with us they were going to go ahead and do it, so it was fine. They went ahead and did the surgery.” (The father of an infant with extreme prematurity, shared during an interview.)

<b>Codes Used</b>	<b>Research Question</b>	<b>Definition</b>	<b>Quote</b>
Options	2	Information presented to make a decision; choices offered	"...for the most part it wasn't really wasn't like 'hey you have option A or option B' it was like 'this is what we're doing, we just want to make sure you're okay with it'..." (A father of an infant with extreme prematurity, stated regarding information provided during hospitalization.)
Comfort	2	Information resulting in reassurance of the parent	"...they communicated great with us up here. So whatever they tell us I mean they explain it to us and what they're going to do and how they're going to do it. And what time frame they're going to do it so I like the way they do things around here." (The father of an infant with extreme prematurity stated during the month two interview.)
Books and magazines	3	Sought, found, or given resource	"...really that's about it, that little library they [NICU] used to have or they still have somewhere...was pretty good when we first got here, I mean I think a lot of stuff was helpful in the beginning..." (The father of an infant with extreme prematurity, said during his three month interview.)
Providers	3	When more than one health care provider is included or discussed	"...my first couple weeks and I'm sure a lot of nurses got annoyed with me because I would ask them a million questions and then I would be like 'well how does this work, how does that go in'...you know and be like 'well no like seriously how does it work' and they'd be giving me science class..." (The father of an infant with extreme prematurity reflected during the one year interview.)
Support System	3	Relatives and friends who provide encouragement and backing	"It [meeting other families and talking] feels good because you get to learn about their problems and then you see how your baby is." (The mother of an infant with extreme prematurity, stated during the month 2 interview.)

Codes were grouped together to form themes for each research question.

Subthemes emerged from the themes to better show a more descriptive answer to the research questions. Table 7 contains the themes and subthemes for specific aim one.

Table 7. Specific Aim 1- Themes and Subthemes

<b>Research Question</b>	<b>Theme</b>	<b>Subtheme</b>
Research Question One	What is going on with my baby's care?	Consistency of Information
		Common Understanding
Research Question Two	Whose team are you on?	Providers with Providers
		Providers with Parents
		Consistency among Teams
Research Question Three	Help me learn.	Read
		Heard
Research Question Four	Issues before the birth of the infant	

### **Research Question 1**

What topics (categories) of information were sought by parents during their infant's hospitalization?

The topics of information sought by parents during their infant's hospitalization centered on the parents wanting to know if the information being provided was consistent or if an alternative explanation of the information was available. Parents of infants who were born extremely premature sought specific information about the potential complications of being born prematurely, while parents of infants with complex cardiac anomalies sought specific information regarding the infant's surgical procedures and course of treatment following discharge.

The overall theme which was developed from analysis of the data for this research question was ‘What is going on with my baby’s care?’ Parents sought information about their infant in order to better understand how the infant was doing, such as stability of the infant’s condition, or what was happening to the infant, such as the disease process. The subthemes for this research question are ‘Consistency of Information’ and ‘Common Understanding’.

### **Consistency of Information**

The codes ‘information sought’, ‘information received’, and ‘consistency’, which could also represent inconsistency, were often used in areas of the transcripts that provided data about this research question. A subtheme was created known as ‘consistency of information’. Parents often stated that information about the infant’s condition received from a provider was either unknown by another provider or was contradicted by another provider. Parents reported that they needed consistency of information, particularly related to their infant’s plan of care.

The information sought by parents throughout their infant’s hospitalization was either confirmation that the information given by providers was consistent with what they had previously been told, or if there were other alternative explanations for or alternative information about what the providers had told them. For example, according to a mother of an infant with a complex cardiac anomaly during her one year interview when asked what had been the hardest thing about the past year, “...whether it is perceived or whether

it is actually there, our perceived...um...lack of continuity with 'Caroline's care...is, has been...difficult. And it's what we fall asleep worrying about and wake up worrying about..."

Another example of parents seeking consistency is illustrated by the mother of a different infant with a complex cardiac anomalies who stated during the one month interview,

one team of doctors don't know what the other team is doing and then the nurses, they like...I mean I understand that their job is to make sure that he's okay and, you know, take care of him during their shift, okay. Some of them don't know what the doctors have planned or anything...

The mother continued,

Everybody wasn't on the same page. So talking to 'Sherry' [social worker], she's trying to get it together so we can come together to be on the same page. And to us it was like they was just telling us anything to get us out of their face or just to put us at ease. And we told them, when first got here, that forget our feelings, we can get over our feelings but we want to know what's happening...

The father of an infant with extreme prematurity describes an example of inconsistency when he remembers during his eight month interview,

They [providers] called us earlier during the day...and was like they weren't going to do it [procedure], which...was a mistake, so they called us later the afternoon and they were like they are going to do the shunt that day."

Some parents, when faced with inconsistency, sought alternative information or course of action, such as the mother of an infant with a complex cardiac anomalies when she recalled information she received from a provider,

...your son is a very, very specialized case and that [the study hospital] doesn't have...a lot of those cases, so the way his case has been handled is somewhat piecemeal by each of the different...specialist as opposed... [a different hospital] that has a great number of those cases and so then...essentially all the different pieces are discussed kind of as a whole instead of as disparate pieces that...allow for things to fall through the cracks.

### **Common Understanding**

The codes 'understanding', 'lay terms', 'Internet', 'comfort' and 'family conferences' were also noted to cluster together in the data that answered research question one. Parents wanted understanding of their infant's condition in terms they could understand at a deep level, such as the definition of the infant's condition and how the condition might impact the infant's future. This was knowledge the provider already had and may have offered to the parents; however the parents needed the information explained in simpler terms so that the parents would have a common understanding along with the providers. Parents often used the Internet to obtain this information or they requested family conferences as to speak with multiple providers at once. The subtheme of 'common understanding' was created to describe this group of codes.

Of the six cases analyzed, four families (three infants born with complex cardiac anomalies and one infant born prematurely) requested a family conference to 'make sure

what they were told was true'. For example, the father of an infant with a complex cardiac anomaly stated during his initial interview,

...And everybody pretty much was on the same page with that there, so that's what they was doing... Well they had a conference with all the doctors first then they had the conference [with] me and 'Kamilla' [infant's mother] after they had to figure out what they was wanting to do...

The mother of an infant with extreme prematurity stated during her initial interview,

...I pretty much call every day to get an update on how she's doing and everything. Um...if I don't understand something they try to get the...the nurse practitioner...on duty to talk to me so I can understand it. But um, I basically after they tell me in layman's terms...I pretty much get it after they tell me...So I'd rather call and let them explain it to me – then to try digging it myself and then be like worried about it.

Parents of infants born extremely premature and infants born with complex cardiac anomalies sought information on the Internet to further explain the concept in terms they could understand or to find an alternative explanation for the concept. The father of an infant with extreme prematurity stated at the two month interview about information he was receiving from providers,

...I try to most of the time when they [providers] talk to me I try to remember the things that they say....I go home and look them up on the Internet or whatever. It [Internet] helps, it helps a lot I think it helps a whole lot.

The mother of an infant with a complex cardiac anomaly during her first month interview stated, "...when we did our research as far as WebMD® and talked to different

doctors from different hospitals it [the information] was the same information here that was at another [resource]... their information was the same, it matched.” A different mother of another infant with complex cardiac anomaly in her initial interview recalled,

I Googled it [her son’s heart condition] and checked different things to see exactly, but everything looked good. ...everything was basically exactly what they said the different procedures that they could do and stuff. ...they [providers] explained it as best they could ...everything looked good...

Analysis of the Interdisciplinary Patient and Family Education Records of the infants kept by educators during the infant’s hospitalization noted the educator’s evaluation of the parent’s readiness to learn. Options on the record included ‘eagerness to learn’, ‘acknowledges need to learn’, ‘asks questions’ and ‘unreceptive’. The option most noted by educators prior to educating the parents of those sampled was ‘asked questions’. No further information was given regarding the educator’s evaluation of the parent’s readiness to learn. There were no differences found between the parents of infants born extremely premature and parents of infants born with complex cardiac anomalies.

### **Comparison of the Topics of Information Sought by Parents of Infants with Extreme Prematurity and Infants with Complex Cardiac Anomalies During Hospitalization**

The parents of extremely premature infants sought specific information related to prematurity instead of general categories of information, such as potential complications of being born prior to 26 weeks gestation instead of a general classification like

premature infants. Parents of infants with complex cardiac anomalies sought information to confirm the information received from providers about their infant's treatment course. The parents asked very specific questions, particularly prior to discharge, regarding the infant's care needs after hospitalization such as possible medications needed to manage their infant's condition at home. Family conferences, particularly among parents of infants with complex cardiac anomalies, and the Internet were utilized for information seeking. All parents were looking for consistent information among providers and between the providers and other resources, such as the Internet. No differences were found between parents of infants with extreme prematurity or with complex cardiac anomalies in terms of the overall theme of this research question. Both subthemes, consistency of information and common understanding, were found in the transcripts of both populations.

## **Research Question 2**

What topics (categories) of information were discussed by health care providers with parents during their infant's hospitalization?

The topics of information discussed by health care providers with parents during their infant's hospitalization included treatment options such as medications or surgeries, potential complications, and preparation for caring for the infant at home. Providers also discussed their beliefs regarding what information parents should be given as well as to what degree parents should be involved in their infant's plan of care. The infant's

specific situation was also found to be a key factor the providers used in determining what information to give to parents, such as the need for surgical interventions or expectations following discharge.

The Interdisciplinary Patient and Family Education Records of the infants kept by educators during the infant's hospitalization were analyzed for specific topics of education given to parents. Typical parent education includes topics such as medications, diagnosis, and nutrition. There was also a topic noted as 'other' where the educator could add information needed for the individual infant. Topics specifically noted for more than one infant were ostomy bag changing, wound care, nasogastric tube placement and care, and pain management. There were no differences found between the parents of infants born extremely premature and parents of infants born with complex cardiac anomalies.

The overarching theme of 'Whose team are you on?' was developed in the analysis of this research question. Some providers' comments indicated that they felt that the providers were on their own team, separate from the parents. Information provided was on a 'need to know' basis when talking with parents. The code 'fact' was found more often in the transcripts of providers who seemed to relate more to other providers than to the parents. Other providers felt they were on a team with the infant's parents. Information given to parents by these providers was consistent with a belief that parents were partners in planning care for the infant. The codes 'alternative' and 'option' were found more in transcripts of providers who offered information consistent with being on the team with parents. Thus three subthemes were evident, two indicating opinions about how much parents should be involved, and one that pertained to all providers, no matter

what their preferences about parent involvement. The subtheme ‘providers with providers’ was generated for providers who reported parents need not actively participate in their infant’s plan of care, and the subtheme ‘providers with parents’ was generated for providers who reflected that parents should actively participate in their infant’s care. The final subtheme concerned ‘consistency among teams’. Teams were able to give a more consistent plan of care for the infant when the parents were involved. No differences were found between providers of infants born with complex cardiac anomalies and infants born extremely premature with regard to selection of a ‘team’.

#### **The Differing Teams of ‘Providers with Providers’ or ‘Providers with Parents’**

The code ‘information provided’ was found paired with interactions between a provider and another provider, such as the discussion of an infant’s care between providers, or between a provider and a parent, such as when a provider was discussing an infant’s care with a parent. Thus, two points of view about the infant’s care, or two teams emerged. As the provider’s opinion about the information that should be shared with parents determined whether the provider was teamed with other providers or with the parents, providers on the same case were sometimes on different teams. Some providers felt that sharing details about the infant’s care with parents was for information only and not for parental input into their infant’s plan of care, which was characteristic of the view of providers on teams with other providers. For example, an attending physician of an infant born prematurely stated during the initial interview,

...in the NICU it really matters for the majority of the things that we do, we think we know the best way for the baby and so, I’m not, usually it’s not my...aim to

solicit the parents' input on some of those things, now I mean I think there are some decisions, that when you get toward end of life care, and...how far to go with some of the babies, that we don't know what the right answer is and so obviously I think parent input is important when you get there. But for sort of the day-to-day things for the baby, um, it gets, it was very frustrating when the parents want to have a role in that sort of decision making because that's not what, I mean, that's what they pay me to do.

A fellow on the same case was on the team with infant's parents and offered a totally opposite view. This provider felt that parents should be on a team with the providers when planning infant care. This provider stated,

I feel like it's the physician's responsibility to educate the parents enough that they can make their own decision about things. I think historically and often even now, physicians find it easy to take the role of saying 'this is what we should do' or 'this is the right thing to do' which I think may even be appropriate in cases but I guess I think what I strive to do is to present everything that I know or present everything ...to the family to get them to the point that they can understand all the facts that are involved so that they can make the decision.

### **Consistency among Teams**

This view of providers being on a team with other providers or on a team with the infant's parents often led to issues of the information provided being consistent or inconsistent in the view of the parents, as discussed in Research Question 1. When parents were excluded from the team, providers gave parents information that the parents found to be inconsistent. Even the providers thought the information parents received from providers was inconsistent. A fellow in the case of an infant born with complex cardiac anomalies stated on the initial interview, "Mother was furious, she was angry...and...confused. And felt like she was receiving conflicting information from uh

the providers which we often are at fault of doing.” The same fellow continued later in the same interview,

I do think overall that we [fellows] do a better job than physicians of communicating, being on the same page with how we communicate information to parents ‘cause I hear this all the time that um...parents and patients hear conflicting things from different people. And that’s because sometimes we’re not on the same page.

He continued, “But I think that it’s important for whomever is communicating with the patient or their parents or guardians to be consistent.” A neonatal Nurse Practitioner on the case of an infant born prematurely stated during the initial interview regarding consistency of information provided, “‘Cause there are times when they don’t even agree with each other, you know? ...And they don’t even agree with each other,...”

An attending physician for an infant born prematurely reflected that measures are being taken to increase the consistency of information provided between health care providers. Beginning in April of 2010, the hospital where the CTLC study was conducted introduced new family centered care initiatives. The idea of Family Centered Care supports providers being on the same team with the parents. He stated during the first interview,

...so in general I like it um, the things we’re doing to support Family Centered Care, um one of the big ones for us is to have parents on rounds,...Uh I think it really, it improves communication because the parents don’t think that there’s a secret meeting going on about their baby that, that involves the interventions that we’re going to do to their baby that they’re not invited to. They see exactly how things happen and they’re involved in the process. I think it makes the parents much happier. And I think it increases the amount of time you spend on rounds a little bit, um just because you kind of have to explain the, medical-ese to the

parents, but I think ultimately it really decreases the amount of time that you have to spend you know, communicating with parents during the day because they're up-to-date every single morning. So they get to see every single day how things are. And you don't have to spend these long, two hour meetings you know kind of...catching up with parents who have you know, who feel even though you tell them what you think's important, they feel that they're being left out of something that you think is trivial.

Even when providers chose to team with the infant's parents, some situations did not allow for parents to have options or alternatives when information was provided, such as a cardiac defect which only had one known treatment. The codes 'alternative', 'fact', and 'option' were grouped together with information provided in transcripts that described situations like this. The code 'fact' applied more to providers who chose to team with other providers and the codes 'alternative' and 'option' applied more to providers who chose to team with the infant's parents.

The following quotes are from providers who were on the team with other providers. The father of an infant with extreme prematurity shared during an interview regarding the decision to go ahead with the infant's surgery,

Um basically, basically they [providers] came and told us what they needed to do. They were like, if it was fine with us they were going to go ahead and do it, so it was fine. They went ahead and did the surgery.

There were infants with certain complications of complex cardiac anomalies or extreme prematurity that allowed a provider to offer more specific information, for example a standard pattern of advancing bottle feedings for infants born extremely

premature, however the parent's input was not requested. For example, a father of an infant with extreme prematurity stated regarding information provided during hospitalization,

...for the most part it...really wasn't like 'hey you have option A or option B' it was like 'this is what we're doing, we just want to make sure you're okay with it' and you know we didn't really know any better so we'd be like 'okay sure that sounds good.

An attending for the same infant offered during the initial interview,

...we [providers] did talk with the parents when I mean it seemed like 'Aaron' was not making much progress, that, and him being so premature, that there was a likelihood, we talked about steroids and there's really two types of steroids we use; we use hydrocortisone to support blood pressure and Decadron to get kids off the ventilator and we talked about the side effects a little bit with Decadron and that we don't think hydrocortisone has those side effects. And almost the very next day he went on hydrocortisone for, for low blood pressure, um, and I told the parents that was very common for babies his size...

The attending continued later in the interview,

...as many times as we use it [hydrocortisone] we should know a lot more but based on the previous hundred babies that we treated with hydrocortisone we feel like it's the right thing to do in certain clinical instances and so we typically use it, or the same thing with antibiotics or when the baby needs a blood transfusion or you know, those sorts of things. We, you know, I'm happy to tell the parents and sort of anticipate that those things will happen, but I'm not really looking for them to tell me when they should or should not happen, ...

A fellow on the same case stated after an event,

...typically we let parents know when there's significant changes, so we called them when the baby had to be intubated. They were there at the bedside when we

actually reintubated him and so then as things progress, we tell them more, so at that time we were concerned that he might be sick so we let them know that we're going to start investigating once we had something that like, ... 'yes, he's infected, we've been talking to you about how we think he's sick but now we think it might be the intestines because he has, you know, these findings on the x-ray'.

### **Comparison of Topics of Information Discussed by Providers with Parents of Infants with Extreme Prematurity and Infants with Complex Cardiac Anomalies During Hospitalization**

The topics of information discussed by health care providers with parents during their infant's hospitalization were similar despite differing reasons for hospitalization. Both infants with extreme prematurity and infants with complex cardiac anomalies required medications and surgeries, as well as had the potential for long-term complications, and required preparation for caring for the infant at home. The only difference found in information given by providers was found between providers themselves, depending on whether the provider was on the team with other providers or on the team with the parents of the infant. Individual providers gave varying levels of depth information, such as general versus specific information, and had different methods of delivering the information, such as using medical terms versus lay terms. No pattern was found among types of providers and the method they chose to deliver information to parents. Providers' statements in their interviews described varying beliefs regarding the level of information parents should receive and how much they should be involved in the infant's treatment plan. Therefore, no differences were found between infants with

extreme prematurity and infants with complex cardiac anomalies regarding information given by providers to parents during hospitalization, even though the informational needs of the parents were different.

### **Research Question 3**

From whom and from what outside resources did parents seek information during their infant's hospitalization?

Outside resources were utilized by parents when seeking information during their infant's hospitalization. Parents specifically mentioned the Internet, books, magazines, newsletters, family conferences, and support groups. Parents of infants with complex cardiac anomalies cited use of the Internet more while parents of infants with extreme prematurity referenced more books and health care providers.

All of these outside resources could be grouped into two formats, written and spoken, or read and heard. The codes 'Internet', 'books', 'magazines', and 'newsletters' were grouped together as all types of resources in writing to form the subtheme 'read'. The codes 'family conference' and 'support group' were grouped together as types of spoken resources to form the subtheme 'heard'. These mirror two prominent ways adults learn, by listening or by reading. No matter the resource utilized, all parents seemed to say 'Help me learn', which was the overall theme for this research question.

### **Read**

The Internet was referenced as an outside resource when parents sought information during their infant's hospitalization. References were made to the search engine Google, such as, "I Googled it and checked different things to see exactly, but

everything looked good.” as noted by the mother of an infant with complex cardiac anomalies during her initial interview. Another mother of an infant with complex cardiac anomalies noted the use of a database during her initial interview, “Yeah and so when we did our research as far as WebMD® – and talked to different doctors from different hospitals – It was the same information here...”

A nurse caring for an infant born with complex cardiac anomalies noted during the initial interview,

...very educated family - ...um...did lots of their own research before ‘Caroline’ was even born. And never were unreasonable though which was nice ‘cause sometimes you have the Internet-seeking families that are crazy but you know mom acknowledged right off the bat ‘I’ve looked at the Internet, I know there’s the good, the bad, and the ugly and I just have questions for you.’ And that was, it was like the perfect way to do it I think –

The father of an infant with extreme prematurity during his second month interview, “...I go home and look them up on the Internet or whatever – It helps, it helps a lot I think it helps a whole lot – “ The father of an infant with extreme prematurity said during his three month interview when asked about helpfulness of resources,

I think I looked at it [parent handbook] once when I was bored and he was like two weeks old but I haven’t touched it really since then. ... I think the little newsletter they print that says what’s going on is pretty good...really that’s about it, that little library they [NICU] used to have or they still have somewhere...was pretty good when we first got here, I mean I think a lot of stuff was helpful in the beginning but now it’s just I guess you know we’ve been doing it for a while so it really doesn’t, I don’t even think about that.

The mother of the same infant stated when asked if she uses any of the resources that the nursery offers during her one month interview, “Well I have a premie book and I have read the handbook and I have a copy of the handbook so, I’ve read that stuff, so you know, I’m not a very computer person...”

### **Heard**

The father of an infant with extreme prematurity reflected about his infant’s hospitalization resources during the one year interview,

...my first couple weeks and I’m sure a lot of nurses got annoyed with me because I would ask them a million questions and then I would be like ‘well how does this work, how does that go in’...you know and be like ‘well no like seriously how does it work’ and they’d be giving me science class...

The mother of an infant with extreme prematurity stated during the month 2 interview, “It [meeting other families and talking] feels good because you get to learn about their problems and then you see how your baby is.” The father of an infant with extreme prematurity stated during his two month interview,

...she [mother of the infant] has a meeting, I think we have a meeting with the doctors, well she does she’s going to meet with them I think next week – I’m going to plan for what they’re going to do with her [infant] and stuff like that. Yeah, she meets with the doctors and the NNPs and then she gives me information about what they’re going to do.

A social worker participating in the coordination of care for the same infant offered during an interview following an event,

And she (infant's mother) does a very good job of when a new attending comes on, she schedules a meeting and we have family meetings. And she you know runs the meetings, the first one that I had been with her on, she did without her mother (infant's grandmother), was the first one that she had done without her mother. And she was very nervous...

### **Comparison of Outside Resources Utilized by Parents of Infants with Extreme Prematurity and Infants with Complex Cardiac Anomalies During Hospitalization**

Outside resources utilized by parents of infants with extreme prematurity were primarily talking to providers and their support system, categorized as 'heard'. Parents of infants with complex cardiac anomalies noted use of the Internet and Internet-based resources, categorized as 'read'. Potential considerations may be the fact that infants with extreme prematurity were hospitalized longer than infants with complex cardiac anomalies. Parents of infants with complex cardiac anomalies also knew of their infant's diagnoses for a longer period of time than parents of infants with extreme prematurity, giving them longer to seek out resources prior to the infant's birth.

Infants who are born extremely premature have a predictable pattern of maturity, barring any unforeseen issues. Complications also come at predictable age ranges, such as problems with bottle feedings between 32-34 weeks adjusted gestation, or at six weeks of age for an infant born at 26 weeks gestation (Breton & Steinwender, 2008). These topics are frequently discussed with parents by providers. Infants who are born with complex cardiac anomalies typically have individual illnesses trajectories. Even two infants born with a specific anomalies, such as a ventricular septal defect, can have varying degrees of responses to the condition depending on the size of the infant and the size of the defect. These wide variations lend themselves to parents seeking information

they can read; such as that which can be looked up on websites. Since infants with the same diagnosis can have a variety of symptoms or outcomes, a list of each potential scenario is potentially easier to understand when read about than when heard.

#### **Research Question 4**

What contextual variables were present which may have influenced information needs of parents during their infant's hospitalization?

Parents were challenged by contextual variables that may have influenced their information needs while their infants were hospitalized. Examples include having had a previous infant born prematurely, having social issues such as the father of the baby not being the mother's current significant other, and a family living more than an hour away from a hospital able to care for the infant in case of an emergency. A range of topics did have one common theme 'Issues before the Birth of the Infant' as all contextual variables occurred before the birth of the infant and did not change after the infant was born in this sample. No subthemes were evident during transcript analysis.

The Interdisciplinary Patient and Family Education Records kept by providers during the infant's hospitalization also noted potential barriers to learning noted by the provider prior to giving education to the parents. Options available included language, emotional, cultural, and cognitive. The most listed barrier to learning was emotional. In the space where the educator could write details or explain the reason behind selecting the barrier, comments provided were 'emotional response to the NICU environment' and 'mom anxious'. Individual barriers of the parents to learning could be seen as contextual variables since barriers to learning may alter the parent's learning needs. There were no

differences found in contextual variables between the parents of infants born extremely premature and parents of infants born with complex cardiac anomalies.

### **Issues Before the Birth of the Infant**

The mother of an infant with extreme prematurity stated upon study entry, “Cause we have the visitations for her and me, her daddy ‘cause we’re not together anymore.” This mother’s current partner is not the baby’s father. The mother lives with her current significant other and not the infant’s father. The infant’s mother and father did not visit at the same time. The infant’s father was to be the infant’s primary care provider when the infant was discharged from the hospital. A nurse of the same infant explained during the discharge interview,

Um so she’s still here and the other issue that’s holding her here is um social issue of her family, mom seems to be the breadwinner for the family. I think she works very long hours in a meat packing plant, isn’t allowed to come to the phone. So our contact with her is very limited; sometimes she’ll come in the evening but that’s about the only time we see her even though we’ve asked her to come on the weekends – That’s not been happening as we would have liked. The father much to my surprise after having cared for the baby for at least a month, is Spanish-Speaking only.

This presented a language barrier. The nurse continued in the same interview,

The social situation is...a different...thing. Because even if the dad needed to pick up the phone and call 911...I don’t know at this moment in time how long it’s going to take an emergency person to get out where they live. Um...it takes them a while to get here now, at least an hour.

This presents a distance barrier. These contextual variables were present before the infant was born. The mother had a different significant other than the father of the baby, but had not changed jobs, nor moved.

The father of an infant born with complex cardiac anomalies was asked during the initial interview about a son of his born earlier that was hospitalized at birth in the same facility as the research site. The father stated that his son had lived “a month and fifteen days.” He went on to share about how this past experience was impacting this son’s current hospitalization, “kind of rough in a way but I know he’s [the current son] going to pull through more. It was up to him he’s got more get and go, he’s got more, months, he go to watch over him [the son who passed].” A social worker on this infant’s case commented on the parent’s point of view as having had a previous infant born prematurely, “I imagine from their perspective, they don’t even really compare ‘Bethany’ to that baby.

I imagine because he wasn’t born, at twenty-four weeks or whatever it was you know, and so this is I think they see him as a totally different child, with a totally different chance at life, and...um...I was pleasantly surprised by their demeanors and they just were very excited about their baby and happy he was here and just very optimistic.

A neonatal Nurse Practitioner caring for infant born with complex cardiac anomalies recalled at the discharge interview,

Um I was concerned that he [infant] was not going to get his feeds or medication in the timely manner that he needed to thrive. Based on the reaction, based on I think the...tension between mom and dad and the uh, the plan, their plan of care was so fragmented between who goes to work when, how they’re going to get the

baby from here to there, it was very fragmented care where someone's going to watch him for two hours until the next person comes home and they're going to take him somewhere else for two hours. So it was just a challenge, but I think with everything I knew that once he got home he was going to fly or fail and that they get into their routine.

This contextual variable came from the fact the infant had a large family who helped each other. The number of caregivers at home was the contextual variable that led to the concern of potentially fragmented care to the infant after discharge.

### **Comparison of Contextual Variables of Infants Born Extremely Premature and Infants with Complex Cardiac Anomalies During Hospitalization**

Since contextual variables are by definition inconsistent factors within the case, no pattern was noted in the study findings regarding differences between infants with extreme prematurity and infants with complex cardiac anomalies. The researcher, however, did identify potential contextual variables. The infants who were born extremely premature were hospitalized for four, six, and eight months whereas the infants who were born with complex cardiac anomalies were hospitalized for one month and four months. Infants who were born extremely premature were hospitalized much longer than infants with complex cardiac anomalies and thus their parents did more interviews during hospitalization. Conversely, the parents of infants with complex cardiac anomalies provided more interviews after their infants were discharged. Parents of infants with extreme prematurity provided more information for Specific Aim 1 than parents of infants with complex cardiac anomalies. Thus, for Specific Aim 1, parents and providers

of infants who were born extremely premature provided more information and, for Specific Aim 2, parents and providers of infants born with complex cardiac anomalies provided more information.

A second potential contextual variable noted by the researcher was the time frame of diagnosis prenatally. Parents of infants born extremely premature were told by providers days or hours before the infant's birth, as prediction of premature birth is not possible. Parents of infants with complex cardiac anomalies were told by health care providers months before the infant's birth as the infant's anomalies were noted on prenatal ultrasound. This allowed parents of infants with complex cardiac anomalies a longer time frame to ask questions and research their infant's condition prior to birth. For example, the mother of an infant with extreme prematurity offered during her initial interview,

...they told me about umm, that the baby she might not live but there's a chance there could be a slight chance, zero percent, not much percent that they gave me but um 'cause she didn't have much fluid around her. And they said that they didn't have the umm, the MRI pictures so they can actually see what they can do for her.

An attending physician for the same infant offered during the first interview,

The most difficult one [case] was the, kind of the prenatal recommendations and uh...you know we didn't really know what to tell them to expect and they didn't know what to expect and they hadn't had you know, I guess...pre-conceived notions about what a premie meant and so they told us to use our judgment...

The father of an infant with extreme prematurity reflected during the initial interview on the information given to him by the providers prior to the infant's birth,

...the doctors basically when he came in told me he was like, it's going to be...your child could possibly be born with disabilities and stuff like that like...being on the oxygen her whole life or...brain and stuff like that that's what he basically told us was a possibility. He asked us were we ready to take on that kind of responsibility if, and I was like, I felt as though we were I mean, either if the child, if our child does have disability I think we are capable of taking care of her.

Conversely, the father of an infant with complex cardiac anomalies responded when asked about the remainder of the pregnancy after learning of the infant's diagnosis, "Uh we really didn't do much more 'til like the last month kept to ourselves, I just uh..me and her just talked about it and everything."

Since parent of infants who were born extremely premature did not know of their infant's diagnosis and potential complications until right before birth, the parents had to rely on the information they heard from providers. There was not time for seeking information from other resources prior to birth. Parents of infants with complex cardiac anomalies had time before the infant's birth to read and consider information from places such as the Internet. There was time for thought and acceptance of the infant's diagnosis before birth also.

### **Summary of Specific Aim 1**

While infants were hospitalized, parents of infants with extreme prematurity and of infants with complex cardiac anomalies both sought information to confirm consistency of or to find alternative explanations for information given by providers. All information sought centered on the theme of parents wanting to know 'What is going on with my baby's care?' Subthemes of 'consistency of information' and 'common

understanding' were noted. Parents were seeking out information in response to information given to them by providers. The parents wanted to have explanations for the information given in other formats, such as written, or to have the information explained in a different way, such as with the use of lay terms.

Providers differed in the information they gave to parents during their infant's hospitalization, based on the provider's personal beliefs about what parents needed to know about their infant's treatment plan. Providers were on teams with other providers or on teams with parents of the infant, creating the overall theme of 'Whose team are you on?' Providers who chose to be on teams with other providers offered just facts about the treatment plan, while providers who chose to be on teams with parents of the infant offered options and alternatives to parents. This difference created the subthemes of 'providers with providers' and 'providers with parents'. Providers, particularly those on the team with parents, would update the parents on their infant's condition or would come speak with parents in response to a request for additional information about their infant, as with providers who were on teams with other providers. While speaking with parents of the infants, providers would often begin by updating the parents; however the parents of the infants would then ask questions or seek alternative explanations for the information given by the provider. Therefore, while the providers began the communication with the parents, the parents were the ones noted to continue or drive the request for more information.

Parents of infants born with extreme prematurity and parents of infants born with complex cardiac anomalies requested different information from providers. As noted,

parents of infants born with extreme prematurity requested information regarding the potential complications of being born extremely premature, such as issues with feeding and development, whereas parents of infants born with complex cardiac anomalies sought information regarding aspects of their infant's illnesses, such as surgery or medication. How providers responded to parents did not vary by the information requested. Provider's responses depended more on whether the provider was on the same team with other providers or whether the provider was on the same team with parents of the infants for which they were caring.

The codes of 'comfort' and 'understanding' were found grouped with information given by providers. Parents found comfort when they understood information, such as when it was presented in lay terms, thus parents and providers had a common understanding of the infant's plan of care. Even when providers chose to team with other providers instead of with the parents of the infant, parents seemed to find any information given by providers helpful. The father of an infant with extreme prematurity stated,

...they communicated great with us up here. So whatever they tell us I mean they explain it to us and what they're going to do and how they're going to do it. And what time frame they're going to do it so I like the way they do things around here.

regarding communication with the providers during the month two interview. The same father offered during his month seven interview,

They [providers] tell us in an appropriate way. I mean, whatever they tell us they always – they call and let us know what they’re doing and why they’re not doing it. And things like that they always let us know, you know inform us. I mean I trust them, I think.

During the eight month interview, the same parent stated, “They [providers] have done a great job preparing us. ...it [hospitalization] was quite comfortable.” These quotes are all from one parent. They represent the notion that any information is beneficial to parents, no matter whose team the provider was on. Parents of infants with extreme prematurity primarily sought information from sources where they heard the information, such as from their support systems, for example parents of infants with similar conditions as theirs, more frequently than other outside resources. These parents were grouped together in the subtheme ‘heard’. While support groups in the community are commonly available for parents with infants born extremely premature, support groups for parents of infants born with complex cardiac anomalies are not as readily available. Infants born with complex cardiac anomalies mainly cited the use of outside resources that allowed them to read the information during their infant’s hospitalization. These parents were grouped together in the subtheme ‘read’. All parents were seeking information about their infant, which was the overarching theme ‘Help me learn’.

Contextual variables were identified while their infant was hospitalized and all identified along the common theme of ‘Issues before the birth of the Infant’. The topics of the contextual variables were having previous experience with a chronically ill infant and having inconsistent caregivers prepared to care for the infant after discharge. No subthemes were noted. The researcher considered two possible contextual variables

because they may have influenced the information needs of parents while their infant was hospitalized: the infant’s length of hospitalization and the length of time parents knew about their infant’s diagnoses prior to birth. No themes or subthemes emerged due to the individual nature of contextual variables themselves.

### **Specific Aim 2**

To determine the information needs of parents of infants with life threatening conditions compared with information given by health care providers to the parents following their infant’s discharge from the hospital.

Codes used to answer research questions along with their definitions and salient quotes are presented in Table 8. Though some of the codes and definitions are the same used to answer research questions to Specific Aim 1, the context is different as noted by the quotes.

Table 8. Specific Aim 2 - Codes Used Along with Definitions and Quotes

<b>Codes Used</b>	<b>Research Question</b>	<b>Definition</b>	<b>Quote</b>
Consistency/ Inconsistency	1, 2	Same information from more than one source	“I mean I was shocked the other day when we came in for pre-op clinic on Monday, and they asked where we stood with Dr. ‘Beamer’...So clearly they were still waiting on Dr. ‘Beamer’ to stand up and weigh in on the [surgical procedure].” (The mother of an infant with complex cardiac anomalies stated during her months four and five interview.)

<b>Codes Used</b>	<b>Research Question</b>	<b>Definition</b>	<b>Quote</b>
Alternative	1	Another path or option; break from the normal course of treatment	“I can’t really draw any conclusions yet, but we stopped the acupuncture because of the trip. Um...and so he went about two weeks without having acupuncture, and then he started throwing up again.” (The father of an infant with complex cardiac anomaly offered during his nine month interview.)
Comfort	1, 2	Information resulting in reassurance of the parent	“Yeah she [infant’s mother], she made the uh...um lady taking blood today give ‘Aaron’s’ hematocrit level...she was like ‘did they give a hematocrit’ and the lady [person drawing blood] was like ‘no’ she’s like ‘well can we get one of those ‘cause I want to know what it is’. I was like ‘you’re ridiculous, let’s be serious, he’s fine, he’s pink, he’s breathing, we’re good’.” (The father of an infant with extreme prematurity reflected during the one year interview.)
Understanding	1, 2	Comprehension of information	“...Dr. ‘Drake’ was wonderful he spent like two Thursday nights with us on the phone because we wanted, we were very calm about it, but we wanted to clarify um how much of this does matter.” (The mother of an infant with complex cardiac anomalies discussed during her months four and five interview.)
Facts	2	Standardized practice	Dr. Blue said ‘well I really think it’ll be before eighteen and twenty-four months’ he said ‘we’re doing them younger and younger.’ (The mother of an infant with complex cardiac anomalies commented during her one year interview.)

<b>Codes Used</b>	<b>Research Question</b>	<b>Definition</b>	<b>Quote</b>
Options	2	Information presented to make a decision; choices offered	"...you know luckily, luckily we only had one option for how to treat him. Um I think our decisions would have been a little crazier if we had three surgical options, and it was up to us to choose." (The mother of an infant with complex cardiac anomalies commented during her one year interview.)
Internet	3	Information found on the world wide web	"...we asked around you know obviously Googled it and uh we looked it up on the Internet and asked um..." (The father of an infant with extreme prematurity during one year interview.)
Support System	3	Relatives and friends who provide encouragement and backing	"...And everybody [parents of other infants with complex cardiac anomalies] told us up front they're like, 'feeding is going to be a problem.' And they were, they were right...." (The father of an infant with complex cardiac anomalies during one year interview.)
Providers	3	When more than one health care provider is included or discussed	"Yeah, she'll [mother of the infant] call me like if she's coming, or if she needs help with something." (A social worker involved with an infant with extreme prematurity offered during the final interview.)

Codes were grouped together to form themes for each research question.

Subthemes emerged from the themes to better show a more descriptive answer to the research questions. In Table 9 are the themes and subthemes for Specific Aim 2.

Table 9. Specific Aim 2 – Themes and Subthemes

<b>Research Question</b>	<b>Theme</b>	<b>Subtheme</b>
Research Question One	What is going on with my baby's care?	Continuity of Care
		Alternatives to Care
Research Question Two	Whose team are you on?	Providers in Isolation
		Providers with Evidence
Research Question Three	Help me learn.	Read and Heard
		Heard
Research Question Four	Adjustment to everyday life	

### **Research Question 1**

What topics (categories) of information were sought by parents following the infant's discharge from the hospital?

Following the infant's discharge from the hospital, topics of information sought by parents were related to consistency and alternative explanations, as was the case during hospitalization. After discharge, however topics dealt more with treatment of symptoms related to the infant's chronic condition, locations for follow-up care, and second opinions about the infant's care. Parents of infants born with extreme prematurity sought information to confirm their infant was healthy and doing well. Parents of infants born with complex cardiac anomalies sought information about treatment options.

The overall theme that developed from analysis of the data for this research question was 'What is going on with my baby's care?' Though the specific topics of information sought by parents were different while hospitalized compared to those after discharge, the overall theme remained the same. The parent's primary concern was for their infant. The subthemes for this research question are 'Continuity of Care',

‘Alternatives to Care’, and ‘Common Understanding’. These subthemes clarify the more specific information parents sought after their infant was discharged from the hospital.

### **Continuity of Care**

The codes ‘information sought’, ‘information received’, and ‘consistency’, which could also represent inconsistency, were often used in areas of the transcripts that provided data about this research question. Though the codes answering this question were the same as for Specific Aim 1, Research Question 1, the subthemes are different. A subtheme was created known as ‘Continuity of Care’. Parents wanted all providers treating their infant after discharge from the hospital to be working together. The concept of all health care providers working together toward a common goal throughout the client’s illnesses is known as continuity of care.

The mother of an infant with complex cardiac anomalies stated during her months four and five interview regarding consistency in management of her son’s care,

Our pediatrician had referred us to a specialist but in hindsight, the ball really got dropped there because I went back home with a surgery date in a holding pattern and not really quite understanding why.

She continues,

Okay, um one I had to seek out Dr. ‘Beamer’ myself. Two, she [receptionist of Dr. ‘Beamer’] said she had the baton and would be responsible for handing it off to somebody. Three, she never followed up. Four, when she did, she did it through a nurse who had not yet even met ‘Caroline’ with an entirely new approach, and then we’re totally – it’s fine we Googled baclofen and did our own research, but I’m not sure that...that we should have to be doing that to close the loop.

Regarding the situation later in the same interview,

...I got to the point where I thought 'oh my gosh' you know 'I'm a little nervous continuing to take my child over to this...doctor.' And to be honest, she never even to this day, we...I mean I was shocked the other day when we came in for pre-op clinic on Monday, and they asked where we stood with Dr. 'Beamer'...So clearly they were still waiting on Dr. 'Beamer' to stand up and weigh in on the [surgical procedure].

### **Alternative Treatments**

When parents were not satisfied with the course of their infant's care or with the treatment options presented by providers, the parents went in search of alternative treatments. The codes 'alternative', 'fact', and 'option' were often found together when analyzing data for this research question. Even if solutions to the infant's chronic conditions were not found, treatments were found to help with the infant's symptoms. The parents of an infant born with complex cardiac anomalies, 'Caroline', were the only parents who offered information related to seeking alternative treatments. The parents sought these alternatives themselves instead of waiting for providers to offer options for their infant's treatment.

The father of an infant with complex cardiac anomalies offered during his six month interview,

I don't think anybody has any idea what's going on except that this happened, this happens a lot so um to heart kids...In fact when you Google acupuncture and vomiting the second response or thing that comes up is a study from [the research facility] that shows that acupuncture...works better than medication.

During the month eight interview, the same father commented,

the night after he went [to acupuncture] the first time was the first time he slept through the night without throwing up. And then uh the same thing the second time so he uh, he went from a - he was good for about a week and then he went back to acupuncturist and um, he stopped throwing up again. And so you know, is that coincidence or is it causality, I don't know. Um....but uh it certainly, 'Misty' said he's very relaxed and seems like he's in a.....in a good place when he's there, so that's good.

The following month, the father continued,

I can't really draw any conclusions yet, but we stopped the acupuncture because of the trip. Um...and so he went about two weeks without having acupuncture, and then he started throwing up again.

### **Common Understanding**

When analyzing data for this research question, the codes 'understanding', 'comfort' and 'lay terms', and 'provider' were noted together in the transcripts. After discharge from the hospital, parents sought comfort and understanding from providers. Sometimes hearing common medical terms helped the parent gauge how their infant was doing, while other times having information discussed using lay terms helped the parent.

Specific information brought comfort to the parents of an infant with extreme prematurity after discharge. The father reflected during the one year interview,

Yeah she [infant's mother], she made the uh...um lady taking blood today give 'Aaron's hematocrit level...she was like 'did they give a hematocrit' and the lady [person drawing blood] was like 'no' she's like 'well can we get one of those 'cause I want to know what it is'. I was like 'you're ridiculous, let's be serious, he's fine, he's pink, he's breathing, we're good'.

Knowing their infant's hematocrit level, though a medical gauge of the infant's condition, brought comfort to the parent because during hospitalization this level was used by providers. The parents had learned to understand what this lab value meant with regard to their infant.

The mother of an infant with complex cardiac anomalies discussed during her months four and five interview,

...Dr. 'Drake' was wonderful he spent like two Thursday nights with us on the phone because we wanted, we were very calm about it, but we wanted to clarify um how much of this does matter." Later in the same interview the mother continued, "...we did sit down with Dr. 'Drake' and he was very, um as he is, just very, he was very informative, very patient, very frank about um...where we can go, um so new approaches to finding a GI specialist, if we weren't happy with Dr. 'Beamer'. Um, ways to...um he you know, but at the same time knowing full well that it shouldn't necessarily be the cardiologist quarterbacking a non-cardiac issue.

### **Comparison of the Topics of Information Sought by Parents of Infants with Extreme Prematurity and Infants with Complex Cardiac Anomalies After Discharge**

The information sought by parents following their infant's discharge from the hospital was more specific in content compared to the more general information sought by parents while the infant was hospitalized. This difference was consistent between parents of infants with extreme prematurity and parents of infants with complex cardiac anomalies. Parents of infants with complex cardiac anomalies sought information regarding alternative treatments or management of the infant's chronic conditions, known as continuity of care. Parents of infants with extreme prematurity sought information

related to making themselves more comfortable with their infant's condition, such as knowledge of their infant's lab work, or a common understanding.

## **Research Question 2**

What topics (categories) of information were discussed by health care providers with parents following their infant's discharge from the hospital?

The information discussed by health care providers with parents following the infant's discharge focused on monitoring of the infant's progress and special needs such as procedures and feedings. After discharge, there was not a coordinator of the infant's care, such as a case manager, as during hospitalization. The parents took over some of the responsibilities of managing their infant's care, such as making sure the providers all focused on a common goal; however the parents did not feel they had the adequate skills for this role. Despite the fact that inconsistencies in information continued after discharge, parents expressed comfort with the health care providers.

The overarching theme of 'Whose team are you on?' was developed in the analysis of this research question. Even though the same theme was established with this research question as in Research Question 2 of Specific Aim 1, subthemes were different. Providers remained on the same team with other providers; however providers did not seem to communicate with one another, or seemingly were a team by themselves. These providers based the information they offered to parents on the provider's previous knowledge and resulted in the subtheme 'providers in isolation'. Other providers who were on the same team with other providers did communicate with each other; however they did so through accessing current literature and research findings. The provider team

is unlike the team ‘providers with providers’ as during the infant’s hospitalization because now the providers were on a team with often distant providers who sought out, conducted, and published evidence-based practice about the infant’s condition. The codes ‘fact’, ‘information provided’, and ‘consistency’ were most often noted in transcript analysis for this research question. The notion of providers being on the same team with parents was not evident in this research question. Thus the second team was ‘providers with evidence’.

### **The Differing Teams of ‘Providers in Isolation’ or ‘Providers with Evidence’**

The code ‘information provided’ was found paired with interactions about a provider, such as a provider who was discussing an infant’s care based on previous knowledge of the diagnosis, or between a provider and a parent, such as when a provider was giving information to a parent about their infant’s care based on ‘facts’. Thus, two points of view about the infant’s care, or two teams, emerged.

For example, the mother of an infant with complex cardiac anomalies commented during her one year interview about the consistency of information given,

...and he’s [surgeon] kind of you know non-committal...And he said...you know ‘I don’t know, we don’t usually do them [surgical procedure] before two and I can’t really think of a reason why we would do it before two.’ And I brought that conversation up to Dr. ‘Blue’ last week and he said ‘well I really think it’ll be before eighteen and twenty-four months’ he said ‘we’re doing them younger and younger.’ And he said you know the surgeon’s probably not going to commit and he was really nice about it, but he said ‘yeah I’m going to stick by that window I really think that’s what it’s going to be.’...I just offer that up because it is kind of a mixed-message.

In this example, the first provider was speaking in isolation, alone without evidence, whereas the second provider, Dr. 'Blue', was using evidence to convey information to parents.

There were times when providers with evidence could offer not options to parents. The mother of an infant with complex cardiac anomalies commented during her one year interview,

After 'Caroline' was born, um...we needed to make decisions about...you know luckily, luckily we only had one option for how to treat her. Um I think our decisions would have been a little crazier if we had three surgical options, and it was up to us to choose. We probably would have had to carry that responsibility a little differently.

The mother continued,

...it gave us enough of a taste of what it would be like to be looking at a doctor and having the doctor say 'what would you like to do' would you like for me to go and try to do this...Or would you like for me to do this? And 'Eric' [infant's father] and I were like 'how in the heck do two people make that decision?' ...So that gave us enough of a taste to be forever thankful for the fact that it wasn't up to us...

The mother continued,

Like it had been made clear by the last [research facility] admission that there's nothing more that [research facility's] GI can do for us. ...Well, Dr. 'Red' had told us that back when we saw him in like late May he's like 'yeah I mean there's really nothing else that we have to offer.'

## **Consistency Among Teams**

As long as information was given by providers, some parents were unconcerned whose team the provider was on. Parents expressed their feelings of comfort with the health care providers after their infant was discharged, regardless of the information given. The father of an infant with extreme prematurity stated during his ten month interview when asked if he had been well-informed by the doctors,

Yeah they inform, they inform us. We've been part of the decision and ...and they let us in on anything that they're going to do or any test or anything that they're going to do. They inform us about it all.

The father of an infant with complex cardiac anomalies stated at the one year interview,

...when they [providers] talked to us they made sure we understood everything they said, they...they were like instead of using the book terms they come down to our terms we were understanding more. ...they were going to give us everything we needed,...

## **Comparison of Topics of Information Discussed by Providers with Parents of Infants with Extreme Prematurity and Infants with Complex Cardiac Anomalies After Discharge**

Providers offered information to parents of infants born extremely premature and infants with complex cardiac anomalies after discharge from the hospital which was either based on the provider's past experiences or based on research findings. Providers offered general information centering on the management of the infant's care that did not necessarily match the information given by another provider, such as when the

information given by a provider in isolation was compared with the information provided by a provider with evidence. Parents of infants with extreme prematurity and parents of infants with complex cardiac anomalies were comfortable with the information given whether from providers in isolation or providers with evidence.

### **Research Question 3**

From whom and from what outside resources did parents seek information following their infant's discharge from the hospital?

Parents continued to utilize a variety of outside resources when seeking information following their infant's discharge from the hospital. Specifically, the Internet, user groups, and email were mentioned. These resources have the option of being read over and over again since they are in print online, however most are the personal opinions of those who wrote them, also giving them a sense of personal connection, much like what one would hear in a conversation or in-person support. The subthemes of 'read' and 'heard' were noted again, however a bit differently. A subtheme of 'read and heard' was evident as was a subtheme of 'heard' alone. The overall theme of this research question was 'Help me Learn' as in Specific Aim 1, Research Question 3. The reasons for learning were different; however the resources utilized were the same.

### **Read and Heard**

The code 'Internet' was the most prominent code noted in analysis of transcripts for this research question. Typically the Internet lends itself to information that is read. Since the Internet was used by parents for activities such as blogging and user groups,

this information could also be considered 'heard' as both are the opinions of the one who wrote them, as would occur in a conversation one would hear. Thus, the subtheme 'read and heard' was created.

The parents of an infant with extreme prematurity used the Internet and the infant's health care providers. The mother noted during her nine month interview, "...so of course I had to go freak myself out, and start looking RSV online and..." The father commented during his one year interview,

...we asked around you know obviously Googled it and uh we looked it up on the Internet and asked um...you know some of our parent's friends who are doctors or whatever you know kind of what they thought and ..um..whether or not it would be best for him and in the end we decided I mean it helped too I'm sure,...

In the same interview the father offered,

...the neurosurgeon in particular like I emailed him a couple time he emailed me back that day...

The father of an infant with complex cardiac anomalies commented during his month six interview, "...we joined a Yahoo users group for kids with heterotaxy..." He continued later in the same interview, "In fact when you Google acupuncture and vomiting .' The mother of the same infant noted during her months four and five interview,

We made, I made the decision during a time, when I wasn't sleeping very well to go downstairs and get on the damn Google. And I started researching...

In the same interview, the mother continued,

...we should find out more about that. I mean even in going on the blogs like...you have to take blogs with a grain of salt but even and, there are not a lot of them out there and a lot of them are in Europe, ...

In the month six interview, the mother stated,

You know every time I get online and look at these blogs with these other kids who – with other families who have kids like ‘Caroline’...

The mother continued,

‘Aaron’ [infant’s father] got online the other night and he didn’t even tell me he was doing this but he actually hooked up with an online heterotaxy foundation – and I can report symptoms but when you have to start going online and getting in chat rooms with other moms and dads who are equally worried...

The parents of an infant with complex cardiac anomalies used online support groups, other parents with infants with complex cardiac anomalies, and Internet blogs.

The father when asked about resources used for information replied, “Yeah I joined a Yahoo users group for kids with heterotaxy. ...across the world, there’s only two hundred and fifty people on the site.” At his nine month interview, the father discussed helpful resources,

...And everybody [parents of other infants with complex cardiac anomalies] told us up front they’re like, ‘feeding is going to be a problem.’ And they were, they were right....Everybody says ‘well, they’re just slower’ or you know ‘my kid had the same thing yours did and it’s just taking him longer to eat, and crawl and, but now he’s just as normal as everybody else.’

The mother shared during her months four and five interview,

...we should find out more about that. I mean even in going on the blogs like...you have to take blogs with a grain of salt but even and, there are not a lot of them out there and a lot of them are in Europe, but...when you go on the parents, it's just interesting...

The same mother offered during her month six interview,

...we were worried about her falling behind. And you know every time I get online and look at these blogs with these other kids who – with other families who have kids like 'Caroline' you know the ones who get a feeding tube, they usually end up having it for years.

The mother reflected during her one year interview,

'Caroline's' first year sort of coincided with like um like this explosion of social media. And like now when you Google 'Caroline's' symptoms, you get hooked into a parent awareness group for heterotaxy kids and their parents and their feeding issues. I mean that just didn't exist when we had 'Caroline'.

The mother of an infant with complex cardiac anomalies offered during her final interview,

I mean then we talk about it a lot, it's I guess because we've got a better understanding of it now that we know more about it versus when we first were there whether we didn't know anything about it. But the research that the doctors gave us and the literature we found on Google you know? So we got to really research and ...

During the one year interview, the father of an infant with extreme prematurity noted, "...the neurosurgeon in particular like I emailed him a couple of times he emailed me back that day..."

## Heard

Parents of infants born extremely premature continued to utilize providers for information after their infant was discharged from the hospital. This fact is understandable since infants born with extreme prematurity remained hospitalized after birth much longer than infants born with complex cardiac anomalies. The subtheme 'heard' was given to this need for verbal communication between parents of infants who were born extremely premature and providers.

A social worker involved with an infant with extreme prematurity offered during the final interview,

Yeah, she'll [mother of the infant] call me like if she's coming, or if she needs help with something. And we were continuing to work on the transportation stuff because she was trying to drive her car, and her car didn't have air conditioning. And she wasn't sure if it was going to make it or not – she's riding with this medically fragile – she can dehydrate really easily so, they were just all. I was writing letters to Medicaid trying to get her transportation figured out.

An attending physician working with an infant with extreme prematurity noted during the one year interview,

I remember one night when she [infant's mother] actually paged – she would never page me in the middle of the night unless she was on her way to the ER – but she paged me one night at around nine thirty or ten o'clock. But she'd always page me through the hospital operator and give her name and call back number.

## **Comparison of Outside Resources Utilized by Parents of Infants with Extreme Prematurity and Infants with Complex Cardiac Anomalies After Discharge**

Resources used by parents of infants born extremely premature and infants with complex cardiac anomalies focused on the Internet after the infant was discharged home from the hospital. Both types of parents sought information from Internet sources such as blogs, user groups, and emailed information from providers. The information given by these resources were both ‘read and heard’ as noted by the value they placed in the resources. Parents of infants born extremely premature sought information from the providers, such as the social worker and the physician, even after discharge from the hospital. This notes their need for the subtheme ‘heard’ alone. No quotes from parents of infants with complex cardiac anomalies were noted regarding the use of providers as resources after discharge from the hospital.

### **Research Question 4**

What contextual variables were present which may have influenced information needs of parents following their infant’s discharge from the hospital?

The contextual variables present that may have influenced information needs of parents following their infant’s discharge from the hospital centered mainly on the effects of incorporating a chronically ill infant into the family. While one mother was concerned about keeping her job, the remaining comments were about difficulty with either the sibling or family as a whole adjusting to life with the infant after discharge. The overall theme of this research question was ‘Adjusting to Everyday Life’ indicating that all contextual variables dealt with incorporating the infant into the family’s daily routine

after discharge from the hospital. Since both infants born extremely premature and infants born with complex cardiac anomalies were likely to have long term complications after discharge, the special needs of the infant were likely to continue for several months to years. This fact posed changes to the family unit that was significant. No subthemes emerged from the transcript analysis.

### **Adjustment to Everyday Life**

After discharge from the hospital, the mother of an infant with extremely prematurity considers her job in reference to her infant's follow-up care appointments. She stated at the one year interview,

Well like I said my job I mean I don't want to lose it and everything like that. I mean trying to go back and forth to [city of research site] like I said if I could get a doctor close by I wouldn't have to worry so much because I won't have to take a whole day from 'Friendly' [location of work] I'd say about, if it's only about thirty-five minutes from here, and early that morning, I'd be back about half a day. It won't take us a whole day you see what I'm saying?

A distance barrier is noted as the mother has to take a day off from work in order to take the infant to receive follow-up care.

The older sisters of two infants had difficulty with their new role as big sister after the infant was discharged. The mother of an infant with complex cardiac anomaly stated during the seven month interview when asked how the infant's big sister, 2 years old, is doing with him, "Oh she's doing good she's letting him get his bottle and holding his

bottle up; she ain't beating up on him as much. Yeah she's calmed down. We 'bout got her broke of that now." The sibling's reaction was to seek the attention she used to receive from her parents before the infant's birth.

This sibling needed intervention, a professional counselor, after the infant was brought home from the hospital. The mother of a different infant with complex cardiac anomalies commented during her one year interview,

...because I think we would, we would not be living fully and fairly and I think that 'Myra' [the infant's older sister, 3-years-old] and 'Caroline' [the infant] and our marriage would all...feel the results of...if we didn't do the hard work to get back on track. And I think you know thankfully you know, one of the little blessings of 'Caroline' is I think we'll end up in a better place than we ever would have been in without the...the experience of having a 'Caroline' with you know major medical issues.

When asked if there were family issues that needed to be worked through as the result of having an infant with complex cardiac anomalies, the mother continued,

Yeah, I think we kind of knew it in theory and in the last month we've both been like 'oh this is what it looks like when it finally shows up' and I think that just kind of how life is - it's just - and there are lots of things that can um...can put you in a position where you have to do this kind of work. When we were in the mountains we were with my extended family and they lived through Katrina, and they live in Gulfport, Mississippi. And it was interesting how similar the...experiences were and the coping and the kids getting through that - what it meant and what it took and how to manage that trauma...just how you just kind of put life on hold and how you package that trauma for the children in your home. You know I can remember my, my um cousin saying that it was all in how we packaged it, we just acted you know like it was completely normal to be swimming in your living room [laughter]. You know, and - And she had also...um...had done a lot of reading on just how to manage trauma so that it's...um...it doesn't take over and get...I don't know kind of, guess managed proactively...

Later in the same interview, the mother offered,

...it's hard to say but from watching her [infant's older sister] and seeing how she manifests her anxiety and she doesn't understand it and she's having trouble putting, identifying what's causing her fears. And I'm like 'you know what that's really not unlike what 'Aaron' [the infant's father] and I have struggled with for the past year.' So you know here we are reading these books to learn about...how to help 'Myra' [the infant's older sister] through this and what we're learning is also immediately applicable to ourselves as well, so...

The infant's family structure was changed so dramatically that the adjustment needed was compared with a natural disaster. The sister's life was altered forever.

Marriages were also altered after the infant was discharged home from the hospital. The mother of an infant with extreme prematurity offered during her month ten interview, "We've been married for two years so through it all it's been hard but we're making it; we're supposed to um also do counseling, start doing counseling sessions. So hopefully that'll help too,..." Again, the addition of the new infant into the parent's everyday routine needed professional assistance to overcome.

### **Comparison of Contextual Variables of Infants Born Extremely Premature and Infants with Complex Cardiac Anomalies After Discharge**

Contextual variables related to the informational needs of parents with infants born extremely premature and infants born with complex cardiac anomalies had the overall theme of 'Adjustment to Everyday Life'. The mother of an infant born with extreme prematurity needed job security which was being hindered by taking time off from work to take the infant for follow-up care. This parent wanted management of the infant's chronic illnesses closer to home after discharge from the hospital. Parents of

another infant born extremely premature sought marriage counseling after their infant's discharge from the hospital, as a result of the infant's chronic illnesses. The infant's presence at home impacted the couple's bond.

Siblings of two infants born with complex cardiac anomalies had difficulty adjusting to the arrival of the infant in the home environment. They needed tools such as books and counseling to modify to the changes at home. Adjustment to everyday life was not an easy transition for families of infants born with extreme prematurity or parents of infants born with complex cardiac anomalies.

### **Summary of Specific Aim 2**

After infants were discharged from the hospital, parents of infants with extreme prematurity and of infants with complex cardiac anomalies both continued to seek information to note consistency of information or to find alternative explanations for the information given by providers regarding the management of their infant's care. Parents of infants with complex cardiac anomalies stated they were appreciative to not have providers offer options with regard to their infant's care management after discharge from the hospital. Parents of infants born with extreme prematurity sought specific information such as lab values, that the parents were used to hearing about during their infant's hospitalization. These parents stated that these concrete values provided comfort and understanding after discharge from the hospital. The overall theme 'What is going on with my baby's care?' was evident in the analysis of the transcripts. The subthemes 'Continuity of Care' and 'Alternatives to Care' summarized the general types of information sought.

Information given by providers after the infant's discharge was not specific and not necessarily in agreement with other providers who were part of the infant's care team, however parents continued to note they were comfortable with and understood the information given by providers after the infant was discharged from the hospital. The overall theme of 'Whose team are you on?' continued after discharge. The subthemes, however, were different after discharge and had evolved into 'providers in isolation' or 'providers with evidence' depending on what the provider saw as the basis of the information provided. 'Providers in isolation' noted past experiences or the way things were as their basis of information provided, while 'providers with evidence' talked to other providers or sought new evidence through literature and research. Both parents of infants born with extreme prematurity and parents of infants born with complex cardiac anomalies sought information from the Internet. Parents noted the use of blogs, user groups, and websites. The overall theme continued to be 'Help me Learn', however the subthemes changed a bit into 'read and heard' and 'heard'. All parents seemed to appreciate having information they could read on the Internet, however some sources, such as user groups, were the opinions of other parents as what one might hear in a conversation. Parents of infants born extremely premature sought information from providers after the infant's discharge from the hospital, though parents of infants born with complex cardiac anomalies did not.

Contextual variables presented themselves to parents after their infant was discharged from the hospital, such as the need to have the infant's follow-up care closer to home for employment reasons and the need for assistance in incorporating the

chronically ill infant into the home environment. The overall theme was ‘Adjusting to Everyday Life’ since all contextual variables noted after the infant’s discharge from the hospital were related to incorporating the chronically ill infant into the family. No subthemes were noted.

The researcher hypothesizes that parents of infants with extreme prematurity sought information more from providers and in person support systems than parents of infants with complex cardiac anomalies, possibly because the infants with extreme prematurity were hospitalized longer and had more time to form trusting relationships with providers. Also, since parents of infants with extreme prematurity did not know about their infant’s diagnosis long before the infant was born, they did not have prior information from other sources before the infant was born, whereas parents of infant with complex cardiac anomalies knew weeks or months before their infant was born and had the opportunity to research the infant’s condition.

### **Specific Aim 3**

To compare the information needs of parents of infants with life threatening conditions compared with information given by health care providers to the parents over time from hospitalization (time 1) to after discharge (time 2).

A comparison of themes and subthemes from Specific Aims 1 and 2 is presented in Table 10. Each research question is presented in the left, the themes in the middle, and the subthemes from Specific Aim 1 on the right and Specific Aim 2 on the left. This format is offered for easy comparison as needed to answer research questions to Specific Aim 3.

Table 10. Specific Aims 1 and 2 – Themes and Subthemes

<b>Research Questions</b>	<b>Subthemes from Specific Aim One</b>	<b>Themes</b>	<b>Subthemes from Specific Aim Two</b>
One	Consistency of Information	What is going on with my baby’s care?	Continuity of Care
	Common Understanding		Alternatives to Care
Two	Providers with Providers	Whose team are you on?	Providers in Isolation
	Providers with Parents		
	Consistency among Teams		Providers with Evidence
Three	Read	Help me learn.	Read and Heard
	Heard		Heard
Four	Issues before the birth of the infant		Adjusting to everyday life

**Research Question 1**

What topics (categories) of information were sought by parents during their infant’s hospitalization compared to the information parents sought after discharge?

The overall theme that emerged from analysis of transcripts for parents of infants born with extreme prematurity and infants born with complex cardiac anomalies regarding the topics of information sought by parents during hospitalization compared to after the infant’s discharge was ‘What is going on with my baby’s care?’. Subthemes during hospitalization included ‘consistency of information’ and ‘common understanding’. Recall that during hospitalization parents wanted to know if the information being given to them by health care providers was accurate. Parents also looked for alternative explanations, primarily on the Internet. After discharge from the

hospital, subthemes were ‘continuity of care’, ‘alternative treatments’, and ‘common understanding’. Parents sought information regarding treatment of their infant’s chronic symptoms or their chronic disease management, again mostly using the Internet. Consistency of information seemed to mean parents wanted to know if more than one resource stated the same thing, however continuity of care seemed to mean parents wanted their infant’s care to center on the same goal, even when the providers were different. The main difference between hospitalization and discharge informational needs was that after discharge, one set of parents sought alternative treatments to supplement their infant’s care. Parents may have sought alternatives treatments to manage their infant’s symptoms because after discharge, parent took over the role of managing their infant’s care, whereas in the hospital, a case manager coordinated their infant’s care.

### **Comparison of the Topics of Information Sought by Parents of Infants with Extreme Prematurity and Infants with Complex Cardiac Anomalies During Hospitalization with After Discharge**

The parents of extremely premature infants sought specific information topics related to prematurity instead of general categories of information, such as potential complications of being born prior to 26 weeks gestation. Parents of infants with complex cardiac anomalies sought to confirm the information received by providers about their infant’s treatment course. The parents asked very specific questions, particularly prior to discharge, regarding the infant’s care needs after hospitalization. Family conferences, particularly among parents of infants with complex cardiac anomalies, and the Internet

were utilized for information seeking. Parents were looking for consistent information among providers and between the providers and other resources, such as the Internet.

The information sought by parents following their infant's discharge from the hospital was more specific in content compared to the more general information sought by parents while the infant was hospitalized. This difference was consistent between parents of infants with extreme prematurity and parents of infants with complex cardiac anomalies. Parents of infants with complex cardiac anomalies sought information regarding alternative treatments or management of the infant's chronic conditions. Parents of infants with extreme prematurity sought information about their infant to assist them in maintaining emotional comfort or stability related to their infant's overall condition, such as knowledge of their infant's lab work as in the hospital.

### **Research Question 2**

What topics (categories) of information were discussed by health care providers with parents during their infant's hospitalization compared to information discussed by the health care provider after their infant's discharge from the hospital?

The topics of information discussed by health care providers with parents during their infant's hospitalization compared to information discussed by health care providers after their infant's discharge from the hospital were different. The overall theme, however, was the same, 'Whose Team are you on?' During hospitalization, health care providers talked with parents about treatment options such as surgeries and medications and potential complications. The subthemes were the two teams which emerged from transcript analysis, 'providers with providers' and 'providers with parents'. After

hospitalization, health care providers discussed monitoring of their infant's condition and care of the infant's special needs. The two teams, or subthemes, that were evident after discharge were 'providers in isolation' and 'providers with evidence'. The subtheme 'providers with providers' noted during hospitalization mirrored the subtheme 'providers in isolation' noted after the infant's discharge from the hospital. Providers worked with other providers in the work environment or hospital and providers worked in isolation or alone during the infant's follow-up care. The subtheme 'providers with parents' noted during the infant's hospitalization could be viewed similarly to the subtheme 'providers with evidence' after the infant's discharge from the hospital. Providers worked with parents in planning the infant's care during hospitalization and researched the best way to offer care to the infant after discharge. The primary difference noted was the location of the infant, hospitalized or discharged to the home environment, when determining whose team the physician was on.

### **Comparison of Topics of Information Discussed by Providers with Parents of Infants with Extreme Prematurity and Infants with Complex Cardiac Anomalies During Hospitalization with After Discharge**

The topics of information discussed by health care providers with parents during their infant's hospitalization were similar despite the infant's reason for hospitalization. Both infants with extreme prematurity and infants with complex cardiac anomalies required medications and surgeries as well as had the potential for long-term complications, and required preparation for caring for the infant at home. The only difference found in information given by providers was found between providers

themselves. As found, providers had varying beliefs regarding the level of information parents should receive and how much they should be involved in the infant's treatment plan. Therefore, no differences were found between infants with extreme prematurity and infants with complex cardiac anomalies regarding information given by providers to parents during hospitalization.

Information given by providers to parents of infants born extremely premature and infants with complex cardiac anomalies after discharge from the hospital was inconsistent. Providers offered general information centering on the management of the infant's care that did not necessarily match the information given by another provider. One parent of an infant with complex cardiac anomaly noted gratitude for not having options presented regarding the infant's treatment while hospitalized, just the facts of what needed to be done to aid the infant, such as surgery. Parents of infants with extreme prematurity and parents of infants with complex cardiac anomalies stated that they understood the information provided and it provided them comfort.

### **Research Question 3**

From whom and from what outside resources did parents seek information during their infant's hospitalization compared to the information sought and outside resources used after their infant's discharge from the hospital?

Outside resources utilized by parents when seeking information during their infant's hospitalization compared to those used by parents after the infant's discharge from the hospital were similar. The overall theme of 'Help me Learn' was evident during analysis of transcripts for both time points. During hospitalization, parents sought

information from books and magazines, support groups, and the Internet. The subthemes of ‘read’ and ‘heard’ emerged as the Internet and books and magazines were resources that were read and family conferences and support groups were resources that were heard. After discharge, parents made use of online parent support groups, providers, and the Internet. The subthemes of ‘read and heard’ and ‘heard’ were evident, separating Internet resources, read and heard, clearly from providers, heard. A noted difference was the use of family conferences during hospitalization which were not available after the infant’s discharge. The Internet remained the primary source used for information seeking by parents during and after their infant’s hospitalization. At both time points, parents noted any information given by providers was better than no information given by providers.

### **Comparison of Outside Resources Utilized by Parents of Infants with Extreme Prematurity and Infants with Complex Cardiac Anomalies During Hospitalization and After Discharge**

Outside resources utilized by parents of infants with extreme prematurity during the infant’s hospitalization were primarily books, providers, and their support system. Parents of infants with complex cardiac anomalies noted use of the Internet and Internet-based resources during their infant’s hospitalization. Potential reasons for this may be the fact that infants with extreme prematurity were hospitalized longer than infants with complex cardiac anomalies. Parents of infants with complex cardiac anomalies also knew of their infant’s diagnoses for a longer period of time than parents of infants with extreme prematurity, giving them longer to seek out resources prior to the infant’s birth.

Resources used by parents of infants born extremely premature and infants with complex cardiac anomalies after the infant's discharge from the hospital focused on the Internet after the infant was discharged home from the hospital. Both types of parents sought information from Internet sources such as blogs, user groups, and emailed information from providers. The information given by these resources were presented as the parent's support systems by the value they placed in the resources. Parents of infants born extremely premature sought information from the providers, such as the social worker and the physician, even after discharge from the hospital. No quotes from parents of infants with complex cardiac anomalies were noted regarding the use of providers as resources after discharge from the hospital.

#### **Research Question 4**

What contextual variables were present which may have influenced information needs of parents during their infant's hospitalization compared to the contextual variables present after their infant's discharge from the hospital?

Contextual variables that may have influenced information needs of parents during their infant's hospitalization compared to those after the infant's discharge from the hospital were altered by the infant's location. During the infant's hospitalization, contextual variables included the influence of the birth of a previous infant with life threatening illnesses. Social issues such as the mother's current significant other not being the father of the baby and the primary caregiver of the infant after discharge not

speaking English were factors. Also, the distance an infant lived from a care facility was mentioned. The overall theme of 'Issues before the Infant's Birth' was evident in analysis of transcripts during the infant's hospitalization.

After discharge, contextual variables focused on the infant being at home, requiring special care, and impacting the family. Siblings were having a difficult time adjusting to the infant's presence in their life. One couple was also seeking counseling as the infant's special needs continued. All of these things impacted the parent's information needs both during hospitalization and after discharge. The overall theme of 'Adjustment to Everyday Life' emerged from analysis of transcripts after the infant's discharge home from the hospital.

Mainly, contextual variables were categorized as the parent's life before the infant's birth and after the infant's discharge home from the hospital. Adding a new member to a family takes time and flexibility. When the new addition is chronically ill, this adaptation takes more adjustment from all family members, including siblings.

### **Comparison of Contextual Variables of Infants Born Extremely Premature and Infants with Complex Cardiac Anomalies During Hospitalization and After Discharge**

As contextual variables were random, no pattern was noted in the study findings regarding differences between infants with extreme prematurity and infants with complex cardiac anomalies. The researcher, however, did identify potential contextual variables. The infants who were born extremely premature were hospitalized for four, six, and eight months whereas the infants who with complex cardiac anomalies were hospitalized for

one month and four months. Infants with extreme prematurity provided more information for specific aim one than infants with complex cardiac anomalies, who provided more information for Specific Aim 2.

A second potential variable noted by the researcher was the time frame of diagnosis prenatally. Parents of infants born extremely premature were told by providers hours or days before the infant's birth, as prediction of premature birth is not possible. Parents of infants with complex cardiac anomalies were told by health care providers months before the infant's birth as the infant's anomalies were noted on prenatal ultrasound. This allowed parents of infants with complex cardiac anomalies a longer time frame to ask questions and research their infant's condition prior to birth.

### **Summary of Specific Aim 3**

While the infants were hospitalized, parents of infants with extreme prematurity and of infants with complex cardiac anomalies both sought information to confirm or provide an alternate explanation for the information given by providers. The overall theme of 'What is going on with my baby's care?' with subthemes of 'consistency of information' and 'common understanding' were evident in the analysis of transcripts. After infants were discharged from the hospital, parents of infants with extreme prematurity and of infants with complex cardiac anomalies both continued to seek information for the same reasons. While the overall theme remained the same, the subthemes evolved after the infant's discharge from the hospital to 'continuity of care' and 'alternatives to care'. During hospitalization, a case manager was in charge of coordinating the infant's care whereas after the infant was discharged from the hospital,

the parents took on the role of coordinating their infant's care. This led parents to search for continuity after discharge instead of consistency and for alternative treatments instead of common understanding.

Providers differed in the information given to parents during their infant's hospitalization, based on the provider's personal beliefs about the parent's level of involvement in their infant's treatment plan. The overall theme of 'Whose Team are you on?' was evident in the analysis of transcripts. Some providers offered just facts about the treatment plan, which was the basis for the subtheme 'providers with providers'. Other providers offered options and alternatives to parents, thus the subtheme 'providers with parents' was apparent. After discharge, the overall theme remained the same, however the subthemes changed. The subtheme 'providers in isolation' emerged from the transcripts for providers who based the information they gave parents on previous knowledge. Providers who based the information they gave parents off of research were given the subtheme 'providers with evidence'. Parents claimed they were comfortable with and understood their infant's condition, regardless of the information provided.

Outside resources most frequently cited by parents of infants with extreme prematurity were books, providers, and their support system, while parents of infants with complex cardiac anomalies noted the Internet as a resource during their infant's hospitalization. The overall theme of 'Help me Learn' was evident during analysis of transcripts. Subthemes were 'read', which grouped outside resources such as books, magazines, and the Internet, while outside resources such as support groups and family conferences were grouped together for the subtheme 'heard'. Parents of infants with

extreme prematurity primarily sought information from books, magazines, and from their support systems more frequently than other outside resources, while infants with complex cardiac anomalies mainly cited the use of the Internet during their infant's hospitalization. After the infant's discharge from the hospital, the overall theme continued. Parents of infants born extremely premature noted providers as an outside resource after the infant's discharge from the hospital, as noted in the subtheme 'heard', whereas parents of infants born with complex cardiac anomalies did not. All parents noted use of the Internet as an outside resource after their infant's discharge from the hospital. Blogs and user groups were noted as resources that were read, but contained opinions and personal views, such as those heard in conversations. Thus the subtheme 'read and heard' was evident.

Parents noted contextual variables while their infant was hospitalized that may have altered their informational needs. The overall theme of 'Issues Before the Infant's Birth' was given to contextual variables noted during the infant's hospitalization as all contextual variables were in place and impacting the family prior to the infant's birth. After the infant was discharged from the hospital, contextual variables were given the overall theme of 'Adjustment to Everyday Life'. All contextual variables were the result of incorporating the chronically ill infant into the family. The researcher considered two possible contextual variables that may have influenced the information needs of parents while their infant was hospitalized: the infant's length of hospitalization and the length of time parents knew about their infant's diagnoses prior to birth. The researcher hypothesizes that parents of infants with extreme prematurity sought information more from providers and in person support systems than parents of infants with complex

cardiac anomalies, possibly because the infants with extreme prematurity were hospitalized longer and had more time to form trusting relationships with providers. Also, since parents of infants with extreme prematurity did not know about their infant's diagnosis long before the infant was born, they did not have prior information from other sources before the infant was born, whereas parents of infant with complex cardiac anomalies knew weeks or months before their infant was born and had the opportunity to research the infant's condition.

### **Conclusion**

The study findings presented here are broken down by specific aim and research question. The results compare the informational need of parents of infants with extreme prematurity to those of parents of infants with complex cardiac anomalies. The findings of this study have the potential to impact the care of these populations in the future. A discussion of these findings is presented in the next chapter.

## **CHAPTER V**

### **DISCUSSION**

#### **Introduction**

This chapter provides an overview of the study, a brief summary of the findings, and focuses on the discussion of these findings. The results of the study are compared to current research and evidence-based practice about the information needs of parents in the studied populations. Further research will be needed to continue to enhance learning of parents who have infants with chronic illnesses due to being born extremely premature or with complex cardiac anomalies.

#### **Summary of the Study**

The purpose of this study was to compare the parental information needs and sources of information for parents of infants with complex life-threatening illnesses while the infant is hospitalized and after the infant's discharge. Assessing information and learning needs of parents of infants in the ICU environment is an essential component of caring for these infants. Determining the information needs and learning preferences of parents of infants with life threatening conditions during the infant's hospitalization and after discharge could positively impact infant morbidity in this population.

#### **Overview of the Problem**

Infant morbidity and mortality continues to be a significant problem in the U. S. despite attempts to lower these rates. Preterm birth and/or low birth weight and

congenital anomalies are primary causes of infant morbidity and mortality. These infants are often admitted to the ICU for treatment, monitored growth, feeding, and regulation. Researchers have shown links between high levels of maternal knowledge and low infant morbidity. Providing relevant education to mothers who have infants in the ICU may lead to lower infant morbidity rates. The principles of Knowles' Theory of Adult Learning can play a role in increasing maternal knowledge by allowing the nurse to individualize education according to the parent's needs.

### **Methodology**

This study was descriptive in nature using data from a prospective longitudinal, case based, mixed-method research study. Systematic review of the parent and provider interview transcripts from six cases and nurse-kept Interdisciplinary Patient and Family Education Records was conducted to determine parent education needs and provider given information during and after the infant's hospitalization.

### **Use of Knowles' Theory of Adult Learning in this Study**

Instruction about home care for infants with life threatening illnesses must be done while the infant is still hospitalized. Due to this fact, nurses must predict what education parents will need prior to discharge of the infant. Once the parents are at home with the infant, the parents may discover additional information that they need in order to care for their infant. Using Knowles' Theory of Adult Learning, the information parents received and the provider's method of instruction during hospitalization were reviewed and compared against the parent's information needs and preferred method of instruction after the infant was discharged. Information gained by this comparison will assist nurses

to better instruct parents of infants with life threatening conditions in the future, both while the infant is hospitalized and after discharge. See Appendix B for a model of Knowles' theory as it pertains to ICU parents.

## **Major Findings and Discussion**

### **Information Seeking Needs of Parents**

As parents of infants in the ICU adjust to parenthood, they often require guidance and teaching to learn about their infant's specific needs (Heermann, Wilson, & Wilhelm, 2005). Parents need support and information about treatments the infant is receiving and they need teaching to be individualized to their infant (Cleveland, 2008; Mundy, 2010; Sargent, 2009). This study found that while infants were hospitalized, parents of infants with extreme prematurity and of infants with complex cardiac anomalies both sought information to confirm or provide an alternate explanation for the information given by providers. The overall theme of 'What is going on with my baby's care?' with subthemes of 'consistency of information' and 'common understanding' were evident in the analysis of transcripts. After infants were discharged from the hospital, parents of infants with extreme prematurity and of infants with complex cardiac anomalies both continued to seek information for the same reasons. While the overall theme remained the same, the subthemes evident after the infant's discharge from the hospital were 'continuity of care' and 'alternatives to care'. During hospitalization, a case manager was in charge of coordinating the infant's care whereas after the infant was discharged from the hospital,

the parents took on the role of coordinating their infant's care. This led parents to search for continuity after discharge instead of consistency and for alternative treatments instead of common understanding.

The researcher was interested by the finding that parents sought information in order to advocate for their infant, almost as a form of protection. Parents did not know about their infant's condition or course of treatment and therefore explored this information. Being able to protect their infant by asking the provider questions also seemed to give the parent a sense of control over the ICU experience. Empowering parents and allowing them to take part in their infant's care was one reason behind the concept of family-centered care (Dokken & Ahmann, 2006; Dokken, Simms, Cole, & Ahmann, 2007; Gooding, Cooper, Blaine, Franck, Howse, & Berns, 2011). Advocate is one role of the parent as outlined in family-centered care. Parents can advocate for their infants through being a member of a unit based committee and assisting with provider education about parent issues such as communication (Dokken & Ahmann, 2006; Dokken, Simms, Cole, & Ahmann, 2007; Gooding, Cooper, Blaine, Franck, Howse, & Berns, 2011 ). Opportunities such as this may aid parents in feeling a sense of control while their infant is hospitalized and may offer providers a different point of view related to the infant's plan of care, even after the infant is discharged from the hospital. Offering parents the chance to help should be considered by providers in the ICU.

After their infant's discharge from the hospital, parents were being forced to take on additional roles for their infant aside from just being a parent. The parents had to also give medications, watch for signs and symptoms, and coordinate their infant's follow-up

care to help keep all providers working toward the same goal. During the infant's hospitalization, providers work toward helping parents to learn to care for their infant's basic needs, such as diaper changing and feeding, and their individual needs, like how to give medication and when to call the provider when the infant needs assistance. Providers do not teach parents about the need for coordinating their infant's care, much less how to do it.

Providers give education to parents of infants in the ICU environment based on their educational needs, or the needs of the parent as perceived by the provider. These needs are not necessarily the learning needs of the parent, or by definition, the parent's perceived learning needs. The study did not note if the parent's learning needs matched the provider's known educational needs. Therefore, there may have been a gap between the information given by providers or educational needs and the needs of the parent or their learning needs.

The ICU environment is different from that of the general nursery. Parents often respond to the ICU environment by reporting increased stress and anxiety levels (Erdem, 2010; Feeley, et al., 2007; Melnyk, et al., 2001; Turan, et al., 2008). A mother of an infant with complex cardiac anomalies likened having an infant in the ICU to being displaced by hurricane Katrina. The level of trauma experienced by the storm and the required adaptation to the new environment were noted as surprisingly similar. The stress and anxiety forced the parents to react by wanting to know about their infant. Even though parents were under a great deal of stress and anxiety while their infant was in the ICU, the desire to learn was present. This reflects Knowles' fourth principle of learning.

According to Knowles' fourth principle of adult learning, adults become ready to learn when a life situation presents a need to learn (Knowles, 2011). Having a child born with extreme prematurity or with complex cardiac anomalies is such a life situations. Parents look for information related to their infant's changing needs and condition, asking 'What is going on with my infant's care?' Parenting roles not taught during the infant's hospitalization were a topic parents needed to seek information about.

Knowles' fourth principle of adult learning also notes that adults cannot be forced or made to learn if they are not ready. Appropriate evaluation of the parent's readiness to learn has not been thoroughly evaluated. This study demonstrated that the majority of parents displayed readiness to learn by asking the provider questions. The number of questions or the topic of the questions asked by parents during hospitalization was not noted by the educator as part of the Interdisciplinary Parent Education Record and was not part of the interview data available for analysis.

### **Information Giving Patterns of Providers**

The relationship which develops between the parent of an infant in the ICU and the nurse caring for that infant is important (Fegran, Fagermoen, & Helseth, 2008; Kavanaugh, Moro, & Savage, 2010). The more a parent knows about the infant's condition and is able to provide direct care for the infant, the less stress a mother reports and the closer to the infant the parent reports feeling (Aagaard & Hall; Wigert, et al.).

This study found that providers differed in the information given to parents during their infant's hospitalization, based on the provider's personal beliefs about the parent's level of involvement in their infant's treatment plan. The overall theme of 'Whose Team

are you on?’ was evident in the analysis of transcripts. Some providers offered just facts about the treatment plan, which was the basis for the subtheme ‘providers with providers’. Other providers offered options and alternatives to parents, thus the subtheme ‘providers with parents’ was apparent. After the infant’s discharge, the overall theme remained the same, however the subthemes changed. The subtheme ‘providers in isolation’ described providers who based the information they gave parents on previous knowledge. Providers who based the information they gave parents on research fit the subtheme ‘providers with evidence’. Parents claimed they were comfortable with and understood their infant’s condition, regardless of the type of information provided. This supports the fact that open communication between the providers and the infant’s parents assists in allowing parents to feel like active participants in their infant’s care (Gephart & McGrath, 2012). If standardized education was given to all patients and reviewed with them routinely, consistent education offered to patients would be increased. Providers often do not understand the importance of reviewing materials with patients verbally instead of giving the information to the patient to read themselves. While reviewing printed materials with patients may take more time for the provider, presenting consistent information to all patients may save time when the patients have questions for the provider later.

Interestingly, the researcher noted providers seemingly wanted to feel in control over the infant’s condition by determining which pieces of information to share with the parent instead of offering as much information as the provider knew or the parent requested. The infant belongs to the parents, not the providers. The infant’s plan of care

is important to share with parents as the plan of care keeps providers working toward the same goal. Studies of providers of adult cancer patients noted that providers feel that the more information they share with the patient, the more hope the patient has about their condition (Gordon & Daugherty, 2003; Sardell & Trierweiler, 1993). Providers may feel the need to control the patient's hope, particularly in cases where the outcome is unpredictable, thus keeping their expectations realistic (Gordon & Daugherty; Sardell & Trierweiler, 1993). Conversely, another study showed that patients who collaborate with providers to plan care on medical/surgical units often have an increased length of stay, however a smaller chance of subsequent admission after discharge from the hospital (Tschannen & Kalisch, 2009).

Infants born with extreme prematurity remained hospitalized longer than infants born with complex cardiac anomalies, allowing parents to form a stronger attachment to providers. Parents of infants born with complex cardiac anomalies knew of their infant's diagnosis prior to birth and had time to seek information from multiple outside resources, primarily Internet based, such as websites, user groups, and blogs. Parental adaptation to their infant's diagnosis has been linked to the parent's cultural background, support system, and the attitude of the provider during presentation of the diagnosis, such as the provider's willingness to answer parent's questions (Choi, Lee, & Yoo, 2011). No literature was found relating timing of diagnosis to type of information seeking patterns by patients. Therefore, research is needed to determine if the timing of diagnosis alters patient's information seeking patterns. This information could influence the timing of patient education by providers.

After learning of their infant's diagnosis, whether before birth or right after birth, many parents sought information related to the diagnosis on the Internet. When parents of infants born with complex cardiac anomalies searched for information, they were able to look for detailed information, such as their infant's specific cardiac anomalies, which provided exact information. When parents of infants born extremely premature searched the Internet, they were only able to find general information, such as potential complications of being born prematurely. Thus, parents of infants born with complex cardiac anomalies may have found information from the Internet more helpful in assisting them to understand about their infant than did parents of infants born extremely premature. This may have led to the fact that parents of infants born with complex cardiac anomalies utilized the Internet for information consistently throughout their infant's illness and not just after discharge from the hospital.

When an infant who needs the skills of the ICU is born, the parents do not get to select who their providers are going to be as the provider becomes whoever is on call at the time of the infant's birth. Parents do not get to ask them their beliefs or values when the baby is born, they must simply trust their fragile infant to the provider(s) who come to help the infant during a critical time. This means that parents do not have any say in whose team their infant's provider is on during the infant's hospitalization. While evidence of adults who require intensive care unit treatments experiencing stress was documented, no evidence was found regarding the source of the stress coming from lack of provider selection (Stayt, 2009). After discharge, most parents seek follow-up care from the provider the infant is referred to by the providers in the ICU. While the parents

may have chosen a follow-up provider for their infant, if the infant is born with extreme prematurity or born with complex cardiac anomalies, the provider the parents chose for follow-up care may not have the knowledge or capability to care for the infant. None of the parents singled out nurses as the primary provider from whom information was requested. Since nurses are the provider at the infant's bedside the most, information seeking from nurses may have been a natural occurrence, however no parent specifically mentioned this.

The second principle of adult learning by Knowles (2011), states that adults have a deep need to be self-directed. Since parents are unable to select their provider or the manner in which information is given to them by a provider, this principle is not being considered or utilized in patient education. Parents, as adult learners, want to be in control of their learning and providers who are on teams with other providers or who are in isolation do not allow the parent control over their learning. Reliable resources should be given to parents, such as websites, books, and support groups, thereby allowing parents to choose their method of education when they are ready to learn.

A parent's readiness to learn was noted by the educator on the Interdisciplinary Parent Education Record prior to providing information in the ICU environment. The majority of parent readiness was indicated by the fact the parents asked the provider a question. The information did not indicate the types of questions asked by parents or the number of questions asked, such as focusing on one or more topics, was not noted.

Knowles' first principle of adult learning is also reflected here: adults have a need to know why they should learn something. By asking questions, parents are expressing their need to know information.

At the facility where the CTLC study was conducted, infants born with complex cardiac anomalies were transferred to the pediatric cardiac intensive care unit, while infants born extremely premature were transferred to the neonatal intensive care unit. The fact that these populations were not taken to the same unit after birth to receive care may have contributed to the fact that parents of infants born with complex cardiac anomalies did not contact providers directly after their infant was discharged from the hospital while parents of infants born extremely premature did. This difference may be contributed to the infant's context of care

### **Outside Resources Accessed by Parents**

This study found that the outside resources most frequently cited by parents of infants with extreme prematurity were books, providers, and their support system, while parents of infants with complex cardiac anomalies used the Internet during their infant's hospitalization. The overall theme of 'Help me Learn' was evident during analysis of transcripts. Subthemes were 'read' and 'heard'. 'Read' included outside resources such as books, magazines, and the Internet, while 'heard' included outside resources such as support groups and family conferences. After the infant's discharge from the hospital, the overall theme continued. Parents of infants born extremely premature noted providers as an outside resource after the infant's discharge from the hospital, as noted in the subtheme 'heard', whereas parents of infants born with complex cardiac anomalies did

not. All parents noted use of the Internet as an outside resource after their infant's discharge from the hospital. Blogs and user groups were noted as resources that were read, but contained opinions and personal views, such as those heard in conversations, creating the subtheme 'read and heard'. This supports the idea of presenting patient information in more than one format (Henson, 2000). Establishing effective two-way communication between the patient and provider can be difficult given the hospital setting, emotions of the patient, and the variety of health care providers. Therefore having information available in more than one format, such as in both written and audio format may be beneficial to the patient (Henson, 2000).

This study showed evidence that parents of infants born with extreme prematurity formed a bond with providers during their infant's hospitalization that apparently either did not have the time to form or was not offered by providers caring for infants born with complex cardiac anomalies. This was demonstrated by the fact that parents of infants with born with extreme prematurity sought information from providers after the infant was discharged from the hospital, whereas parents of infants born with complex cardiac anomalies did not. Parents of infants born with complex cardiac anomalies consistently utilized the Internet in some form as their primary outside resource for information.

These parents knew of their infant's cardiac diagnoses weeks or months before the infant was born. This fact also gave parents of infants born with complex cardiac anomalies time to search on the Internet for information prior to their infant's birth. Since providers were the first source of information about the infant for parents of infants born with extreme prematurity and the Internet was the first resource for parents of infants born

with complex cardiac anomalies after the initial diagnosis, parents may just be more comfortable and/or confident with the source of information utilized first. Recall that studies have been performed evaluating the effectiveness of the Internet education during pregnancy to access information about their infant, demonstrating that parents may utilize the Internet early on in their pregnancy (Lagan, Sinclair, & Kernohan, 2010). Also, parent's use of the Internet as a supplement to other forms of education during their third trimester of pregnancy was studied, indicating parental use of the Internet for education prior to their infant's birth (Kuo, Chen, Lin, Lee, & Hsu, 2009). Retrospective studies have not been performed to note whether or not parents of infants born extremely premature or parents of infants born with complex cardiac anomalies utilized the Internet prenatally prior to knowing their infant's diagnosis. Further research is needed to replicate studies of term infant populations on infants requiring care in the ICU.

Adults enter into a learning experience with a task-centered orientation, which is Knowles' fifth learning principle. When parents of infants born with extreme prematurity or with complex cardiac anomalies needed information, they turned toward trusted outside resources. Parents had one goal in mind, to get information in order to better understand their infant's condition both during hospitalization and after their infant's discharge from the hospital. Parents needed information during hospitalization to clarify information given by providers and after discharge from the hospital to better know when to seek follow-up care for their infant. These were the tasks parents needed to complete

and thus the focus of their educational needs. The first principle of Knowles' adult learning theory is also reflected here: adults have a need to know why they should learn something. The parent's 'need to know' was their task.

### **Contextual Influences**

Analysis of the data highlighted noted contextual variables that may have altered parent's information needs. Contextual variables noted during the infant's hospitalization were in place and impacting the family prior to the infant's birth, resulting in the overall theme of 'Issues Before the Infant's Birth'. These contextual variables were present from the time of the infant's admission to the NICU. After the infant was discharged from the hospital, contextual variables were given the overall theme of 'Adjustment to Everyday Life'. Contextual variables at this point were the result of incorporating the chronically ill infant into the family.

The researcher considered two possible contextual variables that may have influenced the information needs of parents while their infant was hospitalized: the infant's length of hospitalization and the length of time parents knew about their infant's diagnoses prior to birth. The researcher hypothesizes that parents of infants with extreme prematurity sought information more from providers and in-person support systems than parents of infants with complex cardiac anomalies did, possibly because the infants with extreme prematurity were hospitalized longer and had more time to form trusting relationships with providers. Also, since parents of infants with extreme prematurity did not know about their infant's diagnosis long before the infant was born, they did not have prior information from other sources before the infant was born, whereas parents of infant

with complex cardiac anomalies knew weeks or months before their infant was born and had the opportunity to research the infant's condition. No research could be found to confirm this relationship, therefore, research studies are needed to determine if an infant's length of stay in the ICU or length of time from knowledge of the diagnosis to the infant's delivery does influence the informational needs of parents.

Prior to providing education in the ICU, the educator documented the parent's potential barriers to learning on the Interdisciplinary Parent Education Record. The primary barrier recorded by the educator was emotional. In the space provided where the educator could elaborate on the barrier to learning, the only details given were 'anxious' and 'appropriate reaction to NICU environment'. These perceived learning barriers are similar to the contextual variables noted in the study as the contextual variables were also potential alterations in the parent's learning needs. As noted earlier, stress and anxiety alter how an adult learns. While literature exists to assist providers in evaluating patient's readiness for discharge (Bobay, Jerofke, Weiss, & Yakusheva, 2010; Lerret, 2009), no literature was found about providers evaluating patient's readiness to learn. Provider evaluation of children diagnosed with type one diabetes for readiness for self-care management was found (Kelo, Martikainen, & Eriksson, 2011). The study noted that children must express readiness to learn themselves, such as by asking questions and requesting to learn, and that each child will express readiness individually depending on their developmental level. Further research is needed in order to better understand a patient's readiness to learn as the study by Kelo, Martikainen, & Eriksson (2011) was the only one found concerning parents of infants with chronic illnesses.

This study leads the researcher to believe that the choices a parent makes before birth related to issues such as their significant other and their employment as well as the parent's history, such as other pregnancies or births, have the potential to impact infants when they are born. Parents do not often consider the future, particularly related to their future child, when making decisions in life. Also, bringing a new member into a family impacts all members of the family to some degree (Lee, Lin, Huang, Hsu, & Bartlett, 2009; Olshtain-Mann & Auslander, 2008). Incorporating an infant into a family is traditionally an adjustment the family looks forward to and prepares for before the infant's birth. When an infant is born extremely premature or with complex cardiac anomalies, the family has a larger adjustment to make and may not have much notice before the infant's birth as compared with infants who are born full term (Lee, Lin, Huang, Hsu, & Bartlett, 2009; Olshtain-Mann & Auslander, 2008).

Knowles' third principle of adult learning states that adults have a greater volume and higher quality of experiences than children (Knowles, 2011). Parent's past knowledge and choices help form the role the parent assumes. Thus, the parent brings past experiences into the child's life that may have influenced the parent's informational needs, such as knowing how to change an infant's diaper due to the fact the parent has a younger sibling. The educator needs to consider the contextual variables of the patient when providing education. Knowledge of contextual variables can aid the educator in building on the patient's current knowledge, therefore making learning easier for the patient.

## **Limitations**

Limitations to CLTC include the fact that the study was conducted at one facility. Though some infants were transferred from other tertiary facilities, this restricted the available sampled population. The same interviewer was not necessarily available to collect all data with an individual on a case study. Rapport, or lack thereof, may have compromised willingness to divulge all information from providers and parents.

Drawbacks to case study methodology include the large amount of data that comes from following one case (Payne, 2007). For example, after the parent gets to know the researcher, the parent may only decide to give the data he/she knows the researcher is looking for versus the entire story. This method also is only generalizable to similar populations in geographically similar locations and facilities (Payne, 2007).

Lastly, the fact that analysis of existing data was used limited the researcher to previously collected data. The researcher was not able to ask additional questions of the parents as the chosen sample was of completed cases. Interviews and Interdisciplinary Patient and Family Education Records available for analysis were not completed with the research questions of this study in mind, so information was extrapolated from interviews and other data as a whole.

## **Conclusion**

The findings of this study lead to potential generalization to other populations and concepts. Parents wanted consistent information in terms they could understand related

to the status or condition of their infant. While this is true for parents of infants who require treatment in the ICU, this finding may hold true for all parents, regardless of their infant's condition.

Providers determine the type and amount of information offered to parents about their infant in the ICU. This reflects upon the provider's education and personal beliefs about caregiving, both of which are diverse. Standardized written hospital created information used to educate patients in certain areas of the hospital, such as a medical unit, has limited the amount of disease specific and management information given by providers verbally. The provider reviews the standard information with the client and then leaves the handout with the adult client. While this type of education does not individualize education to the specific client, handouts do standardize the depth and quantity of education initiated by the provider. This style of education has provided a more consistent and standard format for providers (Ben-Morderchai, Herman, Kerzman, & Irony, 2010; Frank-Bader, Beltran, Dojlidko, 2011). Potentially, this method could work with providers in other areas, such as the ICU. Making providers aware of the importance of these handouts would be essential.

A variety of outside resources were utilized by parents when seeking information about their infant. Adults learn differently, each having a style, such as listening, reading, or doing, which works best for the individual person. Having a variety of reliable resources available to parents seems to be essential. While parents utilized the Internet for information about their infant, the reliability of the websites used was undetermined and likely varied. Promotion of evidence-based websites, such as those sponsored by the

government, would potentially provide a resource for parents, as well as all clients to utilize. Future research on the types of Internet sources used by parents and the reliability of the information provided is needed.

Past experiences of the parent influence their learning needs later in life. Making the parent aware of this could help the parent better learn about their infant by making the parents aware of the knowledge they already possess. Building on the understanding parents bring with them can make educating parents easier for providers. Adults learn by linking new material to past experiences (Knowles, 2011). Making both providers and learners aware of this fact could help parents build their new learning more quickly. This information could benefit adult clients and their families as well. Education about learning could potentially assist adults to more quickly and thoroughly learn.

### **Implications for Nursing Action**

The findings of this study may impact providers who care for infants who are born extremely premature or with complex cardiac anomalies. Providers need to be aware of the learning needs of parents, potential factors that may influence this learning, and to consider these needs when giving infant care. The individual learning needs of parents must be met prior to the infant's discharge from the hospital. A greater understanding of these needs could result in more thorough parent education.

Parents of infants born with extreme prematurity or with complex cardiac anomalies could also benefit from this study. A better understanding of the potential stressors of the ICU and the varying roles of the providers could help parents understand

when to request information as well as from whom to request information. Also, knowing the format options for information available and how the parent best learns may increase the parent's ability to learn.

Providers need to consider the additional roles parents will be taking on after their infant is discharged home from the hospital. Discussing coordination of care and management goals with the parent during hospitalization may increase the parent's confidence in caring for their infant after discharge. Knowing what to expect and who to contact first if a provider is needed could decrease the infant's complications of their chronic illnesses once in the full time care of the parent in the home environment.

### **Recommendations for Further Research**

Future research is needed in this area. One focus could be to determine ways to decrease or manage parent stress and anxiety in the ICU, thus increasing the learning potential of parents. Research is also needed to determine if education regarding coordination of care by the parent would influence their infant's follow-up care. If parents know to expect to take on this new role after the infant is discharged home from the hospital, they may be better equipped to assist with management of their infant's care needs.

The results of the study suggest that further research toward consistency of information given to parents about their infant by providers is needed. A more central communication record or standardized, consistent, scripted terminology may increase the provider's ability to offer information to parents in a more consistent and thorough manner. Additionally, further research is needed to determine if length of hospital stay

alters the type of provider, such as nurse or medical doctor, that the parent trusts and relies upon for information about their infant. The longer the infant remains hospitalized, the greater the number of providers the parents will come in contact with and possibly the larger the amount of information the parent will need.

More research is needed to determine the value of the Internet as a reliable source for parent education. While the majority of parents in this study did at some point utilize the Internet, other variables about their typical Internet use were not known. The reliability of the websites visited, for example, is not known. Potentially, the Internet could become a standard resource for written materials for parents; however this would only assist parents who learn best through reading. Research has not been conducted related to providing of educational materials for parents with infants requiring ICU care or the reinforcement of educational materials via the Internet. Therefore studies are needed to confirm the effectiveness of teaching methods whereby the parent is introduced to the material, such as via a website, prior to a face-to-face educational session. Studies comparing giving parents of infants in the ICU education via just face-to-face or Internet approaches or a blending of the two methods are needed.

Based on these findings, research is needed to determine the types of contextual variables that may positively or negatively influence a parent's ability to learn needed information to care for their infant. A parent who had younger siblings or who worked in a hospital may be better equipped to learn to care for their infant, for example.

Understanding the impact of such contextual variables on the parent by the provider may

aid the provider in structuring new learning for the parent. Factors such as past experiences may impact the parent's ability to build new information on top of previous knowledge gained from experiences.

### **Summary**

The importance of consistent, thorough parent education in the ICU was confirmed by this study. Providers must be available to answer parent questions and concerns in terms the parent can understand. The fact that providers do not offer education to parents in a consistent manner was also confirmed. Each provider has opinions and beliefs about parent involvement in their infant's plan of care. When information is not known by parents and provider explanation has not satisfied the parent's learning needs, parents will seek information from outside resources. The study confirmed the use of a variety of resources, such as books, magazines, support systems, websites, and user groups. The past experiences of parents can alter the parent's ability to learn and rate of learning. Contextual variables influenced the learning needs of certain parents with chronically ill infants.

The study did not demonstrate which provider parents most sought information from during hospitalization or following the infant's discharge. While other research studies indicated the nurse as being the provider in the role of educator, this study did not confirm those findings. This study indicated that parents of infants born with extreme prematurity sought information from a variety of providers both during hospitalization and after the infant was discharged home.

Parents of infants born with complex cardiac anomalies did not utilize providers for information after their infant was discharged home from the hospital. The finding that providers give inconsistent information based on their personal values and beliefs about parent involvement in their infant's plan of care was unique to this study and is an area of potential future research. The provider's education or personal past experiences may be factors that influence the amount of information the provider shares with the parents. Being aware of these factors could assist providers in better understanding the needs of the parent to be involved with their infant's plan of care. The use of the Internet in a variety of ways as the primary source of information seeking by parents of infants born with complex cardiac anomalies during hospitalization and following discharge from the hospital was also a finding exclusive to this study. The fact that parents of infants born with extreme prematurity relied on providers more than other outside resources was also a finding unique to this study.

The learning needs of parent of infants requiring the specialized care offered in the ICU will continue to be an area for further research and development.

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APPENDIX A

CTLC TOOLS ADMINISTERED AND PURPOSES

<b>When Tool Given and to Whom</b>	<b>Name of Tool</b>	<b>Purpose of Tool</b>
Every Parent Interview; Completed by Parent	The Parental Stressor Scale: Infant Hospitalization (PSS-IH) total scores	To assess parent perceptions of illnesses-related stress during the hospitalization of their infant. Parents rate their stress related to alterations in their parental role, the appearance and behavior of their infant, and sights and sounds of the unit on a 5-point Likert scale. Parents receive 1 point for "not at all stressful" to 5 points for "extremely stressful."
	The Spielberger State-Trait Anxiety Inventory (STAI) total scores	To measure parental anxiety. Subjects rate 20 descriptive statements about their current feelings on a 4-point scale from 1 "not at all" to 4 "very much". Scores range from 20 to 80, with higher scores indicating more
	Impact of Events Scale-Revised (IES-R) total scores	To assess current distress in response to a specific life event. This 22-item scale reflects posttraumatic stress symptoms including intrusion, avoidance, and hyperarousal. Respondents rate each item on a scale of 0 (not at all), 1 (a little bit), 2 (moderately), 3 (quite a bit), and 4 (extremely) for the past 7 days. Scores range from 0 to 88 with higher scores indicating "quite a bit" of parental stress in the last 7 days.

<b>When Tool Given and to Whom</b>	<b>Name of Tool</b>	<b>Purpose of Tool</b>
Weekly while Hospitalized and until 40 days post-transplant for BMT infants; Completed by Research Nurse	Pediatric Early Warning System Score (PEWS) total scores	To identify increasing severity of illnesses and children who are likely to require resuscitation to treat cardiopulmonary arrest. This 16-item (9 static and 7 dynamic) instrument has a score range of 0-26 that quantifies illnesses severity.
Weekly while Hospitalized and until 40 days post-transplant for BMT infants, then monthly; Completed by Research Nurse	Technology Dependence Scale total scores	To measure the severity of the infant's illnesses. This 12-item tool rates the infant's care environment and invasiveness of procedures, monitors, and technological support needed. Points are given according to the frequency or number of items needed and the points totaled. Higher numbers indicate more dependence on technology and lower numbers indicate less dependence.
Every Parent and Provider Interview; Completed by Parent and Provider at time of interview	Hope Line	An elicitation device with 5 anchors ranging from 'No Hope' to 'Extremely Hopeful'. The parent or provider, depending on who is being interviewed, is asked to place a mark along the line or continuum of how much hope they have for the infant. The further to left the mark is placed, the less hope is had, while the further to the right the mark is placed, the more hope is held.

<b>When Tool Given and to Whom</b>	<b>Name of Tool</b>	<b>Purpose of Tool</b>
	Discomfort Line	An elicitation device with 4 anchors ranging from 'No Discomfort' to 'Severe Discomfort'. The parent or provider, depending on who is being interviewed, is asked to place a mark along the line or continuum for how much discomfort they believe the infant is in at the time. The further to the left the mark is placed, the less discomfort, while the further to the right the mark is placed, the less discomfort.
One Year Post Enrollment; Completed by Parent	Ryff Psychological Well-Being Scale	To measure psychological well-being in mothers. This 18-item tool measures psychological growth. Parents rate statements on a 6 point Likert scale with 1 being 'strongly disagree' and 6 being 'strongly agree'. Lower numbers indicate little or no growth while higher numbers indicate more growth.

## APPENDIX B

### PARENT INTERVIEW AT STUDY ENTRY

#### Narrative Interview Guide - Parent Interviews

**Directions:** This is a narrative interview to be conducted within 1 week of enrollment into the study.

**Focus:** Telling of the mother's (father's) story about her (his) infant's life-threatening illnesses and how the family came to choose initiation of treatment at DH.

**Main Narration: (turn on audio recorder)** Ask parent a broad question that will initiate their story about the infant's illnesses and how they came to begin treatment. Eg., Tell me the story about how you and your infant came to be here in this unit. Probes can be used to encourage the parent to give a more complete story. Eg., What happened next?

**Questioning Phase:** Once the parent has appeared to have completed her/his story, questions should be asked to fill in areas that may not have been covered.

Areas to ensure coverage:

Tell about when you were first told about your infant's illnesses.

Take me down the path from diagnosis to delivery. What were the steps/decisions along the way?

Did you get any information?

If yes, what sources? for instance, friends, the Internet, other family members, etc? Did this information help you make decisions?

What else is important to help you make decisions?

Since baby's birth, did you receive any new information?

Did anyone talk to you about a treatment plan before your infant/child was born?

(All units) What kind of information were you given before/after your child was admitted to the unit?

Probes: tour, handouts, phone call, team phone #'s, parent handbook.

When did you first see your baby?

What was that like for you?

What were your thoughts and feelings?

Has a decision been made regarding how your infant's illnesses will be treated?

What will be the first step in the treatment regimen?

How was the decision to initiate treatment arrived at?

Why did you make the decision you made? or What were you thinking when you made that decision - what led to it?

How do you feel about the initiation of this treatment plan?

Did anyone disagree with the decision that was made?

At this point in time, what medical technologies would you agree to have used if your infant's health status were to suddenly become worse?

Probe with specific technologies if not mentioned: tube in lungs for breathing, machine for breathing, CPR.

What is your hope for your infant at this point in time? *Hopeline*

*After discomfort line ask: Do you think your child is suffering?*

Are you comfortable with the health care decisions for your child?

Has your spirituality or belief in God influenced your decision-making?

How about your family?

**Closure and Small Talk: (turn off audio recorder)**

Engage in relaxed talk with parent while materials are being gathered and organized. Remember that this is often the period of time when parent will feel like sharing extra information.

**Field Notes:**

Record information describing the interview experience. Any impressions or events that occurred during the interview.

## APPENDIX C

### PARENT INTERVIEW MONTHLY

#### Narrative Interview Guide - Parent Interviews

**Directions:** This is a narrative interview to be conducted every month throughout the year-long data collection period or until death.

**Focus:** These interviews will focus on the continuation of the mother's (father's) story about the events that have occurred since the previous interview

**Main Narration: (turn on audio recorder)**

Ask parent a broad question that will initiate the continuation of their story about the infant's illnesses and how the infant and family has been doing since last interview.

Eg., Tell me about what has been going on with you and your infant since I last spoke with you. Probes can be used to encourage the parent to give a more complete story.

Eg., What happened last week?

When you look at your son/daughter, what are your thoughts about his/her illnesses and treatments?

How much have you been able to be involved in his care?

**Questioning Phase:** Once the parent has appeared to have completed her/his story, questions should be asked to fill in areas that may not have been covered.

**Questions will address what life is like to be a parent of a chronically ill infant**

Eg. What is your home life like with your infant?

Tell me about what a day is like caring for your infant at home.

How has having a chronically ill infant changed your employment situation [before and after]? How have your personal goals changed since your infant was born or diagnosed?

What is in the future for you? [try to get at parent's future]

**Questions will address perceptions of decisions made**

Eg., Have any treatment decisions been made since I spoke with you last? What are they?

How was that decision made? Why did you make the decision you made? Or what were you thinking when you made that decision - what led to it? How were you involved in the decision? Did anyone disagree with the decision?

Do you and your partner still agree with the treatment plan?

**Questions will address any changes in their plans for treatment.**

Eg., Has there been any changes in the type of treatment your infant is getting?

At this point in time, what medical technologies would you agree to have used if your infant's health status were to suddenly become worse?

Probe with specific technologies if not mentioned: intubation, ventilation, CPR).

What is your hope for your infant at this point in time?

**Questions will address trust in providers and continuity of care.** Eg., How is your relationship with the health care providers?

Can you describe what trust means to you? {probe: provider trust, leaving hospital}  
Which members of your infant's health care team have been most helpful?

Do you know who to go to when asking questions about your infant's treatment?

Do you feel you have come to know the doctor (nurse, NP, social worker) who is caring for your infant? Have you experienced any problems?

Has your spirituality or belief in God influenced your decision-making? How about your family?

**Questions will address context of care (unit environment).**

Eg., Can you tell me how you deal with the physical environment of the unit? How does it make you feel? Have those feelings changed over the past month? What things make you feel \_\_\_\_\_? Probe with specific physical stressors: noisy machines, busy rooms, no space, lack of privacy, (Social) Have you met other parents, families during your time here? How has that been for you? Do you go to the group gatherings that are offered? Do you look for others? Do you keep to yourself?

Probes: made friends, annoying people, supportive people

(Emotional) Are you aware of the other babies being cared for? Have any of them gotten very sick or died? How has this affected you? What do you do with these thoughts and feelings? (Resources): What kind of family resources have you been given? Were they useful? Has your handbook been useful? Do you use the unit computer? Are there other resources that have been helpful to you?

We would like to know what it has been like for you to be in this study. Can you tell us a little bit about your experience? (Probe. “Did you feel that the interviews were difficult?” Scheduling, Time Commitment, Emotional, Tough Questions etc.). Were the interviews helpful in anyway?

Thank you so much for sharing this with us. Is there anything else you would like to tell us about?

**Closure and Small Talk: (turn off audio recorder)**

Engage in relaxed talk with parent while materials are being gathered and organized. Remember that this is often the period of time when parent will feel like sharing extra information.

**Field Notes:**

Record information describing the interview experience. Any impressions or events that occurred during the interview.

## APPENDIX D

### PARENT INTERVIEW POST LIFE-THREATENING EVENT/SIGNIFICANT CHANGE IN TREATMENT

#### Narrative Interview Guide - Parent Interviews

**Directions:** This is a narrative interview to be conducted within 1 week following a life-threatening event. A life-threatening event is defined as an acute, unexpected event in which the health status of the infant has suddenly changed requiring a change in the treatment. This may include the need for emergency procedures (e.g., chest tubes, surgery), addition of life-sustaining treatments (e.g., vasopressors), or cardio pulmonary resuscitation. A significant change in treatment is defined as making the decision to intensify curative treatment, shifting from curative to symptom-focused palliative care, and/or withholding or withdrawing treatment.

**Focus:** Telling of the mother's (father's) story about the specific event or significant change in treatment that occurred over the past few days.

**Main Narration: (turn on audio recorder)**

Ask parent a broad question that will initiate their story about what has happened to the infant surrounding the event.

Eg., Tell me what happened to your infant on Tuesday.

What has happened to your infant since Tuesday?

Probes can be used to encourage the parent to give a more complete story. Eg., How is your infant now?

Where were you when this happened?

**Questioning Phase:**

Once the parent has appeared to have completed her/his story, questions should be asked to fill in areas that may not have been covered.

Areas to ensure coverage:

How and when were you told about this event?

Who was present when you were told about this event?

Were you comfortable with the location where you were told? Did you need more privacy? Would you have liked this to occur a different way?

How would you have liked this handled differently?

How was the decision made to do X? How did you participate in the decision?

(probe) Who helped you make the decision? What was like for you?

Did you feel your wishes were respected? Is there anything you would change?

When did you first get to see your baby after the event?

Has there been any change to the treatment plan for your infant?

Tell me about that decision.

What medical technologies is your infant on at this point? What medical technologies would you agree to have used at this point in time? Probe with specific technologies if not mentioned: tube in lungs for breathing, machine for breathing, CPR.

When you look at your son/daughter, what are your thoughts now about his/her illnesses and treatments? Has there been any change in how much have you been able to be involved in his care?

What is your hope for your infant at this point in time? *Hopeline*

*After discomfort line ask:* Do you think your child is suffering?

Are you comfortable with the health care decisions for your child?

Has your spirituality or belief in God influenced your decision-making? How about your family?

**Closure and Small Talk: (turn off audio recorder)**

Engage in relaxed talk with parent while materials are being gathered and organized. Remember that this is often the period of time when parent will feel like sharing extra information.

**Field Notes:**

Record information describing the interview experience. Any impressions or events that occurred during the interview.

## APPENDIX E

### PARENT INTERVIEW POST DISCHARGE

#### Narrative Interview Guide - Parent Interviews

**Directions:** This is a narrative interview to be conducted within 1 week prior to discharge from the inpatient setting.

**Focus:** Will be a retrospective look at the infant's illnesses and hospitalization.

**Main Narration: (turn on audio recorder)**

Ask parent a broad question that will initiate their story about their experience with hospitalization.

Eg., Tell me about your infant's hospitalization.

Probes can be used to encourage the parent to give a more complete story. Eg., What are your thoughts now about his/her illnesses and hospitalization?

What do you think was the most difficult experience for you during the hospitalization?

What was the best experience for you during the hospitalization?

It will also focus on the discharge process.

Eg., What are your hopes as you take your baby home? What are your worries and concerns?

What are you most looking forward to after discharge?

Have there been any decisions that you have made related to discharge?

Is there anything that anyone could have done that would have made this hospitalization easier for you?

**Questioning Phase:**

Once the parent has appeared to have completed her/his story, questions should be asked to fill in areas that may not have been covered.

Areas to ensure coverage:

Would you change any decisions that were made about your child's care?

Is there anything that anyone could have done that would have made this hospitalization easier for you?

What made decisions easy/difficult for you?

**Closure and Small Talk: (turn off audio recorder)**

Engage in relaxed talk with parent while materials are being gathered and organized. Remember that this is often the period of time when parent will feel like sharing extra information.

**Field Notes:**

Record information describing the interview experience. Any impressions or events that occurred during the interview.

## APPENDIX F

### PARENT INTERVIEW 12-MONTH POST-INFANT ENROLLMENT

#### Narrative Interview Guide - Parent Interviews

**Directions:** This is a narrative interview to be conducted 1 week following the anniversary of the parents' 1-year study enrollment.

**Focus:** Telling of the mother's (father's) story about perceptions of decision-making some distance from the event.

**Main Narration: (turn on audio recorder)**

Ask parent a broad question that will initiate their story about their infant has been doing over the past several months.

First parents will be asked to update the research team on their infant's development and health and they will be asked about their experiences in parenting their child since discharge.

*Tell us about how your child has been doing?*

Probes can be used to encourage the parent to give a more complete story.

*When you think about his/her time during the early months of life, what comes to mind?*

*What have been the highlights of the past year?*

*What are some of your happy memories of that time?*

*What was the most difficult experience for you during this past year?*

Probe: What are the most painful memories?

*What are some of the key decisions you have made for your child over the past year?*

*What makes the decision about X a key decision?*

*What was it like for you to make this decision?*

*Would you change any decisions that were made about your child's care?*

*What about the decision to XXXX? I recall that you spoke about this at an earlier time.*

*Who or what was the most helpful to you in making decisions?*

*What have you learned about yourself or decision making from this experience?*

**Questioning Phase:**

Once the parent has appeared to have completed her/his story, questions should be asked to fill in areas that may not have been covered.

Areas to ensure coverage:

What activities were helpful to you to process, cope and adapt to your situation over the past year?

*We would like to know what it has been like for you to be in this study. Can you tell us a little bit about your experience?*

(Probe. “Did you feel that the interviews were difficult?” Scheduling, Time Commitment, Emotional, Tough Questions etc.) Were the interviews helpful in anyway?

Is there anything that we have not asked you about this experience that you think is important for us to know?

**Closure and Small Talk: (turn off audio recorder)**

Engage in relaxed talk with parent while materials are being gathered and organized. Remember that this is often the period of time when parent will feel like sharing extra information.

**Field Notes:**

Record information describing the interview experience. Any impressions or events that occurred during the interview.

APPENDIX G

INTERDISCIPLINARY PATIENT AND FAMILY EDUCATION RECORD



**Intensive Care Nursery/  
Infant Transitional Care Unit/Special Care Nursery  
Interdisciplinary Patient and Family Education Record**

Name:

HC #:

Addressograph:

Fill in the appropriate number under each column, including date and signature, if "Other" please specify.

Date/Time	Topics	Readiness	Barriers	Taught to Whom	Methods	Learner Outcomes	Evaluation	Signature/Title
	<ol style="list-style-type: none"> <li>Medication</li> <li>Diagnosis</li> <li>Nutrition</li> <li>Test/Procedures</li> <li>CPR</li> <li>Developmental Care</li> <li>Discharge Instructions</li> <li>Other*</li> </ol>	<ol style="list-style-type: none"> <li>Asks questions</li> <li>Eager to learn</li> <li>Recognizes need to know</li> <li>Unreceptive</li> <li>Anxious</li> <li>Denies need</li> <li>Refuses instructions</li> <li>Other*</li> </ol>	<ol style="list-style-type: none"> <li>Language</li> <li>Cultural/Religious</li> <li>Emotional</li> <li>Inability to learn</li> <li>Speaking</li> <li>Hearing</li> <li>Literacy</li> <li>Vision</li> <li>Physical</li> <li>Cognitive</li> <li>None</li> <li>Other*</li> </ol>	<ol style="list-style-type: none"> <li>Father</li> <li>Mother</li> <li>Grandparent</li> <li>Support Person</li> <li>Other*</li> </ol>	<ol style="list-style-type: none"> <li>Explanation</li> <li>Group Session</li> <li>Audio/Visual</li> <li>Role play</li> <li>Demonstration</li> <li>Phone contact</li> <li>Handout</li> <li>Use of Interpreter</li> <li>Other*</li> </ol>	<ol style="list-style-type: none"> <li>Complete understanding</li> <li>Partial understanding</li> <li>No understanding</li> <li>Demonstrates with assistance</li> <li>Demonstrates independently</li> <li>Refuses to learn</li> <li>Unable to learn</li> <li>Other*</li> </ol>	<ol style="list-style-type: none"> <li>No further teaching needed</li> <li>Further teaching needed</li> <li>Seek additional support / Educational Consult (see note)</li> <li>Practice needed</li> <li>Reinforce content (see note)</li> </ol>	

<ol style="list-style-type: none"> <li>Medications                             <ol style="list-style-type: none"> <li>Electrolyte supplements</li> <li>Respiratory Treatments</li> <li>Reflex medications</li> <li>Vitamins</li> <li>Immunizations</li> <li>Prescriptions</li> <li>Other*</li> </ol> </li> </ol>	<ol style="list-style-type: none"> <li>Diagnosis                             <ol style="list-style-type: none"> <li>Agnosia of Prematurity</li> <li>GERD</li> <li>Retinopathy of Prematurity</li> <li>Chronic Lung Disease</li> <li>Other*</li> </ol> </li> </ol>	<ol style="list-style-type: none"> <li>Nutrition                             <ol style="list-style-type: none"> <li>Breast Milk</li> <li>Formula</li> <li>Formula Preparation</li> <li>Additives</li> <li>Other*</li> </ol> </li> </ol>	<ol style="list-style-type: none"> <li>Tests/Procedures                             <ol style="list-style-type: none"> <li>X-rays</li> <li>Blood Work</li> <li>Respiratory Studies</li> <li>ROP exam</li> <li>MRI</li> <li>Head US</li> <li>Renal US</li> <li>Echocardiogram</li> <li>Hearing Screen</li> <li>Car Seat Monitor</li> <li>Discussion</li> <li>Other*</li> </ol> </li> </ol>	<ol style="list-style-type: none"> <li>CPR                             <ol style="list-style-type: none"> <li>Video Viewed</li> <li>CPR Demonstrated</li> <li>CPR Reviewed</li> <li>Other*</li> </ol> </li> </ol>	<ol style="list-style-type: none"> <li>Discharge Instructions                             <ol style="list-style-type: none"> <li>Bath Sprinkler</li> <li>SS Bottle</li> <li>Temp Taking</li> <li>Diaper</li> <li>Diapering</li> <li>Home Safety</li> <li>Stoking Position</li> <li>Behavioral Cues</li> </ol> </li> </ol>	<ol style="list-style-type: none"> <li>Formula Preparation</li> <li>Breast Feeding</li> <li>Substituting Feeding</li> <li>OTU Appointments</li> <li>Car Seats</li> <li>Discharge Care</li> <li>Card Care</li> <li>Other*</li> </ol>
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Date/Time	Topics	Readiness	Barriers	Taught to Whom	Methods	Outcomes	Evaluation	Signature Title
	5 a, b, c	1, 2, 3	11	2	1, 3, 5	1, 5	1	

Content/Note: CPR training completed in preparation for anticipated discharge next week.

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Content/Note:

Date/Time	Topics	Readiness	Barriers	Taught to Whom	Methods	Learner Outcomes	Evaluation	Signature/Title
<b>Discharge</b>	<ol style="list-style-type: none"> <li>1. Medication</li> <li>2. Diagnosis</li> <li>3. Nutrition</li> <li>4. Test/Procedures</li> <li>5. CPR</li> <li>6. Developmental Care</li> <li>7. Discharge Instructions</li> <li>8. Other*</li> </ol>	<ol style="list-style-type: none"> <li>1. Asks questions</li> <li>2. eager to learn</li> <li>3. Recognizes need to know</li> <li>4. Unreceptive</li> <li>5. Anxious</li> <li>6. Denies need</li> <li>7. Refuses instructions</li> <li>8. Other*</li> </ol>	<ol style="list-style-type: none"> <li>1. Language</li> <li>2. Cultural/Religious</li> <li>3. Emotional</li> <li>4. Inability to learn</li> <li>5. Speaking</li> <li>6. Hearing</li> <li>7. Literacy</li> <li>8. Vision</li> <li>9. Physical</li> <li>10. Cognitive</li> <li>11. None</li> <li>12. Other*</li> </ol>	<ol style="list-style-type: none"> <li>1. Father</li> <li>2. Mother</li> <li>3. Grandparent</li> <li>4. Support Person</li> <li>5. Other*</li> </ol>	<ol style="list-style-type: none"> <li>1. Explanation</li> <li>2. Group Session</li> <li>3. Audio/Visual</li> <li>4. Role play</li> <li>5. Demonstration</li> <li>6. Phone contact</li> <li>7. Handout</li> <li>8. Use of Interpreter</li> <li>9. Other*</li> </ol>	<ol style="list-style-type: none"> <li>1. Complete understanding</li> <li>2. Partial understanding</li> <li>3. No understanding</li> <li>4. Demonstrates with assistance</li> <li>5. Demonstrates independently</li> <li>6. Refuses to learn</li> <li>7. Unable to learn</li> <li>8. Other*</li> </ol>	<ol style="list-style-type: none"> <li>1. No further teaching needed</li> <li>2. Further teaching needed</li> <li>3. Seek additional support / Educational Consult (see note)</li> <li>4. Practice needed</li> <li>5. Reinforce content (see note)</li> </ol>	<b>Signature/Title</b>
Date/Time	Topics	Readiness	Barriers	Taught to Whom	Methods	Outcomes	Evaluation	Signature Title
Content/Note:								
Content/Note:								
Content/Note:								
Content/Note:								

## APPENDIX H

### PROVIDER INTERVIEW AT STUDY ENTRY

#### Narrative Interview Guide - Provider Interviews

**Directions:** This is a narrative interview to be conducted within 1 week of infant enrollment into the study.

**Focus:** Telling of the provider's story about how he (she) came to care for the infant and issues related to the initiation of treatment.

**Main Narration: (turn on audio recorder)**

Ask provider a broad question that will initiate their story about the infant and how they came to be involved in the infant's care.

Eg., Tell me the story about how you first met this infant and his/her family. Probes can be used to encourage the provider to give a more complete story.

Eg., What happened next?

**Questioning Phase:**

Once the provider has appeared to have completed her/his story, questions should be asked to fill in areas that may not have been covered.

Areas to ensure coverage:

Did anyone talk to the parents about treatment before this infant was born?  
I'd like to know about the decision to initiate treatment. What decisions were made initially?

Who was involved in those decisions?

How have the parents participated in decision making? What factors influenced the decision you made?

How do you feel about the initiation of this treatment plan? Did anyone disagree with the decision that was made?

What factors/experiences in your (personal) life have contributed to the decisions you made/recommended? (or) What influences those decisions for you?

What factors do you think influenced the parents' decisions (eg., spirituality, family, past experience)

How comfortable are you with the decision to initiate treatment?

How comfortable were the parents with this decision?

At this point, if this infant were to get worse, what options would you suggest to the parents? What medical technologies would you agree to have used on this infant if his/her health status were to suddenly become worse? Probe with specific technologies if not mentioned: intubation ventilation, CPR.

What is your hope for this infant at this point in time?

**Closure and Small Talk: (turn off audio recorder)**

Engage in relaxed talk with provider while materials are being gathered and organized. Remember that this is often the period of time when people will feel like sharing extra information.

**Field Notes:**

Record information describing the interview experience. Any impressions or events that occurred during the interview.

## APPENDIX I

### PROVIDER INTERVIEW POST LIFE-THREATENING EVENT/SIGNIFICANT CHANGE IN TREATMENT

#### Narrative Interview Guide - Provider Interviews

**Directions:** This is a narrative interview to be conducted within 1 week following a life-threatening event. A life-threatening event is defined as an acute, unexpected event in which the health status of the infant has suddenly changed, requiring a change in the treatment. This may include the need for emergency procedures (e.g., chest tubes, surgery), addition of life-sustaining treatments (e.g., vasopressors), or cardio pulmonary resuscitation. A significant change in treatment is defined as making the decision to intensify curative treatment, shifting from curative to symptom-focused palliative care and/or withholding or withdrawing treatment.

**Focus:** Telling of the providers' story about the specific event or significant change in treatment that occurred over the past few days.

**Main Narration: (turn on audio recorder)**

Ask provider a broad question that will initiate their story about the infant's status and the event that recently occurred.

Eg., Tell me what happened to this infant this week. Did you anticipate this event?

Probes can be used to encourage the provider to give a more complete story. Eg., How is the infant now?

Where were you when this happened? How were you involved in what transpired?

**Questioning Phase:**

Once the provider has appeared to have completed her/his story, questions should be asked to fill in areas that may not have been covered.

Areas to ensure coverage:

How and when were you told about this event?

Did you anticipate this event?

How was the event communicated to the parents?

Who was present when they were told about this event? What decisions were made regarding the infant's treatment? Who was involved in these decisions?

Was there agreement or disagreement between the parents and health care team about the treatment plan?

What is the current focus of the treatment plan at this point?

Would you characterize the main mode of care of this infant as palliative or curative?

Probe: Do you think that parents view this the same as you?

What medical technologies is the infant on at this point? What medical technologies would you agree to have used at this point in time? Probe with specific technologies if not mentioned: intubation, ventilation, CPR.

What is your hope for this infant at this point in time?

What are the parents' hopes for their infant since the decision was made to .....? Are you comfortable with decisions made for this infant?

**Closure and Small Talk: (turn off audio recorder)**

Engage in relaxed talk with provider while materials are being gathered and organized. Remember that this is often the period of time when person will feel like sharing extra information.

**Field Notes:**

Record information describing the interview experience. Any impressions or events that occurred during the interview.

## APPENDIX J

### PROVIDER INTERVIEW POST DISCHARGE

#### Narrative Interview Guide - Provider Interviews

**Directions:** This is a narrative interview to be conducted within 2 weeks following discharge from the inpatient setting.

**Focus:** Will be a retrospective look at the infant's illnesses and hospitalization.

**Main Narration: (turn on audio recorder)**

Ask provider a broad question that will initiate their story about their experience with caring for this infant during hospitalization.

Eg., Tell me about this infant's hospitalization. What are your perceptions of (infant's name) illnesses and hospital course?

Probes can be used to encourage the provider to give a more complete story.

Eg., Would you say that this infant's course was a typical course for his/her condition? It will also focus on the discharge process.

Eg., Do you have any concerns regarding this infant's discharge from the hospital? What are your worries and concerns?

**Questioning Phase:**

Once the provider has appeared to have completed her/his story, questions should be asked to fill in areas that may not have been covered.

Areas to ensure coverage:

What was the most difficult aspect of caring for this infant? What was the most rewarding aspect of caring for this infant? Are you satisfied with the treatment decisions that were made?

Would you change any decisions that were made about this infant's care?

Is there anything that you think could have been done that would have made this hospitalization easier for the family?

**Closure and Small Talk: (turn off audio recorder)**

Engage in relaxed talk with provider while materials are being gathered and organized. Remember that this is often the period of time when person will feel like sharing extra information.

**Field Notes:**

Record information describing the interview experience. Any impressions or events that occurred during the interview.

## APPENDIX K

### PROVIDER INTERVIEW 12-MONTH POST-INFANT ENROLLMENT

#### Narrative Interview Guide - Provider Interviews

**Directions:** This is a narrative interview to be conducted within a month of the anniversary of the infant's 1-year study enrollment.

**Focus:** Telling of the provider's story about perceptions of decision-making some distance from the event.

**Main Narration: (turn on audio recorder)**

Ask provider a broad question that will initiate their story how the infant has been doing over the past several months.

First provider will be asked to update the research team on their infant's development and health and they will be asked about their experiences in caring for the infant since discharge.

Eg., Tell us about how this infant is doing now? Probes can be used to encourage the provider to give a more complete story. Eg., health, development.

What have been the highlights for this infant's health/development over the past year?

Has anything been particularly difficult?

**Questioning Phase:**

Once the provider has appeared to have completed her/his story, questions should be asked to fill in areas that may not have been covered.

Areas to ensure coverage: New treatment decisions. Conflict over decisions

Providers' perceptions of the parents' satisfaction with treatment decisions.

**Closure and Small Talk: (turn off audio recorder)**

Engage in relaxed talk with provider while materials are being gathered and organized. Remember that this is often the period of time when person will feel like sharing extra information.

**Field Notes:**

Record information describing the interview experience. Any impressions or events that occurred during the interview.

APPENDIX L

DUKE UNIVERSITY HOSPITAL SYSTEM INSTITUTIONAL REVIEW BOARD



IRB NOTIFICATION OF CONTINUING REVIEW APPROVAL

**Continuing Review ID:** CR5\_Pro00002345  
**Principal Investigator:** Sharron Docherty  
**Protocol Title:** Decision-Making For Infants with Complex Life-Threatening  
Conditions  
**Sponsor/Funding Source(s):** Department/Division/PI  
National Institutes of Health  
**Federal Funding Agency ID:** 5R01NR010548-02  
**Date of Declared Concordance with federally funded grant, if applicable:** N/A

The Duke University Health System Institutional Review Board for Clinical Investigations has conducted the following activity on the study cited above:

<b>Activity:</b>	Continuing Review	<b>Review Type:</b> Expedited
<b>Review Date:</b>	7/26/2011	
<b>Issue Date:</b>	7/27/2011	
<b>Anniversary Date:</b>	8/23/2011	
<b>Expiration Date:</b>	8/23/2012	

DUHS IRB approval encompasses the following specific components of the study:

<b>Protocol, version/date:</b>	--12/9/2010
<b>Summary, version/date:</b>	--5/9/2011
<b>Consent form reference date:</b>	--7/27/2011
<b>Investigator Brochure, version/date:</b>	--
<b>Pediatric Risk Category:</b>	-- 45CFR46.4 04 and 21 CFR 50.51 as applicable
<b>Other:</b>	--

The DUHS IRB has determined the specific components above to be in compliance with all applicable Health Insurance Portability and Accountability Act ("HIPAA") regulations.

This study expires at 12 AM on the Expiration Date cited above. At that time, all study activity must cease. If you wish to continue specific study activities directly related to subject safety, you must immediately contact Dr. John Falletta or Jody Power. Continuing review submissions (renewals) must be received by the DUHS IRB office 60 to 45 days prior to the Expiration Date.

No change to the protocol, consent form or other approved document may be implemented without first obtaining IRB approval for the change. Any proposed change must be submitted as an amendment. If necessary in a life- threatening situation, where time does not permit your prior consultation with the IRB, you may act contrary to the protocol if the action is in the best interest of the subject. You must notify the IRB of your action within five (5) working days of the event.

The Duke University Health System Institutional Review Board for Clinical Investigations (DUHS IRB), is duly constituted, fulfilling all requirements for diversity, and has written procedures for initial and continuing review of human research protocols. The DUHS IRB complies with all U.S. regulatory requirements related to the protection of human research participants. Specifically, the DUHS IRB complies with 45CFR46, 21CFR50, 21CFR56, 21CFR312, 21CFR812, and 45CFR164.508-514. In addition, the DUHS IRB complies with the Guidelines of the International Conference on Harmonization to the extent required by the U. S. Food and Drug Administration.



DUHS Institutional Review Board  
2424 Erwin Rd | Suite 405 | Durham, NC | 919.668.5111  
Federalwide Assurance No: FWA 00009025

APPENDIX M

SPECIFIC AIMS AND RESEARCH QUESTIONS

Specific Aims and Research Questions	Interview Template Label	Question(s)
<b>Specific Aim 1:</b> To determine the information needs of parents of infants with life-threatening conditions compared with information given by health care providers to the parents during their infant's hospitalization.		
<b>Research Question 1:</b> What topics (categories) of information were sought by parents during their infant's hospitalization?	Parent Interview at Study Entry	Take me down the path from diagnosis to delivery. What were the steps/decisions along the way? Did you get any information? If yes, what sources? For instance, friends, the Internet, other family members, etc? Did this information help you make decisions?
	Parent Interview at Study Entry	What else is important to help you make decisions? Since baby's birth, did you receive any new information?
	Parent Interview at Study Entry	What kinds of information were you given before/after your child was admitted to the unit? Probes: tour, handouts, phone call, team phone #'s, parent handbook
	Parent Interview 12-Month Post-infant Enrollment	What activities were helpful to you to process, cope, and adapt to you situation over the past year?
<b>Research Question 2:</b> What topics (categories) of information were discussed by health care providers with parents during their infant's hospitalization?	Provider Interview at Study Entry	Did anyone talk to the parents about treatment before the infant was born?
	Provider Interview at Study Entry	How have the parents participated in decision making? How comfortable were the parents with this decision?
	Provider Interview Post Life-threatening Even/Significant Change in Treatment	How and when were you told about this event? How was the event communicated to the parents? Who was present when they were told about this event?
<b>Research Question 3:</b> From whom and from what outside resources did parents seek information during their infant's hospitalization?	Parent Interview at Study Entry	Did anyone talk to you about a treatment plan before your infant/child was born?

Specific Aims and Research Questions	Interview Template Label	Question(s)
	Parent Interview Monthly	Which members of your infant's health care team have been most helpful? Do you know who to go to when asking questions about your infant's treatment? Do you feel you have come to know the doctor (nurse, NP, social worker) who is caring for your infant?
	Parent Interview 12-Month Post-Infant Enrollment	Who or what was the most helpful to you in making decisions? What have you learned about yourself or decision making from this experience?
<u>Research Question 4:</u> What contextual variables were present which may have influenced information needs of parents during their infant's hospitalization?	Parent Interview Monthly	What kind of family resources have you been given? Were they useful? Has your handbook been useful? Do you use the unit computer? Are there other resources that have been helpful to you?
	Parent Interview Post Life-Threatening Even/Significant Change in Treatment	Were you comfortable with the location where you were told? Did you need more privacy? Would you have liked this to occur a different way? How would you have liked this handled differently?
	Parent Interview Post Discharge	Is there anything that anyone could have done that would have made this hospitalization easier for you?
<u>Specific Aim 2:</u> To determine the information needs of parents of infants with life-threatening conditions compared with information given by health care providers to the parents following their infant's discharge from the hospital.		
<u>Research Question 1:</u> What topics (categories) of information were sought by parents following the infant's discharge from the hospital?	Parent Interview Post Discharge	What are your hopes as you take your baby home? What are your worries and concerns?
	Parent Interview Post Discharge	What are you most looking forward to after discharge? Have there been any decisions that you have made related to discharge?
	Year 1 Interview	Is there anything that would have been helpful to know upfront?
	Year 1 Interview	Looking back, if there is something you would change, what would it be?
<u>Research Question 2:</u> What topics (categories) of information were discussed by health care providers with parents following their infant's discharge from the hospital?	Provider Interview Post Discharge	Would you change any decisions that were made about this infant's care? Is there anything that you think could have been done that would have made this hospitalization easier for the family?

Specific Aims and Research Questions	Interview Template Label	Question(s)
	Provider Interview 12-Month Post-Infant Enrollment	First provider will be asked to update the research team on their infant's development and health and they will be asked about their experiences in caring for the infant since discharge.
	Provider Interview 12-Month Post-Infant Enrollment	What have been the highlights for this infant's health/development over the past year? Has anything been particularly difficult?
<u>Research Question 3:</u> From whom and from what outside resources did parents seek information following their infant's discharge from the hospital?	Parent Interview Post Discharge	Is there anything that anyone could have done that would have made this hospitalization easier for you? Would you change any decisions that were made about your child's care?
	Parent Interview Post Discharge	Is there anything that anyone could have done that would have made this hospitalization easier for you? What made decisions easy/difficult for you?
	Year 1 Interview	Who have been the most important people in your life over the past year?
	Year 1 Interview	Looking back how important was the support your family gave to you? Who were your most important supporters?
<u>Research Question 4:</u> What contextual variables were present which may have influenced information needs of parents following their infant's discharge from the hospital?	Parent Interview Post Discharge	Is there anything that anyone could have done that would have made this hospitalization easier for you?
	Parent Interview 12-Month Post-Infant Enrollment	What was the most difficult experience for you during the past year?
	Parent Interview 12-Month Post-Infant Enrollment	Who or what was the most helpful to you in making decisions?
<u>Specific Aim 3:</u> To compare the information needs of parents of infants with life-threatening conditions compared with information given by health care providers to the parents over time from hospitalization (time 1) to after discharge (time 2).		
<u>Research Question 1:</u> What topics (categories) of information were sought by parents during their infant's hospitalization compared to the information parents sought after discharge?	Comparison of Specific Aim1 and Specific Aim 2	

<b>Specific Aims and Research Questions</b>	<b>Interview Template Label</b>	<b>Question(s)</b>
<u>Research Question 2:</u> What topics (categories) of information were discussed by health care providers with parents during their infant’s hospitalization compared to information discussed by the health care provider after their infant’s discharge from the hospital?	Comparison of Specific Aim1 and Specific Aim 2	
<u>Research Question 3:</u> From whom and from what outside resources did parents seek information during their infant’s hospitalization compared to the information sought and outside resources used after their infant’s discharge from the hospital?	Comparison of Specific Aim1 and Specific Aim 2	
<u>Research Question 4:</u> What contextual variables were present which may have influenced information needs of parents during their infant’s hospitalization compared to the contextual variables present after their infant’s discharge from the hospital?	Comparison of Specific Aim1 and Specific Aim 2	