

Child Life Specialists in the Neonatal Intensive Care Unit:
Are They Prepared to Work with This Unique Population?

by

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Certified child life specialists (CCLS) are one of many healthcare professionals who work with premature infants hospitalized in the Neonatal Intensive Care Unit (NICU). The current study investigates the role of CCLS and what type of education and training is needed to sustain this role. An online survey was developed for the study with specific questions about CCLS duties and responsibilities in the NICU. Via the Child Life Council forum 69 CCLS completed the survey. Findings indicate there are no clear guidelines about the specific role of a CCLS in the NICU, and that participants received differing education and training prior to and since becoming certified. A more standardized approach to education and training for future CCLS working in the NICU is necessary.

Keywords: child life specialist, NICU, premature infant, training, and education

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CHAPTER 1: INTRODUCTION

As the field of child life expands, their services are being used in multiple hospital environments, as well as in alternative care settings (CLC, n.d.; Thompson & Snow, 2009). Though the rationale for child life services and the essential goals of such services remain the same in all settings, the specific skills needed to work with certain patient populations can differ tremendously. The Child Life Council (CLC), in addition to the American Academy of Pediatrics (AAP) have formulated position statements detailing the purpose and function of child life specialists in pediatric hospital settings (AAP Committee on Hospital Care & CLC, 2006; CLC, 2000). The CLC has also published a position statement concerning child life services in rehabilitation (CLC, 2000) and the AAP has discussed the role of child life in the emergency department (O'Malley, Brown, Krug, & AAP Committee on Pediatric Emergency Medicine, 2008). While the role of CLS in different settings is recognized, no standards of practice for CLS in the NICU exist and even less is known about the education and training required to work with this specific population. The AAP recognizes that child life specialists often develop expertise in working with certain populations (AAP Committee on Hospital Care & CLC, 2006), there is no mention of what type of education is needed to work with specific patient populations.

Systems Theory

Before discussing child life's function in the NICU, it is important to describe the theoretical frameworks that guide this research. Because certified child life specialists (CCLS) are members of a large team of healthcare professionals, it is beneficial to examine their role in providing care from a systems theory perspective. Whitchurch and Constantine (1993) state that the fundamental assumption of systems theory is that the system cannot be understood in terms of its individual parts, rather it must be understood as a whole. The cliché "the whole is greater

than the sum of its parts” is often used to describe this assumption (Whitchurch & Constantine, 1993; White & Klein, 2002). Likewise, if there is a change to one part of the system, the entire system is effected (Whitchurch & Constantine, 1993; White & Klein, 2002). Within the NICU, there are several individual members working together to provide optimum care for the patients. The distinct functions of each healthcare professional come together to produce quality care for their patients. If one part of the system (i.e. the healthcare team) is not performing adequately, the quality of care will suffer.

It is essential that each member of the system is acutely aware of what their role is within the system and has proper education on how to fulfill that role. Clarification on what roles each person plays will keep the team running efficiently and improve the overall outcomes for the patient. If one member of the team is unaware of their function on the team, or makes mistakes because he has not been properly educated on the needs of his patients, other team members will have to “pick up the slack” and the care of the patient will ultimately suffer. A lack of understanding of their specific role in the NICU may be a hindrance to CCLS operating effectively within the multidisciplinary team and could eventually lead to inferior hospital care.

Theories of Development

Another beneficial approach to this issue is to consider the long term developmental outcomes for the infants CCLS in the NICU would serve.

Erikson’s theory of psychosocial development is applicable here. One of Erikson’s goals in developing a theory was to trace how the positive aspects of personality develop (Thomas, 1996). For this reason, Erikson described development as a progression through his eight psychosocial stages. During the first stage, which lasts from birth through the first year of life, a newborn must learn to trust his environment (Thomas, 1996). Trust is formed when an infant can

predict and depend on his own actions and the actions of others (Thomas, 1996). As will be discussed in a later section, many of the infants in the NICU have been born prematurely and their bodies are not yet ready to manage all of the sensory stimulation of the world outside of their mother's womb. Infants who are constantly over stimulated and who experience several painful medical procedures each day may learn to distrust their environment. For a healthy infant living at home with his parents who tend to his every need, learning to trust the world is understandably easier. For a premature infant in the NICU who is bombarded with overwhelming amounts of light, noise, touch, and pain, trusting the environment may be more difficult.

On the same note, Piaget believed that young infants learn about their world through sensory input (Thomas, 1996). Due to exposure to more sensory stimulation than their bodies can handle (e.g. excess noise, light and pain), infants in the NICU learn that the world is stressful and overwhelming. Furthermore, even simply being held can put tremendous demands on a premature infant's body and response systems, so caregivers must come up with unique, and perhaps less efficient, ways of soothing a crying baby. As a consequence of this, the premature infant may learn that no one is capable of meeting her needs, and the mother-infant and father-infant relationships are effected (Feldman, 2002).

According to Erikson's theory, trust issues stemming from experiences early in life cannot be completely resolved, though a positive social environment can help repair some of the damage that has been done (Thomas, 1996). CCLS can help provide a positive social environment through proper stimulation and appropriate interactions between the infant and his family. This will facilitate the development of trust in the infant (Rollins, Bolig, & Mahan, 2005).

In order to thoroughly understand the impact of the problem of the lack specific responsibilities and proper education of CCLS in the NICU, this study will define the role of child life services in the NICU and investigate what child life specialists can do to support NICU infants and their families.

CHAPTER 2: REVIEW OF THE LITERATURE

Child Life Services

Child life specialists are professionals trained in child development who help children and families overcome trying situations (CLC, n.d.). Traditionally, child life specialists work with hospitalized children supporting them and their families throughout the duration of a hospital stay. However, in addition to the hospital, child life specialists may work in alternative care settings such as dentist offices, or even in schools, court systems, or funeral homes (CLC, n.d.).

The CLC outlines four main reasons why child life services are necessary: 1) a child's healthcare encounter can at times be a positive growth experience when truly comprehensive care is given, 2) interruption of normal life experiences can jeopardize growth and development, 3) physical limitations of illness and healthcare encounters have the potential to invite dependency and can erode self-esteem, and 4) anxiety and stress related to illness, separation, hospitalization, and medical encounters interfere with a child's optimal response to medical treatment and care (CLC, n.d.; CLC, 2000).

In general, child life specialists have three roles within the hospital: play, psychological preparation, and family support (AAP Committee on Hospital Care & CLC, 2006).

Play

Play can serve both therapeutic and educational purposes. It helps moderate the patient's anxiety by allowing him to express his feelings, both positive and negative. Play provides an opportunity for normal development and also gives the patient a sense of control over his own actions in an environment where many choices are made for him. Finally, play gives a child life specialist insight into the child's understanding of his surroundings and the procedures that he

will have to undergo. Knowledge of the understanding a child has about his hospital stay will help the child life specialist properly prepare him for anything he will encounter throughout the duration of his admission (AAP Committee on Hospital Care & CLC, 2006).

Psychological Preparation

Psychological preparation provides the child with opportunities to learn about upcoming procedures and coping strategies to help him have a positive experience during the procedure. Medical play, or play involving procedural preparation through use of medical equipment, is often used during psychological preparation (AAP Committee on Hospital Care & CLC, 2006). Research shows that when children are properly prepared for the events of their hospital stay, they will cooperate better during the procedure and will ultimately have a more positive hospital experience (Gaynard, et al., 1990; Rollins, Bolig, & Mahan, 2005).

Family Support

A child life specialist will also offer education and support to family members of the patient. This could involve procedure preparation for parents and siblings, including education and coping strategies, as well as opportunities for play for the siblings (AAP Committee on Hospital Care & CLC, 2006). Child life specialists can have a great impact on how the family copes with the hospitalization of one of its members (Gaynard et al., 1990; Rollins et al., 2005).

Infants in the NICU

Many infants who require care in the (NICU) are those who have been born preterm, or before 37 weeks gestational age (GA). Infants born before 22 weeks GA are not likely to survive (Stoll et al., 2010). In 2006, the Institute of Medicine (IOM) found that premature births accounted for a startling 12.5% of all live births in the United States. This represents a 30% increase in premature births since 1981 (IOM, 2006). Bode et al. (2009) found that between 1985

and 2005 there was a 35% increase in the number of premature infants born. In addition, there was also an 11% (from 82% to 93%) increase in the percentage premature infants who survived in the hospital until they were discharged (Bode et al., 2009). Recent data from the Eunice Kennedy Shriver National Institute of Child Health and Human Development Neonatal Research Network shows that 6% of infants born at 22 weeks GA survive until hospital discharge while 98% born at 28 weeks GA survive (Stoll et al., 2010). As there are more and more premature infants born, and more premature infants surviving at a younger gestational age, it is important to take note of the unique developmental challenges this population will face.

Biological Factors that Influence Development

Premature infants will face a myriad of developmental problems throughout much of their lives. Not only will a child born prematurely likely be physically smaller than his term counterpart, but he will be vulnerable to complications of the respiratory, immune, and central nervous systems, have hearing and visual impairments as well as suffer developmental delays in cognition and language (IOM, 2006). Because of this, it can be extremely difficult to care for a premature infant. Coping with the stress of having a premature infant can be rather overwhelming as clinical staff including doctors, nurses, developmental specialists, and child life specialists, in addition to parents and caregivers must tend to an infant with many unique medical and developmental needs (Olshtain-Mann & Auslander, 2008)

Because the infant is delivered without being fully developed, its body will have tremendous difficulty catching up with standard levels of development. Once outside of the womb, the premature infant has trouble regulating the flow of blood through its body (Hebden et al., 2002; Tsuji et al., 2000) and therefore parts of the body essential to normal development like the brain, kidneys, and liver, do not get enough blood and cannot grow in a typical manner.

Premature infants are often treated for intraventricular hemorrhage (Tsuji et al., 2000; Miceli et al., 2000), sepsis, necrotizing enterocolitis (Miceli et al., 2000), and retinopathy of prematurity (Allen, 2008).

Environmental Factors that Influence Development

As premature infants are delivered before their bodies are ready to experience the outside world, it is important to find just the right balance in the amount of stimulation given to infants in this fragile state. Not enough stimulation can be detrimental to the infant's developmental outcomes (Harris, 1986), while too much can be just as deleterious (Als et al., 1994).

Noise. One environmental factor that can negatively affect the development of a prematurely born infant is the amount of noise in the NICU (AAP Committee on Environmental Health, 1997). While the AAP Committee on Environmental Health (1997) recommends that the noise level in the NICU remain below 45 decibels, Lasky and Williams (2009) found that infants were typically exposed to noise levels of 56.44 decibels. Throughout the entire duration of their time in the NICU, noise levels were only within the limits set up by the AAP 5.51% of the time (Lasky & Williams, 2009). Unfortunately for the infant, much of the medical equipment used to sustain life is rather noisy. Improvements in the design of some of the equipment, such as the isolettes in which preterm infants spend the majority of their time, have made the level of noise more appropriate (Lasky & Williams, 2009).

Additionally, music has been used to drown out some of the excess noise in the NICU (Gooding, 2010). Music can also serve therapeutic purposes for the NICU infant (Gooding, 2010). Collins and Kuck (1991) found that premature infants who listened to music blended with intrauterine sounds had significant increases in their oxygen saturation levels. Thus, playing soft

music for the infant can be an appropriate way to mask extraneous noise while improving developmental outcomes.

Light. Excess exposure to light has also been found to have detrimental effects on the development of premature infants. Out of our five senses, vision is the last to develop and is even not completely developed at birth (Blackburn, 1998). Because of this, preterm infants are extremely sensitive to light and are at an increased risk for several maladies associated with the development of the eye and the ability to see (Blackburn, 1998). Additionally, continuous exposure to light in the NICU can make it very difficult for an infant to develop a circadian rhythm, or day/night cycle (Brandon, Holditch-Davis, & Belyea, 2002). However, light exposure can be altered to mimic this cycle and improve outcomes for the infant (Brandon et al., 2002).

The AAP suggests that light levels should remain at less than 646 lux in the NICU Lasky and Williams (2009) found that this guideline was followed 99.37% of the time. Walsh-Sukys, Reitenbach, Hudson-Barr, and DePompei (2001) also found that most hospitals have adjusted the amount of light in the hospital to be within the recommended limits.

Touch. It is also important to find a balance between too much and not enough physical contact with the premature infant. Too much touch can be over stimulating and can cause the infant stress, while just the right amount of touch can increase weight gain, increase behavioral responses and reduce the length of hospital stay (Field, Diego, & Hernandez-Reif, 2010). Even though the positive impact of developmentally appropriate touch has been well documented, Field, Hernandez-Reif and Freedman (2004) found that only 38% of NICUs provide infant massage for their patients or education about infant massage to parents.

Skin-to-skin contact (i.e. Kangaroo Care) between the premature infant and a caregiver has also been found to be beneficial to preterm infants (Akan, Yigit, & Atici, 2009; Cong,

Ludington-Hoe, McCain, & Fu, 2009; Feldman, Eidelman, Sirota, & Weller, 2002). In addition to reducing pain (Akan et al., 2009), skin-to-skin contact has also been shown to reduce heart rate variability during heel sticks (Cong et al., 2009) and has a positive impact on the infant-parent relationship (Feldman et al., 2002).

Positioning. Because premature infants are born before their bodies are ready to experience the world, simply having too much room to move around outside of the mother's uterus can be overwhelming. The mother's uterus restricts the amount of room a fetus has to move (Aucott, Donohue, Atkins & Allen, 2002). Thus, once outside of the womb, a preterm infant can be comforted by being tightly swaddled in a blanket (van Sleuwen et al., 2007). Swaddling has been shown to decrease physiologic distress, improve motor organization, and improve an infant's ability to self sooth (van Sleuwen et al., 2007). The same study reported that swaddling can help regulate the infant's body temperature and has been shown to reduce pain and discomfort (van Sleuwen et al., 2007).

One must also pay attention to how to hold and physically interact with these fragile infants. Any infant would need to be held during feeding, bathing, or for diaper changes. These simple, everyday activities can be over stimulating and very stressful for the preterm infant. Thus, it has become popular to use rolled up towels to form a "nest" around the infant in an effort to provide them with more support (Comaru & Miura, 2009) and reduce the infant's pain and stress during procedures (Comaru & Miura, 2009; Ferrari et al., 2007). The nest also helps the infant keep his head in the midline position (straight) which has implications for the flow of blood to the infant's brain and his ability to breathe (Pellicer, Gaya, Madero, Quero, & Cabanas, 2002).

Altering the NICU environment so that there are not overwhelming levels of stimulation has many positive impacts on the development of the preterm infant. In most cases, the changes that need to take place in order to improve outcomes for infants in the NICU, though sometimes initially expensive and require a certain amount of planning and cooperation from the healthcare team, are not difficult to implement and may be well within the capabilities of the hospital (Slevin, Farrington, Duffy, Daly, & Murphy, 2000).

Child Life in the NICU

To date, there is not much research on how child life specialists operate in different hospital environments. While the CLC has a position statement for the role of child life in rehabilitation (CLC, 2000) and McGee (2003) has described guidelines for working with children in radiology, no specific research exists on the role of child life in the NICU. Current literature is limited to hospitalized infants in general, not specifically infants in the NICU, or is about how hospital professionals other than CCLS care for these infants. As mentioned above, CCLS have three main roles: play, education and preparation, and family support including sibling support. Because of the unique nature of infants in the NICU, the role of a CCLS also includes helping the infant transition home at discharge. When necessary, CCLS offer palliative care and bereavement support, too.

It is necessary to note that each of these services will be different in a Level I, II, and III NICU. The AAP Committee on Fetus and Newborn (2004) determined that Level I, or “basic neonatal care, is the minimum requirement for any facility that provides inpatient maternity care” (p. 1341). Level II provides care to infants who are “moderately ill with problems that are expected to resolve rapidly” (p. 1342), while Level III “can care for newborn infants with extreme prematurity or who are critically ill or require surgical intervention” (p. 1342). As it is

the job of a CCLS to provide developmentally appropriate care (AAP Committee on Hospital Care & CLC, 2006; CLC 2001), play, education, and family support will differ depending on the acuity level of the infant.

Play

For term infants, the function of play is to explore and to simulate the senses (Jessee & Gaynard, 2009). Play provides infants with an opportunity to learn about their world and also helps them gain motor skills such as lifting themselves, crawling, and eventually walking (Thompson & Sanford, 1981). Thompson and Stanford suggest that a “child life worker should design and implement a stimulation program for young infants to insure maximum development while hospitalized” (p. 31), but there is no specific guidance on how to work with premature infants.

There are many challenges to engaging a NICU infant in developmentally appropriate play. First of all, because of the delicate nature of their not yet fully developed bodies, one must be very gentle in handling the infant and must be careful not to cause the infant distress by overwhelming him. Anyone working with a NICU infant must be able to read the infant’s cues in order to provide the optimum amount of stimulation.

A CCLS, if properly educated, can provide the infant with appropriate stimulation in order to help him develop. For example, a CCLS is able to offer infant toys like rattles, soft toys, and music boxes. Play will depend on the infant’s level of acuity and their ability to handle stimulation and should be scheduled based on the infant’s sleeping pattern (Aucott et al., 2002).

Music therapy may also be beneficial to a NICU infant. Music can drown out the many noises associated with the hospital (e.g. alarms, ventilators) and provide the infant with a more peaceful environment (Gooding, 2010). Though some hospitals employ specially trained and

certified music therapists, hospitals in which there is no music therapist may rely on child life staff to provide this type of stimulation to the infants in the NICU.

Psychological Preparation

Procedural support and pain management. Often CCLS, along with a parent or caregiver, will accompany hospitalized children to their procedures and support them throughout the duration of the procedure (Goldberger, Mohl, & Thompson, 2009). This is particularly important to infants in the NICU who can experience up to 14 painful procedures everyday (Simons, et al., 2003).

Pain management is a considerable problem for hospitalized children. The AAP Committee on Psychosocial Aspects of Child and Family Health, along with the American Pain Society Task Force on Pain in Infants, Children and Adolescents (2000) have written a position statement on how to handle pain management for hospitalized youth. Numerous interventions have been suggested to manage pain in hospitalized infants (Yamada, et al., 2008). These include music, kangaroo care, and non-nutritive sucking (i.e. using a pacifier; Yamada et al.). Using containment strategies such as swaddling (van Slewin et al., 2007) or nesting (Comaru & Miura; Ferrari et al., 2007) can also help manage pain in NICU infants. CCLS can advocate for the use of techniques to help reduce the pain of medical procedures. For example, research indicates that using an oral sucrose solution reduces pain for infants in the NICU (Thompson, 2005). A CCLS can promote the use of the sucrose solution during painful procedures for her patients.

Family education and preparation. As well as providing support during the procedure, it is the role of a CCLS to prepare patients for upcoming procedures (CLC, 2000; AAP Committee on Hospital Care & CLC, 2006; Goldberger et al., 2009). Traditional education and preparation are not developmentally appropriate for premature infants so education and

preparation become more important for the patient's family, including siblings (Thompson & Stanford, 1981; Mahan, 2005; Goldberger et al., 2009). Education and preparation include exploration (if appropriate) of the materials that will be used during the procedure, a demonstration of what will happen during the procedure at which time the CCLS will explain the procedure and answer any questions, and an opportunity for mastery such as acting out the procedure on a doll which helps the patient and the family feel a sense of control (Mahan, 2005). Education and preparation will differ based on the CCLS' assessment of the patient and family's needs (Hollon & Skinner, 2009).

Family Support

In general, the main goal of a CCLS is to help the patient cope with the stress of being hospitalized. Because there are barriers to actually interacting with infants in the NICU, however, the role of the CCLS may shift to focus more on the patient's family.

Within the philosophy of the CLC is what is known as family centered care (FCC) which is "an approach to healthcare that is based on mutually beneficial partnerships between patients, families, and healthcare professionals" (Bell, Johnson, Desai, & McLeod, 2009, p. 95). One goal of FCC is to empower the patient's family by encouraging direct participation in the care of the hospitalized member (Bell et al., 2009). Research indicates that FCC improves patient outcomes and patient satisfaction (Johnson, 2000). Thus, it is important to incorporate the needs of the family when planning for the care of the patient.

FCC is particularly important for infants in the NICU. Moore, Coker, DuBuisson, Swett, and Edwards (2003) describe how to successfully implement FCC in the NICU. They recognize that the family should participate in the care of their infant and list the following guidelines to FCC in the NICU: 1) Families are viewed as integral members of the care team and as primary

caregivers to their infants (not as visitors), 2) Families are seen as the primary decision makers for their infants, 3) Families are asked how they would like to participate in their infants' care and are given the education, resources, and support to participate to the level they desire, 4) Families have the opportunity to discuss and record observations of their infant, and 5) The unit welcomes families 24 hours a day, including during rounds and change of shift (pp. e453-e454). It is the role of the child life specialist to advocate for FCC and to ensure that the infant's family's needs are cared for as well (Bell et al., 2009).

Ward (2001) lists ten needs particular to parents of infants in the NICU: 1) To know exactly what is being done for my infant, 2) To see that the NICU staff provide comfort to my infant, such as giving my infant a pacifier, using blankets to support my infant's body, and talking softly to my infant, 3) To know how my infant is being treated medically, 4) To have questions about my infant answered honestly, 5) To be able to visit my infant any time, 6) To be assured that the best care possible is being given to me infant, 7) To know the expected outcome for my infant, 8) To feel that the hospital personnel care about my infant, 9) To know that my infant is being handled gently by healthcare providers, and 10) To know specific facts concerning my infant's progress (p. 284). A CCLS should be aware of each of these needs and the factors that affect whether or not these needs are being met for the parents of her patients. The plan a CCLS sets up to care for her patient's parents should reflect the FCC philosophy by accounting for the needs of the parents and siblings as well as the needs of the patient.

Importance of family support. Interactions between infant and mother (Reissland & Stephenson, 1999; Stern et al., 2000) can affect how the infant develops. Parents with a large amount of stress are much more likely to cope with their infant's hospitalization in maladaptive ways than parents who are not stressed (Miles et al., 2007; Newham, Milgrom, & Skouteris,

2009). Furthermore, Miceli, Goeke-Morey, Whitman, Kolberg, Miller-Loncar and White (2000) found that children of mothers who were distressed when their children were 4 months corrected age displayed more externalizing and internalizing behaviors when they were 36 months of age. Likewise, children of mothers with greater social support during the first few months of their children's lives had better language outcomes and fewer internalizing behaviors at 36 months (Meceli et al., 2000). Thus, attending to the psychological needs of the mother by offering social support will enhance the long-term outcomes for the prematurely born infant (Miceli et al., 2000).

The Newborn Individualized Care and Assessment Program (NIDCAP; discussed in depth in a later section) has a focus on FCC. Infants who were cared for in a hospital that follows NIDCAP guidelines spent fewer days on a ventilator or needing oxygen, gained weight faster, nipple-fed more quickly, and were discharged earlier (Als et al., 1994). Thus, FCC has the added benefit of reducing the cost of care for the family and the hospital. The IOM (2006) estimates that care for preterm infants in the US in 2005 cost \$26.2 billion which is approximately \$51,600 per family. Instituting FCC is cost effective because it reduces the amount of medical care, including a reduction in the total length of hospital stay, preterm infants need.

Sibling support. Hospitalization can have significant negative effects on siblings of the patient (Craft, Wyatt, & Sandell, 1985; O'Brien, Duffy, & Nicholl, 2009). Often times, siblings will be separated from the hospitalized child and even from their parents as parents spend much of their time at the hospital (Pearson, 2009). Shifts in family dynamics and functioning can leave siblings feeling displaced from their family (Craft et al., 1985). Siblings of hospitalized children may show an increase in anxiety and behavior problems (O'Brien et al., 2009). They may also begin to worry about their own health, or feel guilty about the health of their hospitalized sibling

(Barrera, Chung, & Fleming, 2004; Pearson, 2009). Thus, support for the siblings of hospitalized children is sometimes just as important as support for the patient themselves.

The benefits of sibling support are well documented (Barrera, Chung, & Fleming, 2004; Gursky, 2007). Siblings who receive support services during their brother or sister's hospitalization have an increased knowledge about their brother or sister's condition (Barrera et al., 2004) and show a decrease in their level of stress or anxiety and behavioral problems (Barrera et al., 2004; Gursky, 2007). Particular to the NICU, siblings who were able to visit their newborn baby brother or sister were more cooperative in caring for the new baby (Oehler & Vileisis, 1990). In addition, child life specialists can get parents involved in the sibling support process such that the sibling receives continuous support at home (Gursky, 2007).

Rollins et al. (2005), Gursky (2007), Pearson (2009), and Newton, Wolgemuth, Gallivan, and Wrightson (2010) agree that sibling support is within the realm of responsibilities of the CCLS. Davies (1999) has suggested several guidelines for the support of siblings of hospitalized children: 1) Give information about the ill child's condition using developmentally appropriate terms, 2) Promote discussion about feelings between parents and children, 3) Encourage calls to or videoconferences with siblings who cannot come to the hospital, 4) Remind the family to relate important information to their child's school and other child care providers to encourage sibling support, 5) Invite siblings to child life programs, 6) Provide specific group programs for siblings of children in specialty units such as the NICU, and 7) Offer support to parents to help them meet the needs of the well siblings.

Though benefits of sibling support are well documented, Newton et al. (2010) found that only 48% of the pediatric hospitals in their study of the US and Canada provide sibling support services, and only 26% of hospitals set aside funding for these services. Of the all the sites in

their study, however, 94% of the hospitals that did offer sibling support did so through child life. Thus, CCLS need to advocate for sibling support resources to better serve their patients and their families.

Transition to home. Becoming a new parent can be stressful for anyone, but this stress is compounded for parents of NICU infants who may be particularly worried about their parenting competence (Olshtain-Mann & Auslander, 2008). A study comparing parental stress and feelings of competence of parents of both preterm and full term infants indicated that even after two months at home, parents of preterm infants are more stressed and feel less competent than parents of full term infants (Olshtain-Mann & Auslander, 2008). Parents need a substantial amount of education concerning early intervention services and how to care for their infant after discharge. The clinical staff can work together with the child life department to ensure that each family is properly educated and has their questions answered. Child life specialists may be a particularly valuable resource that can reinforce the importance of early intervention services with the family.

Trachtenberg and Golemon (1998) state that along with medical criteria for discharging a premature infant from the hospital, there are social criteria, too. These criteria include 1) verification that the infant's parents are capable of providing for the infant's basic needs, 2) confirmation that parents know how to identify problems if they occur, and 3) a detailed plan of continued healthcare and parental support following discharge (Trachtenberg & Golemon, 1998). A CCLS, along with the clinical staff can work with the families of NICU infants to ensure that the parents are educated and feel competent in caring for their infant when it is time to go home.

After being discharged from the hospital, preterm infants still need a significant amount of healthcare. Pritchard, Colditz, and Beller (2008) explored which factors contribute to whether

or not parents continue to use health services after their infant has been discharged from the NICU. They discovered that parents were more likely to use healthcare services when the services were readily available (even after the family moved to a new location), when full information was given in way that the parents could comprehend, and when the services included the principles of FCC giving in turn the parents a greater sense of self-efficacy (Pritchard et al., 2008).

Spittle et al. (2010) evaluated a preventative care program for preterm infants who had been discharged from the hospital. This program included home visits from a physiotherapist and psychologist. The focus of the program was threefold: the parent-infant relationship, parent's mental health, and the infant's development. Spittle et al. found that the primary caregivers who received the intervention showed a decrease in anxiety and depression and the infants had improved behavioral outcomes. This finding confirms that of Miceli et al. (2000) who concluded that attending to the psychological needs of caregivers is essential to developmental outcomes for infants.

A successful transition to home is crucial to the outcomes of the infant and their family. Early intervention services which focus on improving developmental outcomes for the infant could contribute considerably to this success. Because early intervention services are of a developmental nature, a CCLS who is educated and trained in this field may be a professional who can aid in the implementation of such services. As of right now though, the CCLS' role in the NICU is more focused on preparing the siblings and parents for their infant's homecoming, not on providing post-discharge services (Rollins et al., 2005). However, the education and support that a CCLS provides during this time is critical so that the family can feel comfortable and capable of taking care of their infant (Rollins et al., 2005).

Palliative care and bereavement. Included in family support are palliative care and bereavement services when needed. Pearson (2009) states, “As child life specialists, we are challenged to identify and advocate for particular policies and practices that support the family’s ability to cope within the critical care setting” (pp. 220-221). CCLSs need to understand the psychosocial needs of a grieving family and be ready to offer support wherever it is necessary.

Catlin and Carter (2002) have suggested a protocol for palliative care in the NICU. This protocol includes telling the family that they will not be abandoned, offering complete medical information, introducing the family to other families in a similar situation, utilizing child life services for the family including siblings, and preparing the family for what will happen if/when their infant dies (Catlin & Carter, 2002). In order to truly support families of NICU infants, CCLS should be aware of when and how to offer palliative care and bereavement support.

Current Training of NICU Professionals

There are a number of professionals who are involved in the daily care of infants in the NICU. Many of these professionals require additional training to work with the NICU population. In this section, an overview of the current training and credentialing requirements for a few NICU professionals is presented.

Nurses

According to Nursing-School-Degrees (2010), the minimum amount of education required to become a registered nurse is an Associate’s or Bachelor’s degree. To become a registered nurse, one must also complete the NCLEX certifying exam which differs in each state. No additional education is required to work in the NICU, though some hospitals will require a certain number of years of clinical experience (All Star Directories, 2010). To become a neonatal

nurse practitioner (NNP), a Master's of Science in Nursing degree is required (All Star Directories, 2010).

Occupational and Physical Therapists

Both occupational therapists (OT) and physical therapists (PT) are essential to the care of prematurely born infants. According to the American Occupational Therapy Association (AOTA), there are two levels of professional practice for OT (AOTA, 2007). First the technical level consists of OT assistants (OTA) who gain their education through community or private junior colleges or at certain four year universities. The second level, the professional level, is made up of Master's or entry-level therapists and doctoral-level therapists. Each level of clinician is required to take a national certification exam, and the professional level therapists are also required to obtain a state license before beginning clinical practice. Institutions that offer OT programs must receive accreditation through the Accreditation Council for Occupational Therapy Education (ACOTE; AOTA, 2007).

The length and content of each program vary depending on the degree being acquired (AOTA, 2007). For example, a master's level program may range from thirty to thirty-six credit hours, while a doctor of science (ScD) or a doctor of occupational therapy (OTD) may take several years (AOTA, 2007). Following a doctoral degree, OT may explore postdoctoral education such as a residency or fellowship (AOTA, 2007). AOTA has published a paper on the specialized knowledge and skills an OT needs to work with infants in the NICU (AOTA, 2006).

Education for physical therapists is similar to that of occupational therapists. Before beginning an entry-level PT program, a PT student must acquire a baccalaureate degree, and must obtain a graduate degree before sitting for the state licensing exam that will allow them to practice (APTA, 2011). Institutions providing PT graduate programs must receive accreditation

through the Commission in Accreditation of Physical Therapy Education (CAPTE; Threlekld & Paschal, 2007). As with OT, PT may practice with either a master's or doctoral degree. These programs are usually about three years in length (APTA). After completing this degree, a PT may choose to acquire postdoctoral education and may choose to receive a special certification in area of particular interest through the American Board of Physical Therapy Specialties (APTA, 2011). APTA lists pediatrics as an option for special certification; however NICU is not listed specifically. Special certification is not, at this time, a requirement to work with certain patient populations (APTA, 2011).

Massage Therapists

One type of specialist that may work in a NICU is an infant massage therapist. Along with working directly with patients, an infant massage therapist will often teach parents and family members how to massage their infant. The International Association of Infant Massage offers the Certified Educator of Infant Massage (CEIM) credential through an organization called Infant Massage USA. Training to become a CEIM includes a four day training, an exam, and a practicum in which the CEIM in training must work with five different parents or infants (Infant Massage USA, 2010). The four day training includes information about infant cries and behavioral cues, as well as training on massage for special situations, particularly infants born prematurely (Infant Massage USA, 2010). Those CCLS whose primary work assignment is the NICU may find information and training regarding infant massage to be beneficial to their practice.

Music Therapists

The American Music Therapy Association (2008) notes that a student can receive a Bachelor's, Master's, or doctoral degree in music therapy. Certain protocols have been

developed for conducting music therapy with premature infants. In this protocol, there are three infant stages which require different music therapy techniques (Gooding, 2010). Gooding reviews each stage of therapy: The first stage, survival/ pacification, lasts from birth to when the infant weighs 2.5 pounds. During this phase, therapy mostly consists of simply listening to music. The next phase, cautious stimulation, begins when the infant is about 30 weeks gestational age. At this time, music is combined with skin-to-skin contact and other forms of stimulation in an attempt to increase the infant's tolerance of stimulation. The final stage, interactive learning, begins at approximately 32 weeks gestational age. Here, music therapy is used to help soothe crying infants, and also to help with feeding in addition to reducing pain associated with medical procedures. Music therapists who work with premature infants are aware of each developmental stage and the appropriate amount of stimulation to offer the infant in each stage.

Early Intervention

Infant developmental specialists. In an effort to improve developmental outcomes for preterm infants, early intervention services may be offered to the family. Early intervention involves specialized services for youth who are considered to be at risk. Because of the high potential of developmental delay for preterm infants, early intervention can be quite beneficial, especially in improving cognitive functioning (Orton, Spittle, Doyle, Anderson, & Boyd, 2009). Early intervention has also been found to be economically smart for both families and healthcare providers as, when started at the appropriate time, early intervention services can minimize negative developmental outcomes (Doyle, Harmon, Heckman & Tremblay, 2009).

For preterm infants and their families, early intervention includes working with a social worker, an OT/PT, or a CCLS who is also an infant developmental specialist trained in how to

help infants born prematurely develop physically, cognitively, and socially. Developmental specialists in the NICU offer developmentally appropriate stimulation with the overall goal of helping the infant reduce stress (Vandenberg, 2007). As Vandenberg states, “the approach to the provision and implementation of developmental care does not focus on the achievement of developmental milestones, nor does it seek to stimulate the infant to demonstrate skills and performance. Rather, individualized developmental care seeks to support the infant's stabilization and organization of the autonomic, motor, and state systems at each level of maturation and while reducing stress” (p. 438).

In accordance with the Individuals with Disabilities Education Act (IDEA), standards of training for personnel working in early intervention are determined by each state (Department of Education, 1998). For example, the Florida Department of Health offers the infant toddler developmental specialist (ITDS) certification through Children’s Medical Services (CMS). CMS requires that for certification as an ITDS, one must first obtain an ITDS certificate by completing Bachelor’s degree in child development or a related field through an approved university, or must document five years experience working in the field (Florida Department of Health, 2009.). This also requires that the ITDS applicant enroll in and complete the Early Steps online modules which includes one module on Infants and Toddlers with Special Needs and one module on Intervention with Children with Medically Complex conditions and/or Intensive Special Needs (Florida Department of Health). Before beginning to work with specific early intervention programs, and ITDS in Florida must also document one year of experience in early intervention or participate in a mentorship program.

Likewise, the North Carolina Early Intervention (NCEI) program, in association with the North Carolina Department of Health and the North Carolina Division of Public Health, offers

online professional development training for those seeking certification in infant and toddler development. The NCEI program focuses on the family and how a child with special needs grows in the family and the community. This focus is maintained through the use of an Individualized Family Service Plans (IFSP) which is generated for each family's needs and is adjusted as the child and family develop over time (NC Department of Health & NC Division of Public Health, 2009).

Newborn Individualized Care and Assessment Plan certification. The Newborn Individualized Care and Assessment Plan (NIDCAP) is a unique early intervention certification program aimed at the education of specialists who work in the NICU (Als, 1986). The main objective of NIDCAP is to provide “effective delivery of intensive and special care in a neurodevelopmentally supportive, individualized, and family-centered framework” (Als, p. 4). The following can be found in the NIDCAP Program Guide: The NIDCAP program provides training for (a minimum of) two developmental specialists, a multidisciplinary leadership support team, and for nurses. The program also provides opportunity to develop a parent council, as well as opportunities for continuing education. The extensive training for professionals includes a three day orientation, and an observational study in which trainees observe preterm infants of different levels of acuity before, during, and after any care is given. In addition, the trainees must also observe full term infants. At the conclusion of the observational study, the trainer works at bedside with the trainee after which the trainee can begin her Advanced Practicum, which is the first test of her competency. During the final stage of training, reliability, the trainer and trainee evaluate the environment from the hospital doors to the infant's bed. At each stage of training, the trainee is provided an opportunity for feedback, reflection, and planning (Als, 1986).

Individualized care for preterm infants in the NICU is very important because these infants are so vulnerable to over stimulation. The NIDCAP program takes into consideration all of the unique developmental needs of this population and seeks to form individualized plans such that each infant is receiving the optimum level of care.

Other Organizations which Provide Training for Improved Care in the NICU

There are several organizations who aim to improve care for infants hospitalized in the NICU. Among these are the National Association of Children's Hospitals and Related Institutions (NACHRI) and the National Association for Neonatal Nurses (NANN). Both of these organizations offer continuing education opportunities for professionals who work in the NICU (NACHRI & N.A.C.H., 2009; NANN, n.d.). Also, the National Association for Neonatal Therapists (NANT) provides education opportunities for occupational and speech therapists as well as speech-language pathologists who work with premature infants (NANT, 2009).

NICU-ED is an organization dedicated to the education of NICU professionals (NICU-ED, 2009). Professionals trained by NICU-ED visit hospitals all over the United States to provide individual hospitals with the most recent research concerning conditions of as well as treatment and care of infants in the NICU.

Current Education and Training in Child Life

Education and training have long been a topic of discussion for the AAP and CLC (Kingson, 1984; Jessee, 1990). Previous to the publication of the position statements of both organizations, there were no guidelines as to what the specific roles of child life specialists were, nor was there any indication of how much education or training a child life specialist needed in order to begin clinical practice. In 1986, the Child Life Council Certifying Commission approved the first child life credentialing tool, and in 1998, the CLC approved the use of an exam for

individual certification (Wojtasik & White, 2009). As of 2004, each child life specialist must obtain certification before beginning independent clinical practice (Wojtasik & White, 2009).

At this time, in order to sit for the certification exam, a CCLS candidate must complete a minimum of ten courses in the field of human development or a related subject, have a baccalaureate degree, and complete a minimum of 480 hours clinical experience in an internship under the supervision of an already certified child life specialist (CLC, n.d.). Once certified, many child life specialists develop an interest in a particular population of hospitalized children, but must develop expertise on their own, with no additional formal training (Jessee, 1990; CLS, 2001; AAP Committee on Hospital Care & CLC, 2006).

Though the CLC now has formal guidelines for the training child life students must have, the specifics of the training process are still rather undefined. Which specific classes and hospital/internship experiences are necessary to the comprehensive education of child life students remains undetermined (CLC, 2000).

Turner and Fralic (2009) note that much of the training of child life students is oral, passed down from supervisor to student during the internship. While this may promote strong relationships between child life staff and students, it also means that each student is, in essence, getting a different training from the next. Many hospitals that accept interns offer learning experiences in several hospital environments (e.g., hematology/oncology, rehabilitation, radiology); however, if a student has an interest in a specific population, but does not have an internship rotation with that population, they must acquire additional education through personal research, on-the-job training, or perhaps through continuing education opportunities.

Another informal tool used to educate child life specialists and students is the CLC online forum. Members of the CLC can post questions or concerns online where others can read and

provide feedback. This system of open communication can be very helpful, especially to those with a unique problem that may not be addressed in a textbook. However, the forum should not be a substitute for formal education and training of child life professionals.

The CLC has set out several Operating Principles of the Child Life Profession (CLC, 2000). Among these are: maintaining the child life profession through education and training programs that are diverse, inclusive, continuous, and consistent with the CLC philosophy; maintaining meaningful credentialing for child life practitioners that addresses professional philosophy and knowledge; and, interfacing with other disciplines that provide interventions to infants, children, youth and families, and collaborating with them in the delivery of services (CLC, 2000, p. 5).

A main focus of the CLC is to advocate for comprehensive education for all child life specialists now and in the future. In order to this, however, more detailed guidelines of the role of child life in multiple hospital settings, and the education needed to sustain that role, need to be outlined.

In particular, because of the unique needs of infants in the NICU, additional education and training are essential to the positive impact of child life services in the NICU. Thus, the purpose of this paper is to investigate current CCLS' function in the NICU, the education and training they receive, and whether or not CCLS feel adequately educated to work with this population. Open-ended questions on the survey allowed participants to express their thoughts on what changes in their education and training would benefit them and their patients.

CHAPTER 3: METHODOLOGY

Participants and Data Collection

After receiving IRB approval through East Carolina University (see Appendix A), participants were recruited through the Child Life Council online forum. The link to the online survey and a message inviting professionals to participate was posted on the forum. Permission to use the forum was acquired from the CLC prior to the first posting (see Appendix B). The invitation along with the link was also e-mailed to personal contacts. The link remained active for a period of five months and the invitation message was re-posted on the forum every two weeks for the first three months. Upon clicking on the survey link, participants were presented with a letter of informed consent (see Appendix C). Participation was voluntary and no compensation was provided. All participants were required to be current certified child life specialists. All surveys were submitted anonymously. The data was downloaded from Qualtrics and stored in password protected files on the principal investigator's computer. Data were analyzed using SPSS 19. Open-ended questions were analyzed by the researcher and themes were developed for appropriate reporting.

Instrument

A survey was developed specifically for this study. While the main research questions were related to education and training of CCLS who work in the NICU, questions concerning care of premature infants were also included. Some examples of research questions are: 1) What are the specific job tasks of CCLS who work in the NICU?, 2) What additional training and education do CCLS who work in the NICU receive prior to beginning this role?, 3) What types of continuing education opportunities about infants in the NICU are offered to CCLS?, 4) Is this training and education sufficient to adequately prepare CCLS to work in the NICU?, and 5)

What changes in their education and training do CCLS think would benefit them and their patients? The entire survey can be found in Appendix C.

Reliability

Eleven subscales were used to address each of the research questions. Cronbach's alphas are provided for each scale. For example, the type of special training received to work with NICU infants was assessed by eight questions. See Table 1 for a full list of reliability values.

Specific job tasks. In order to determine the specific job tasks of a CCLS in the NICU, participants were asked to choose the job tasks from a list of 14 potential duties (e.g. providing developmentally appropriate stimulation, music therapy, procedural support). In an accompanying four item scale participants provided information on how often they are involved in potential additional responsibilities of CCLS in the NICU. These responsibilities were communicating with families via phone or e-mail, scheduling follow-up appointments, hosting NICU reunions, and making home visits. The reliability coefficient for the Additional Responsibilities subscale for this study is $\alpha = .654$.

For this research, participants were also asked to indicate their familiarity with a few common developmental assessment tools. These included the Ages and Stages Questionnaire (ASQ), the Denver Developmental Screening Test (DDST-II), the Revised Early Screening Inventory (ESI-R), and the Hawaii Early Learning Profile (HELP). This reliability coefficient for this four item scale for the current study is $\alpha = .883$.

Specific training. For the current study, eleven aspects of infant care were selected and participants were asked a series of questions regarding their preparedness to provide these types of care when working in the NICU. The care items include auditory stimulation, light

Table 1

Reliability of Subscales

| Name of Scale | Number of Items | Cronbach's Alpha |
|--|-----------------|------------------|
| Specific Job Tasks | | |
| Additional Responsibilities | 4 | .654 |
| Knowledge of Standardized Assessment Tools | 4 | .883 |
| Types of Special Training | 8 | .547 |
| Satisfaction with Internship | 11 | .975 |
| Satisfaction with Training Since Certification | 11 | .962 |
| Professional Preparedness | | |
| General Preparation to Work in NICU | 3 | .707 |
| Preparation to Provide Specific Interventions | 11 | .867 |
| NICU Training/Confidence | 5 | .813 |
| Confidence to Work in NICU | | |
| Comfort Level | 6 | .641 |
| Seeking Other Resources | 7 | .615 |
| Perception and Visibility | 10 | .944 |

stimulation, skin-to-skin contact, comfort positioning, play, music, strategies for pain management, procedural support, providing the family with information regarding early intervention services, educating the family about care after the infant's discharge, and palliative care.

In order to determine what types of specific training CCLS receive prior to beginning work in the NICU, participants were asked to indicate whether or not they had received eight different types of specific training (i.e. formal workshops, informal workshops, updated literature, self-teaching methods, on-the-job training, Child Life Council forum, academic coursework, or no training). The reliability alpha for this eight item subscale is $\alpha = .547$.

Participants were also asked to rate their satisfaction with their training concerning eleven aspects of care for NICU infants during their mandatory internship prior to certification. In a Likert type scale, participants indicated that they were very satisfied to very dissatisfied with their training concerning each specific care item. The reliability coefficient for the Satisfaction with Internship for the current study is $\alpha = .975$.

Continuing education. Participants were able to openly list what types of continuing education they received pertaining to each of the eleven care items. Additionally, participants were able to rate their satisfaction with continuing education using a Likert type scale ranging from very satisfied to very dissatisfied indicating education specific to the eleven care items since becoming certified. This Satisfaction with Training since Certification Scale included 11 items and the reliability coefficient for this study sample is $\alpha = .962$.

Professional preparedness. In order to gauge whether or not this training and education is sufficient to adequately prepare CCLS to work in the NICU, several subscales were used. Participants evaluated their general level of preparedness to work in the NICU by rating their

level of agreement (from Strongly Agree to Strongly Disagree) to the following two statements:

1) I am adequately educated on the basic medical procedures, terminology, etiology, and disease process of NICU infants, and 2) I feel adequately prepared to assess a NICU infant's developmental and emotional needs accurately by using appropriate tools. The reliability coefficient for this subscale for the current study is $\alpha = .707$.

Ability to provide specific interventions was measured by the following statement:

“When working with infants in the NICU, I feel adequately prepared to provide...” Participants were able to rate their level of agreement for this statement for each of the eleven care items. The reliability coefficient for this subscale for the current study is $\alpha = .867$. Finally, participants were able to note their level of agreement with five statements regarding training for NICU CCLS and their confidence to be able to work with this population. This subscale included statements such as: “The training I have received has NOT been sufficient in teaching me how to work with NICU infants” and “I would feel more confident working with NICU infants if I had received more training on the needs of this population.” The reliability alpha for this subscale for the present sample is $\alpha = .813$.

Confidence to work in the NICU. A six item scale including statements such as “It is more comfortable to refer children/families who have MEDICAL questions about their infant to the nurse or doctor” and “It is more comfortable to refer children/families who have DEVELOPMENTAL questions about their infant to the nurse or doctor” measured participants' level of comfort to work in the NICU. The reliability coefficient for this subscale for the current study is $\alpha = .641$. Level of comfort was also assessed by asking participants in a Likert type scale how often they seek out other resources for help including their child life supervisor, library or

internet sources, doctors, nurses, occupational/physical therapists, and other professionals. The reliability alpha for this subscale is $\alpha = .615$.

Perception and visibility. Participants also reported on how they feel they are perceived by other members of the healthcare team. Participants were able to report that they are perceived as a “fully integrated member of the interdisciplinary team,” “an included, but not fully integrated member of the interdisciplinary team,” or they could choose that they “are NOT perceived as a fully integrated member of the interdisciplinary team.” Likewise, participants rated how visible they are to other members of the healthcare team by choosing “Not Visible at All,” “Somewhat Visible,” or “Very Visible.” The reliability coefficient for the Perception and Visibility subscale for this sample is $\alpha = .944$.

Open-ended questions. In addition, the questionnaire contained two open-ended questions: 1) If you previously worked in the NICU, but no longer do, what was your reason for leaving? And, 2) What suggestions do you have to improve training for child life specialists who work in the NICU? Answers to these questions were reviewed and themes are presented below.

Subjects

A total of 127 CCLS participated in the online survey. Of these 127, sixty-nine participants completed the entire survey. Females comprise 100% of the population. A majority of the population was White (95.6%, $n = 66$). Most of the participants are married (56.5%, $n = 39$), however a large percentage are also single/ never-married (36.2%, $n = 25$). The largest part of the group have no children (63.8%, $n = 44$), and eleven participants have one child (15.9%), seven have two children (10.1%), and six have three children (8.7%). See Table 2 for complete demographic information.

Table 2

Demographic Information, N = 69

| Variables | <i>n</i> (%) |
|----------------------------|--------------|
| Gender | |
| Male | 0 |
| Female | 69 (100) |
| Ethnicity | |
| White | 66 (95.6) |
| Black | 0 |
| Hispanic | 1 (1.4) |
| Asian | 1 (1.4) |
| Native American/ Alaska | 0 |
| Native | 1 (1.4) |
| White and Asian | |
| Number of Children | |
| Zero | 44 (63.8) |
| One | 11 (15.9) |
| Two | 7 (10.1) |
| Three | 6 (8.7) |
| Four | 1 (1.4) |
| Five | 0 |
| Relationship Status | |
| Single, Never Married | 25 (36.2) |
| Engaged | 1 (1.4) |
| Married | 39 (56.5) |
| Separated | 0 |
| Divorced | 3 (4.3) |
| Widowed | 1 (1.4) |

Most of the participants work in a freestanding children's hospital (47.8%, $n = 33$), but some also work in a children's hospital within an adult hospital (21.7%, $n = 15$), general hospitals (10.1%, $n = 7$), and adult hospitals with pediatric services (10.1%, $n = 7$). Table 3 includes a full list of the types of facilities in which the participants work. Many of the facilities have more than 200 beds (33.3%, $n = 23$). Additionally, 13% ($n = 9$) have between 101 and 200 beds, and 46.3% ($n = 32$) have zero to 100 beds. The NICUs in these hospitals range from less than ten beds (5.8%, $n = 4$) to more than fifty beds (50.7%, $n = 35$) and range from Level I (15.9%, $n = 11$) to Level III (68.1%, $n = 47$). A total of five participants (7.2%) indicated that their facility does not have a NICU. Just under half (49.3%, $n = 34$) of the NICUs are NIDCAP certified.

Formal education of participants ranges from a Bachelors degree (56.5%, $n = 39$) to a Masters degree (42%, $n = 29$). One participant also indicated having a doctoral degree. Relating to their clinical experience as a child life specialist, most of the participants have between one and five years experience as a CCLS (34.8%, $n = 24$). The next largest percentage of participants have six to ten years experience (24.6%, $n = 17$), and ten participants have less than one year experience (14.4%). See Table 4 for Participant Experience.

In the last year, 60.9% ($n = 42$) of the participants have worked in the NICU as their primary assignment and 39.1% ($n = 27$) have worked both in the NICU and other units. Most of the participants (58%, $n = 40$) have held their primary work assignment in the NICU at some point in their career. Furthermore, twenty of the participants completed a rotation in the NICU during their child life internship prior to certification.

Table 3

Facility Information

| | <i>n</i> (%) |
|--|--------------|
| Type of Facility | |
| Freestanding Children's Hospital | 33 (47.8) |
| General Hospital | 7 (10.1) |
| Children's Hospital within an Adult Hospital | 15 (21.7) |
| Adult Hospital with Pediatric Services | 7 (10.1) |
| Adult Hospital with Maternity Services | 1 (1.4) |
| Women's Hospital | 1 (1.4) |
| Women's and Children's Hospital | 1 (1.4) |
| Number of Pediatric Inpatient Beds | |
| 0-50 | 17 (24.6) |
| 51-100 | 15 (21.7) |
| 101-150 | 4 (5.8) |
| 151-200 | 9 (13) |
| More than 200 | 23 (33.3) |
| Number of Beds in NICU | |
| 0-10 | 4 (5.8) |
| 11-20 | 4 (5.8) |
| 21-30 | 6 (8.7) |
| 31-40 | 8 (11.6) |
| 41-50 | 12 (17.4) |
| More than 50 | 35 (50.7) |

Table 3, continued

Facility Information

| | <i>n</i> (%) |
|---|--------------|
| NICU Level | |
| Level I | 11 (15.9) |
| Level II | 6 (8.7) |
| Level III | 47 (68.1) |
| No NICU | 5 (7.2) |
| CLS Coverage Provided to NICU | |
| Full Time | 36 (52.2) |
| Part Time | 9 (13) |
| On-Call or As Needed | 17 (24.6) |
| We do not provide services in to the NICU | 7 (10.1) |
| NIDCAP Certification | |
| Yes | 34 (49.3) |
| No | 32 (46.4) |

Table 4

Participant Experience

| | <i>n</i> (%) |
|----------------------------|--------------|
| Years of Experience | |
| Less than 1 year | 10 (14.4) |
| 1 to 5 years | 24 (34.8) |
| 6 to 10 years | 17 (24.6) |
| 11 to 15 years | 8 (11.6) |
| 16 to 20 years | 3 (4.3) |
| More than 20 years | 7 (10.1) |
| Current Unit* | |
| NICU | 42 (60.9) |
| Not the NICU | 27 (39.1) |
| Primary Unit** | |
| NICU | 40 (58) |
| Not the NICU | 29 (42) |
| Internship Rotation | |
| NICU and other units | 20 (29) |
| Just other units | 49 (71) |
| NICU Experience | |
| Yes | 51 (73.9) |
| No | 18 (26.1) |

* Within previous year, ** Since certification

Statistical Analysis

Missing data. Though 127 participants clicked on the link in order to complete the survey, several participants did not answer each question. In order to remain conservative, only the group of 69 participants who completed the survey was used in the analysis. Pairwise deletion was used when appropriate for the analyses involving analysis of variance (ANOVA).

Measures. For each research question, descriptive statistics are reported. In addition, ANOVA was used to compare groups of participants. Group definitions are described in detail in the results section.

Participants with NICU experience. In order to compare specialists with and without NICU experience, a new variable was produced by combining the information on current primary unit, previous primary unit, and internship rotation. If a participant currently works in the NICU, they were coded as 1 for “Yes” and 2 for “No.” The same process was used for previous primary unit and internship rotation which indicate whether or not the participant has ever had the primary assignment of NICU or had a NICU rotation during their internship, respectively. Thus, a summed score of three indicates that the participant had a NICU rotation during her internship, has worked in the NICU in the past, and currently works in the NICU. A summed score of four or five indicates that the participant had only two or one of these experiences, respectively. A summed score of six indicates that the participant did not have a NICU rotation during her internship, nor has she ever worked in the NICU. Thus, the variable was recoded so that a score of 3, 4, or 5 indicates that this participant has had NICU experience, and a score of six indicates that the participant has not had NICU experience. This variable was then used as the factor in an ANOVA analysis to determine if those participants who have NICU

experience significantly vary from those who do not on time spent doing particular responsibilities of a CCLS in the NICU.

CHAPTER 4: RESULTS

Specific Roles and Responsibilities of CCLS in the NICU

As discussed above, the responsibilities of child life specialists fall into three broad categories: play, psychological preparation and family support. Within these categories, there are many more specific responsibilities that CCLS perform. Fourteen potential responsibilities were listed on the online survey and participants were asked to note whether or not each is part of the job of a CCLS working in the NICU. Table 5 shows the percentages of participants who responded “yes” to each choice. Sibling support, palliative care, and educating the family were the most commonly reported roles. Providing skin-to-skin contact, music, and information about early intervention services were the least commonly reported. A total of 91.3% ($n = 63$) of participants responded that play is applicable to CCLS in the NICU. Additionally, participants agreed that strategies for pain management (73.9%, $n = 51$) and comfort positioning (87%, $n = 60$) are part of the role of a CCLS in the NICU. Only 15.9% ($n = 11$) agree that all of the choices are aspects of the role of a CCLS in the NICU.

When asked to rank responsibilities of CCLS in the NICU in order of how much time the participant would spend doing this responsibility, most participants ranked providing developmentally appropriate stimulation to the baby (including auditory stimulation, light, skin-to-skin contact, play and music) as the responsibility that they would spend the most time doing.

Next, participants were most likely to rank incorporating principles of family centered care as the responsibility they would spend the most time doing. Each of the remaining responsibilities were ranked in first place by at least two (if not more) participants. Participants

Table 5

*Specific Roles and Responsibilities of CCLS
in the NICU*

| Role | Number of Participants <i>n</i> (%) |
|-----------------------------|---|
| Auditory Stimulation | 62 (89.9) |
| Light Stimulation | 59 (85.5) |
| Skin-to-Skin Contact | 40 (58) |
| Comfort Positioning | 60 (87) |
| Play | 63 (91.3) |
| Music | 40 (58) |
| Pain Management | 51 (73.9) |
| Procedural Support | 54 (78.3) |
| Palliative Care | 67 (97.1) |
| Sibling Support | 68 (98.6) |
| Education for Family | 66 (95.7) |
| DC Planning and Education | 50 (72.5) |
| Instituting FCC | 65 (94.2) |
| Providing EI Services | 39 (56.5) |
| Two to Five of the above | 3 (4.3) |
| Six to Ten of the Above | 9 (13) |
| Eleven to Thirteen of Above | 46 (66.7) |
| All of the Above | 11 (15.9) |

most commonly (24.6%, $n = 17$) ranked providing information about early interventions services in last place, suggesting that they would spend the least amount of time performing this responsibility. Refer to Table 6 for complete information on how much time participants would spend performing specific jobs in the NICU.

Participants with NICU Experience

When specialists with experience were compared to those without experience, there was a significant difference in time spent incorporating the principals of family centered care $F(1, 67) = 4.133, p = .046$. No significance was shown for any of the other responsibilities. See Table 7.

Participants were also asked to provide information on follow-up services they might provide to infants after they have been discharged from the NICU. These services included communicating with the patients' families via phone or e-mail, making follow-up appointments, hosting NICU reunions, and making home visits. The overwhelming majority of the participants are not involved in any of these services. However, 20.3% ($n = 14$) and 21.7% ($n = 15$) of participants occasionally communicate with families and host NICU reunions, respectively. An additional 8.7% ($n = 6$) communicate with families often or very often and 20.3% ($n = 14$) host NICU reunions often or very often.

Participants with and without NICU experience varied significantly on communicating with families, $F(1, 68) = 5.903, p = .018$ and hosting NICU reunions, $F(1, 67) = 11.427, p = .001$. There is no significant difference in making follow-up appointments or making home visits. See Table 8.

Table 6

Time Spent Performing Responsibilities of a CCLS in the NICU

| Responsibility | Ranked as No 1 <i>n</i> (%) | Most Common Ranking <i>(n, %)</i> |
|--|--------------------------------|---|
| Providing developmentally appropriate stimulation to the baby | 30 (43.5) | 1 st (30, 43.5) |
| Providing procedural support to the baby | 3 (4.3) | 2 nd (11, 15.9) |
| Providing strategies for pain management to the baby | 4 (5.8) | 4 th or 5 th (16, 23.2) |
| Providing support to the infant's siblings | 5 (7.2) | 3 rd (19, 27.5) |
| Providing education about procedures to the infant's parents or other family | 5 (7.2) | 5 th (13, 18.8) |
| Providing information about early intervention services | 4 (5.8) | 8 th (26, 37.3) |
| Providing education for the baby's transition to home after discharge | 2 (2.9) | 7 th (21, 30.4) |
| Incorporating family centered care principles into interventions for the infant and family | 16 (23.2) | 1 st (16, 23.2) |

Table 7

Time Spent Performing Responsibilities of a CCLS in the NICU Based on NICU Experience

| Responsibility | <i>df</i> | <i>F</i> | <i>p</i> |
|--|-----------|----------|----------|
| Providing developmentally appropriate stimulation to the baby | 64 | .003 | .958 |
| Providing procedural support to the baby | 59 | .031 | .860 |
| Providing strategies for pain management to the baby | 65 | .162 | .689 |
| Providing support to the infant's siblings | 64 | .095 | .759 |
| Providing education about procedures to the infant's parents or other family | 65 | .079 | .780 |
| Providing information about early intervention services | 62 | .115 | .735 |
| Providing education for the baby's transition to home after discharge | 68 | 2.772 | .101 |
| Incorporating family centered care principles into interventions for the infant and family | 68 | 4.133 | .046* |

* Significant at the $p < .05$ level.

Table 8
Additional Responsibilities of CCLS in the NICU Based on NICU Experience

| Responsibility | <i>df</i> | <i>F</i> | <i>p</i> |
|---|-----------|----------|----------|
| Communication with family members via phone or e-mail | 68 | 5.903 | .018* |
| Involvement in follow-up outpatient appointments | 68 | .760 | .386 |
| NICU Reunion | 67 | 11.427 | .001** |
| Home Visits | 68 | .422 | .518 |

* Significant at the $p < .05$ level, ** Significant at the $p < .001$ level.

Education and Training

Internship

Out of all of the participants, twenty (29%) reported having an internship rotation in the NICU. Internship training will be discussed further in the section concerning the adequacy of CCLS training.

Specific Training

Participants were asked to provide information on the kind of training they receive pertaining to eleven aspects of care specific to NICU infants. Participants most commonly indicated that they receive formal workshops or on-the-job training from other healthcare professionals for each of the eleven care items. CCLS reported receiving training from the CLC forum the least. Next to the CL forum, academic coursework was the least commonly reported form of specific training for each of the items except for play.

The top care items participants reported receiving specific training for are play, comfort positioning, skin-to-skin contact, and palliative care. The bottom two are providing information for discharge and music. Refer to Table 9 for complete information regarding which types of specific training participants received for each care item.

Continuing Education

Participants offered information about the types of continuing education they receive related to infants in the NICU at their institution. Choices for type of continuing education included 1) formal workshops for continuing education credit, 2) informal workshops not for continuing education credit, 3) informal “on-the-job” training from doctors, nurses or other healthcare professionals, 4) updated literature and 5) internet based resources. Formal workshops are the most commonly reported form of continuing education with 63.8% ($n = 44$) of the

Table 9

Specific Training to Work with NICU Infants, n (%)

| | Formal Workshops | Informal Workshops | Updated Literature | Self-Taught Methods | On-the-Job | Academic Courses | CLC ListServe | None |
|----------------------|------------------|--------------------|--------------------|---------------------|------------|------------------|---------------|----------|
| Auditory Stimulation | 23 (33.3) | 27 (39.1) | 23 (33.3) | 23 (33.3) | 27 (39.1) | 13 (18.8) | 6 (8.7) | 6 (8.7) |
| Light Stimulation | 21 (30.4) | 27 (39.1) | 23 (33.3) | 19 (27.5) | 26 (37.7) | 12 (17.4) | 7 (10.1) | 5 (7.2) |
| Skin-to-Skin Contact | 38 (55.1) | 21 (30.4) | 35 (50.7) | 28 (40.6) | 29 (42) | 14 (20.3) | 12 (17.4) | 2 (2.9) |
| Comfort Positioning | 36 (52.2) | 32 (46.4) | 27 (39.1) | 25 (36.2) | 35 (50.7) | 17 (24.6) | 12 (17.4) | 2 (2.9) |
| Play Music | 42 (60.9) | 26 (37.7) | 27 (39.1) | 28 (40.6) | 23 (33.3) | 41 (59.4) | 17 (24.6) | 4 (5.8) |
| Pain Management | 19 (27.5) | 22 (31.9) | 18 (26.1) | 16 (23.2) | 18 (26.1) | 11 (15.9) | 6 (8.7) | 9 (13) |
| | 33 (47.8) | 19 (27.5) | 32 (46.4) | 22 (31.9) | 30 (43.5) | 18 (26.1) | 9 (13) | 4 (5.8) |
| Procedural Support | 28 (40.6) | 21 (30.4) | 23 (33.3) | 22 (31.9) | 27 (39.1) | 21 (30.4) | 8 (11.6) | 4 (5.8) |
| Early Intervention | 13 (18.8) | 22 (31.9) | 14 (20.3) | 19 (27.5) | 26 (37.7) | 22 (31.9) | 6 (8.7) | 8 (11.6) |
| Discharge Education | 9 (13) | 19 (27.5) | 10 (14.5) | 19 (27.5) | 32 (46.4) | 11 (15.9) | 7 (10.1) | 9 (13) |
| Palliative Care | 40 (58) | 20 (29) | 28 (40.6) | 20 (29) | 29 (42) | 22 (31.9) | 12 (17.4) | 3 (4.3) |

participants indicating that their institution provides this type of education. The least commonly reported form of continuing education is informal workshops not for continuing education credit (44.9%, $n = 31$). Participants also added that they receive additional education when they acquire supplementary professional certifications and through professional organizations such as the CLC and NANT. Furthermore, 15.9% ($n = 11$) of the participants indicated that they do not receive any type of continuing education. Please refer to Table 10.

There is a significant difference between participants who have and have not had NICU experience when it comes to receiving formal continuing education, $F(1, 67) = 4.053, p = .048$. There is no significant difference for any of the other four types of continuing education when participants with and without NICU experience are compared. See Table 11.

Continuing Education Based on Facility Type

Participants who work in freestanding children's hospital were the most likely to report receiving each type of continuing education. Those who work in a children's hospital within an adult hospital were the next most likely to report receiving each type of continuing education. In freestanding children's hospitals, general hospitals, and children's hospitals within adult hospitals, formal workshops for continuing education credit was the most commonly reported type of continuing education offered.

Using Other Resources

Participants were asked to provide information about how often they seek out information about NICU infants from other healthcare professionals and resources. For the sake of simplicity, the responses of "Often" and "Very Often" are combined and now referred to as "often." Only 11.5% ($n = 7$) of participants reported seeking information from their child life supervisor often.

Table 10

Continuing Education

| Type of Continuing Education | <i>n</i> (%) |
|--|--------------|
| Formal workshops for continuing education credit | 44 (63.8) |
| Informal workshops NOT for continuing education credit | 31 (44.9) |
| Informal training from doctors, nurses, or other professionals | 37 (53.6) |
| Updated literature | 36 (52.2) |
| Internet based resources | 37 (53.6) |
| I do not receive continuing education or special training | 11 (15.9) |
| Through professional organizations | 4 (5.8) |
| Professional certification | 3 (4.3) |
| 2-3 Types of continuing education | 21 (30.4) |
| 4-6 Types of continuing education | 28 (40.6) |

Table 11

Continuing Education Based on NICU Experience

| | <i>df</i> | <i>F</i> | <i>p</i> |
|--|-----------|----------|----------|
| Formal workshops for continuing education credit | 67 | 4.053 | .048* |
| Informal workshops NOT for continuing education credit | 67 | 1.31 | .256 |
| Informal training from doctors, nurses, or other professionals | 66 | .483 | .489 |
| Updated literature | 67 | 1.715 | .195 |
| Internet based resources | 66 | 1.591 | .212 |
| I do not receive continuing education or special training | 67 | 2.567 | .114 |

* Significant at the $p < .05$ level.

Nurses were the most likely healthcare professional to be sought out for information with 79.7% ($n = 55$) of participants indicating that they do so often. Occupational and physical therapists were the next most likely sought out with 66.6% ($n = 46$) of participants seeking information from them often. Participants also indicated that nurses, doctors, and other professionals often provide them with enough information and appropriately explain equipment and procedures (53.6%, $n = 37$). As well as speaking with other healthcare professionals, 49.3% ($n = 34$) of participants report gathering information from the library or internet sources often.

Integration into the Interdisciplinary Team

In addition to answering questions about which healthcare professionals CCLS turn to for information, participants were asked to specify how they think other healthcare professionals perceive their role in the NICU. Of the participants, most reported that they are perceived as a fully integrated member of the team by nurses (34.8%, $n = 24$), occupational and physical therapists (49.3%, $n = 34$), social workers (46.4%, $n = 32$), and chaplains or other religious personnel (46.4%, $n = 32$). However, most (39.1%, $n = 27$) reported being perceived by doctors as included, but not a fully integrated member of the interdisciplinary team. In accordance with this finding, most participants reported being very visible to nurses (53.6%, $n = 37$), occupational and physical therapists (47.8%, $n = 33$), social workers (47.8%, $n = 33$), and chaplains or other religious personnel (39.1%, $n = 27$), but only somewhat visible to doctors (42%, $n = 29$).

Is this education and training adequate?

General ability to work in the NICU. In addition to the specific care items, participants were asked to state their agreement on their general level of preparedness to work in the NICU. Of these, 69.5% ($n = 48$) agreed that they were adequately educated on the basic medical procedures, terminology, etiology, and disease process of NICU infants and 72.5% ($n = 50$)

agreed that they are adequately prepared to assess a NICU infant's developmental and emotional needs accurately. Refer to Table 12.

Though 40.5% ($n = 28$) of the participants agree that they feel adequately prepared to address medical questions the infant's family might have, 82.6% ($n = 57$) agree that it is more comfortable to refer the families to their nurse or doctor to answer these questions. When it comes to developmental questions, however, 89.8% ($n = 62$) of the participants agree that they are adequately prepared to address these questions. Accordingly, 71% ($n = 49$) disagree that it is more comfortable to refer families with developmental questions to their doctor or nurse. Some participants also suggested that they neither agree nor disagree that it is more comfortable to refer developmental questions to another healthcare professional (23.2%, $n = 16$).

Overall, 72.5% ($n = 50$) of participants feel adequately prepared to assess the developmental needs of NICU infants, while 94.2% ($n = 65$) of participants feel comfortable introducing developmentally supportive interventions to the baby and 92.7% ($n = 64$) feel adequately prepared to advocate for the needs of the infants and their families by maintaining an open dialog with health care staff. Furthermore, 55% ($n = 38$) of the participants feel informed and prepared often when working in the NICU.

When a comparison was drawn between participants with and without NICU experience, there was a significant difference between the two groups on feeling adequately educated concerning NICU medical procedures, terminology, and diseases, $F(1, 67) = 16.877, p = .013$, but no significant difference on feeling prepared to accurately assess the developmental and emotional needs of NICU infants. Refer to Table 13.

There was no significant difference between participants with and without NICU experience regarding their comfort level to address both medical and developmental questions.

Table 12

Preparation to Work in NICU, n (%)

| | Strongly Disagree | Disagree | Neither | Agree | Strongly Agree |
|---|-------------------|-----------|-----------|-----------|----------------|
| Educated on medical procedures, terminology, & diseases | 4 (5.8) | 10 (14.5) | 7 (10.1) | 27 (39.1) | 21 (30.4) |
| Able to assess developmental and emotional needs | 2 (2.9) | 8 (11.6) | 9 (13) | 32 (46.4) | 18 (26.1) |
| Able to use developmental tools | 6 (8.7) | 14 (20.3) | 11 (15.9) | 26 (37.7) | 11 (15.9) |
| Able to address MEDICAL questions | 4 (5.8) | 18 (26.1) | 18 (26.1) | 21 (30.4) | 7 (10.1) |
| Able to address DEVELOPMENTAL questions | 1 (1.4) | 2 (2.9) | 4 (5.8) | 33 (47.8) | 29 (42) |
| More comfortable to refer MEDICAL questions | 0 | 2 (2.9) | 10 (14.5) | 33 (47.8) | 24 (34.8) |
| More comfortable to refer DEVELOPMENTAL questions | 13 (18.8) | 36 (52.2) | 16 (23.2) | 3 (4.3) | 1 (1.4) |
| Adequately prepared to advocate for patient needs | 0 | 2 (2.9) | 3 (4.3) | 29 (42) | 35 (50.7) |
| Comfortable introducing interventions to baby | 0 | 1 (1.4) | 3 (4.3) | 21 (30.4) | 44 (63.8) |

Table 13

Preparation to Work in NICU Based on NICU Experience

| | <i>df</i> | <i>F</i> | <i>p</i> |
|---|-----------|----------|----------|
| Educated on medical procedures, terminology, & diseases | 68 | 16.887 | .000** |
| Able to assess developmental and emotional needs | 68 | 3.086 | .084 |
| Able to use developmental tools | 67 | 6.348 | .014* |
| Able to address MEDICAL questions | 67 | 2.580 | .113 |
| Able to address DEVELOPMENTAL questions | 68 | 3.811 | .055 |
| More comfortable to refer MEDICAL questions | 68 | .856 | .358 |
| More comfortable to refer DEVEL questions | 68 | .080 | .779 |
| Adequately prepared to advocate for patient needs | 68 | .781 | .380 |
| Comfortable introducing interventions to baby | 68 | 5.003 | .029* |

*Significant at the $p < .05$ level; **Significant at the $p < .001$ level

Likewise, there is no significant difference between participants with and without NICU experience when it came to feeling more comfortable referring medical and developmental questions to other healthcare professionals. Finally, there was a significant difference in feeling comfortable in providing interventions to the infant $F(1, 67) = 5.003, p = .029$. No significant difference was found in feeling prepared to advocate for the needs of the infants and their families.

Ability to provide specific interventions. Of the participants, 97.1% ($n = 67$) agree that they are adequately prepared to provide developmentally appropriate play to infants in the NICU. Additionally, 94.2% ($n = 65$) agree that they feel adequately prepared to provide comfort positioning. Participants indicated that they felt most prepared to provide these two types of care. The care item participants felt they were least prepared to provide is information about early intervention services with only 50.7% ($n = 35$) of participants indicating agree for this question and 33.3% ($n = 23$) disagreeing that they are prepared to provide such information. These values can be found in Table 14. When a comparison is made, there is a significant difference between participants with and without NICU experience on nine of the eleven care items (except providing strategies for pain management and providing procedural support). Significance levels for this analysis can be found in Table 15.

Standardized assessment tools. Around 40% of the participants reported being aware of each assessment tool (i.e. the ASQ, DDST-II, ESI-R, and HELP), however, only 4.3% routinely use the ASQ and the DDST-II, 1.4% the ESI-R, and 7.2% the HELP. A few of the participants indicated that they were not aware of the tools: ASQ, 2.9%; ESI-R, 13%; and HELP, 10.1%. Many of the participants, however, noted that they would like to receive training on how to use each of the tools: ASQ, 23.2% ($n = 16$); DDST-II, 14.5% ($n = 10$), ESI-R, 34.8% ($n =$

Table 14

Preparation to Provide Specific Interventions, n (%)

| | Strongly Agree | Agree | Neither Agree/Disagree | Disagree | Strongly Disagree |
|----------------------|----------------|-----------|------------------------|-----------|-------------------|
| Auditory Stimulation | 35 (50.7) | 29 (42) | 4 (5.8) | 1 (1.4) | 0 |
| Light Stimulation | 35 (50.7) | 28 (40.6) | 4 (5.8) | 2 (2.9) | 0 |
| Skin-to-Skin Contact | 29 (42) | 20 (29) | 11 (15.9) | 8 (11.6) | 1 (1.4) |
| Comfort Positioning | 41 (59.4) | 24 (34.8) | 2 (2.9) | 2 (2.9) | 0 |
| Play | 47 (68.1) | 20 (29) | 0 | 1 (1.4) | 1 (1.4) |
| Music | 25 (36.2) | 33 (47.8) | 8 (11.6) | 2 (2.9) | 1 (1.4) |
| Pain Management | 23 (33.3) | 33 (47.8) | 7 (10.1) | 4 (5.8) | 1 (1.4) |
| Procedural Support | 33 (47.8) | 31 (44.9) | 2 (2.9) | 3 (4.3) | 0 |
| Early Intervention | 15 (21.7) | 20 (29) | 10 (14.5) | 22 (31.9) | 1 (1.4) |
| Discharge Education | 18 (26.1) | 27 (39.1) | 12 (17.4) | 11 (15.9) | 1 (1.4) |
| Palliative Care | 31 (44.9) | 30 (43.5) | 5 (7.2) | 3 (4.3) | 0 |

Table 15

Ability to Provide Specific Interventions Based on NICU Experience

| Intervention | <i>df</i> | <i>F</i> | <i>p</i> |
|----------------------|-----------|----------|----------|
| Auditory Stimulation | 68 | 5.476 | .022* |
| Light Stimulation | 68 | 13.598 | .000** |
| Skin-to-Skin Contact | 68 | 5.111 | .027* |
| Comfort Positioning | 68 | 4.239 | .043* |
| Play | 68 | 14.222 | .000** |
| Music | 68 | 6.596 | .012* |
| Pain Management | 67 | 1.024 | .315 |
| Procedural Support | 68 | 2.828 | .097 |
| Early Intervention | 67 | 6.779 | .011* |
| Discharge Education | 68 | 5.751 | .019* |
| Palliative Care | 68 | 6.851 | .011* |

* Significant at the $p < .05$ level, **Significant at the $p < .001$ level

24); and HELP, 33.3% ($n = 23$). Please see Table 16 for results concerning standardized assessment tools. A few participants also indicated that they are aware of or use the Newborn Behavioral Observation (NBO), the Developmental Assessment of Young Children (DAYC), the Bayley Scales of Infant Development, the Development Profile III (DP-III) and NIDCAP.

There was no significant difference on knowledge and use of standardized assessment tools based on NICU experience, NICU employment status (e.g. part time, full time), or years of experience in pediatric healthcare.

Satisfaction with Education and Training

For those participants who had an internship rotation in the NICU, few reported being very satisfied with their internship training for each specific care item. Refer to Table 17 for information regarding participant satisfaction with their internship training. Of these participants, 18.8% ($n = 13$) responded that they were very satisfied with their training concerning play. The lowest reported satisfaction was with providing education to the family about the infant's transition to home after discharge with only 2.9% ($n = 2$) of participants being very satisfied and 8.6% ($n = 6$) being dissatisfied or very dissatisfied. Participants most commonly reported being dissatisfied or very dissatisfied with their internship training concerning early intervention services (11.6%, $n = 8$). For each of the other care items, most people reported being either somewhat satisfied or neutral.

When asked to rate their satisfaction with their training since becoming certified, again, participants were very satisfied with their training about play (42%, $n = 29$). For early intervention, providing discharge education, and providing light stimulation only 13% ($n = 9$) of participants indicated they were very satisfied with their training. Most participants answered

Table 16

Knowledge of Standardized Assessment Tools, n (%)

| Tool | Aware of Tool | Able to Use Tool | Routinely Use Tool | Would Like Training | Aware and Like Training | Able to Use, Routinely Use | Aware and Able | Not Aware |
|---------|---------------|------------------|--------------------|---------------------|-------------------------|----------------------------|----------------|-----------|
| ASQ | 29 (42) | 13 (18.8) | 2 (2.9) | 16 (23.2) | 6 (8.7) | 1 (1.4) | 0 | 2 (2.9) |
| DDST II | 25 (36.2) | 23 (33.3) | 1 (1.4) | 10 (14.5) | 8 (11.6) | 2 (2.9) | 0 | 0 |
| ESIR | 28 (40.6) | 7 (10.1) | 0 | 24 (34.8) | 0 | 1 (1.4) | 0 | 9 (13) |
| HELP | 26 (37.7) | 6 (8.7) | 4 (5.8) | 23 (33.3) | 2 (2.9) | 1 (1.4) | 0 | 7 (10.1) |

Table 17

Satisfaction with Internship Education/Training, n (%)

| Care Item | Very Satisfied | Satisfied | Somewhat Satisfied | Neutral | Somewhat Dissatisfied | Dissatisfied | Very Dissatisfied | NA |
|----------------------|----------------|-----------|--------------------|---------|-----------------------|--------------|-------------------|-----------|
| Auditory Stimulation | 6 (8.7) | 6 (8.7) | 4 (5.8) | 4 (5.8) | 1 (1.4) | 1(1.4) | 3 (4.3) | 42 (60.9) |
| Light Stimulation | 5 (7.2) | 7 (10.1) | 3 (4.3) | 4 (5.8) | 2 (2.9) | 1 (1.4) | 3 (4.3) | 42 (60.9) |
| Skin-to-Skin Contact | 3 (4.3) | 9 (13) | 4 (5.8) | 3 (4.3) | 5 (7.2) | 1 (1.4) | 4 (5.8) | 38 (55.1) |
| Comfort Positioning | 7 (10.1) | 9 (13) | 6 (8.7) | 0 | 2 (2.9) | 3 (4.3) | 4 (5.8) | 36 (52.2) |
| Play | 13 (18.8) | 13 (18.8) | 3 (4.3) | 1 (1.4) | 1 (1.4) | 1 (1.4) | 2 (2.9) | 33 (47.8) |
| Music | 4 (5.8) | 6 (8.7) | 8 (11.6) | 6 (8.7) | 2 (2.9) | 1 (1.4) | 3 (4.3) | 37 (53.6) |
| Pain Management | 8 (11.6) | 10 (14.5) | 5 (7.2) | 4 (5.8) | 2 (2.9) | 2 (2.9) | 2 (2.9) | 34 (49.3) |
| Procedural Support | 7 (10.1) | 13 (18.8) | 3 (4.3) | 2 (2.9) | 2 (2.9) | 3 (4.3) | 2 (2.9) | 35 (50.7) |
| Early Intervention | 3 (4.3) | 5 (7.2) | 4 (5.8) | 6 (8.7) | 1 (1.4) | 4 (5.8) | 4 (5.8) | 40 (58) |
| Discharge Education | 2 (2.9) | 4 (5.8) | 5 (7.2) | 9 (13) | 1 (1.4) | 3 (4.3) | 3 (4.3) | 40 (58) |
| Palliative Care | 4 (5.8) | 6 (8.7) | 8 (11.6) | 4 (5.8) | 3 (4.3) | 1 (1.4) | 2 (2.9) | 39 (56.5) |

that they were satisfied or somewhat satisfied with their training concerning each of the care items since becoming certified. See Table 18.

A comparison was made for satisfaction with training/education since becoming certified concerning each of the care items based on the participant's years of experience. There was a significant difference for play, $F(5, 58) = 3.541, p = .007$, early intervention, $F(5, 55) = 3.163, p = .014$, and discharge education, $F(5, 55) = 3.940, p = .004$. Further, the difference for palliative care approached significance, $F(5, 58) = 2.366, p = .051$. Refer to Table 19. For early intervention and discharge education, this difference only existed between those with less than one year experience and those with more than 20 years experience. For play, the difference was significant between those with less than one year experience and those with six to ten years experience as well as between those with less than one year experience and those with more than 20 years experience.

Of the participants, 40.6% ($n = 28$) agree that they would enjoy working in the NICU more if they were better trained to do so. Additionally, 55% ($n = 38$) agree they would feel more confident working with NICU infants if they had received training on the needs of this population. In accordance 69.6% ($n = 48$) wish they had more training to work with NICU infants. Though 91.3% ($n = 63$) of participants agree that education for child life professionals should include information specific to NICU infants, a third (33.3%, $n = 23$) agree that their training has not been sufficient to work with this population. Please see Table 20.

There is a significant difference between participants with and without NICU experience on who believed that their training was not sufficient to work in the NICU, $F(1, 64) = 5.618, p = .021$. Also, the difference for participants who wish they had more training to work in the NICU approached significance, $F(1, 63) = 3.802, p = .056$. Please see Table 21.

Table 18

Satisfaction with Education/Training since Becoming Certified, n (%)

| Care Item | Very Satisfied | Satisfied | Somewhat Satisfied | Neutral | Somewhat Dissatisfied | Dissatisfied | Very Dissatisfied |
|----------------------|----------------|-----------|--------------------|-----------|-----------------------|--------------|-------------------|
| Auditory Stimulation | 10 (14.5) | 18 (26.1) | 12 (17.4) | 10 (14.5) | 4 (5.8) | 7 (10.1) | 2 (2.9) |
| Light Stimulation | 9 (13) | 20 (29) | 12 (17.4) | 10 (14.5) | 3 (4.3) | 7 (10.1) | 1 (1.4) |
| Skin-to-Skin Contact | 22 (31.9) | 15 (21.7) | 6 (8.7) | 12 (17.4) | 2 (2.9) | 5 (7.2) | 1 (1.4) |
| Comfort Positioning | 23 (33.3) | 21 (30.4) | 6 (8.7) | 6 (8.7) | 2 (2.9) | 5 (7.2) | 1 (1.4) |
| Play | 29 (42) | 18 (26.1) | 6 (8.7) | 5 (7.2) | 0 | 4 (5.8) | 2 (2.9) |
| Music | 12 (17.4) | 19 (27.5) | 10 (14.5) | 13 (18.8) | 2 (2.9) | 5 (7.2) | (2.9) |
| Pain Management | 14 (20.3) | 22 (31.9) | 11 (15.9) | 10 (14.5) | 1 (1.4) | 5 (7.2) | 1 (1.4) |
| Procedural Support | 17 (24.6) | 23 (33.3) | 6 (8.7) | 10 (14.5) | 2 (2.9) | 5 (7.2) | 1 (1.4) |
| Early Intervention | 9 (13) | 13 (18.8) | 10 (14.5) | 15 (21.7) | 6 (8.7) | 7 (10.1) | 1 (1.4) |
| Discharge Education | 9 (13) | 14 (20.3) | 8 (11.6) | 14 (20.3) | 7 (10.1) | 7 (10.1) | 2 (2.9) |
| Palliative Care | 21 (30.4) | 14 (20.3) | 9 (13) | 12 (17.4) | 1 (1.4) | 6 (8.7) | 1 (1.4) |

Table 19

Satisfaction with Education/Training since Becoming Certified Based on Years of Experience

| Care Item | <i>df</i> | <i>F</i> | <i>p</i> |
|----------------------|-----------|----------|-------------------|
| Auditory Stimulation | 62 | 1.152 | .344 |
| Light Stimulation | 61 | 1.228 | .308 |
| Skin-to-Skin Contact | 62 | 1.067 | .388 |
| Comfort Positioning | 63 | 1.083 | .379 |
| Play | 63 | 3.541 | .007* |
| Music | 62 | 2.085 | .081 |
| Pain Management | 63 | 1.475 | .212 |
| Procedural Support | 63 | 1.583 | .179 |
| Early Intervention | 60 | 3.163 | .014* |
| Discharge Education | 60 | 3.940 | .004* |
| Palliative Care | 63 | 2.366 | .051 ^a |

* Significant at the $p < .05$ level, ^a Approaches significance

Table 20

NICU Training and Confidence, n (%)

| | Strongly Agree | Agree | Neither | Disagree | Strongly Disagree |
|---|----------------|-----------|-----------|-----------|-------------------|
| Education for CL professionals should include info specific to NICU | 44 (63.8) | 19 (27.5) | 3 (4.3) | 0 | 1 (1.4) |
| Training received has NOT been sufficient | 9 (13) | 14 (20.3) | 16 (23.2) | 17 (24.6) | 10 (14.5) |
| Enjoy working in NICU more with better training | 14 (20.3) | 14 (20.3) | 26 (37.7) | 7 (10.1) | 3 (4.3) |
| I wish I had more training | 18 (26.1) | 30 (43.5) | 14 (20.3) | 3 (4.3) | 0 |
| I would feel more confident with more training | 15 (21.7) | 23 (33.3) | 20 (29) | 5 (7.2) | 2 (2.9) |

Table 21

NICU Training and Confidence Based on NICU Experience

| | <i>df</i> | <i>F</i> | <i>p</i> |
|--|-----------|----------|-------------------|
| Education for CL professionals should include info specific to NICU | 66 | .019 | .891 |
| Training received has NOT been sufficient | 65 | 5.618 | .021* |
| Enjoy working in NICU more with better training | 63 | 2.337 | .131 |
| I wish I had more training | 64 | 3.802 | .056 ^a |
| I would feel more confident with more training | 64 | .802 | .374 |

* Significant at the $p < .05$ level, ^a Approaches significance

Additional Education and Training

Participants were asked to suggest what type of education/training concerning each of the eleven care items would be most beneficial to their practice. For each care item formal workshops for continuing education was the most popular answer. In addition professional certification, namely Certified Infant Massage Instructor, was listed for skin-to-skin contact.

Open-Ended Questions

Participants Who No longer Work in the NICU

In answer to the question for participants who previously worked in the NICU, but no longer do, no participants reported a lack of training/education or confusion about their role as a reason for why they no longer work in the NICU.

Participant Suggestions for Changing Training and Education

Several suggestions on how to improve the training and education of CCLS who work in the NICU were made. The most common suggestion was clear and specific education about typical infant development and the specific developmental needs and medical issues of premature infants ($n = 11$). Along with this, participants proposed a standard curriculum ($n = 6$) noting specifically that more education concerning the needs of parents and siblings of NICU infants ($n = 3$) as well as education about early intervention services ($n = 1$) and childhood standardized assessments ($n = 2$) should be available. Also recommended by some participants were more opportunities to shadow and have hands-on training with current specialists who work in the NICU ($n = 8$). Others suggested that appropriate mediums for this education and training would be an internship rotation in the NICU ($n = 6$) or professional conferences ($n = 5$). Others mentioned that additional certifications (i.e. CIMI ($n = 3$) and NIDCAP ($n = 4$)) would be beneficial, and it was recommended that other healthcare professionals be provided education on

the role of child life specialists in the NICU ($n = 2$). For a complete list of the suggestions, please refer to Table 22.

Table 22

Participant Suggestions for Improving Training/Education of Child Life Professionals

| Suggestion | <i>n</i> |
|--|----------|
| Clear and specific training/education on typical infant development and the specific developmental needs and medical issues of premature infants | 11 |
| Opportunities for shadowing and hands-on training | 8 |
| Standardized curriculum | 6 |
| NICU internship rotation | 6 |
| Education at conferences | 5 |
| NIDCAP training | 4 |
| CIMI certification | 3 |
| Education on the needs of parents and siblings of NICU infants | 3 |
| Education on standardized assessments | 2 |
| Training for other NICU staff | 2 |
| Education on early intervention services | 1 |
| Easier access to information | 1 |
| Make the NICU a dedicated unit (not a coverage unit) | 1 |
| Require sufficient training and education on NICU infants/families prior to certification | 1 |

CHAPTER 5: DISCUSSION, IMPLICATIONS, AND CONCLUSION

Specific Roles and Responsibilities of CCLS in the NICU

One of the purposes of this research is to determine the specific roles and responsibilities of CCLS who work in the NICU. The results of this study indicate that current CCLS have differing opinions as to which specific child life tasks are also applicable to CCLS in the NICU. Interestingly, only 91.3% ($n = 63$) responded that play is a responsibility of CCLS in the NICU. Because both the AAP and the CLC maintain that play is one of the essential roles of any CCLS (AAP Committee on Hospital Care & CLC, 2006; CLC, 2000), it is noteworthy that not every participant agrees that play is within the realm of responsibilities of a CCLS working with this specific population. Likewise, strategies for pain management and comfort positioning are well within the responsibilities of CCLS in other units (Rollins, et al., 2005; Thompson, 2009). However, only 73.9% ($n = 51$) and 87% ($n = 60$), respectively, of participants responded that these were part of the role of a CCLS in the NICU.

Several (26.1%, $n = 18$) of the participants do not have any NICU experience (i.e. an internship rotation, previous work experience, currently work in the NICU) so they may not be fully aware of the day-to-day responsibilities a CCLS working in this environment carries out. Though they may play with, provide comfort positioning and strategies for pain management for patients on other units, and are likely aware of the vulnerability of this population, without hands-on experience, the participants may not be educated on how to play with or provide other interventions to the infants. The participants may be cognizant of the fact that they would not use the same type of play methods or techniques for other interventions with a medically fragile infant and without being completely sure of what types of interventions they would be allowed to provide to such an infant, answered that these specific responsibilities then do not fall within the

realm of the role of a child life specialist. Clear guidelines on how child life specialists should operate within the NICU environment would eliminate this confusion and would also lay the foundation to design a more standard curriculum for the education of future child life specialists.

Participants offered a variety of responses when asked to rank the specific responsibilities of a CCLS in the NICU in order of how much time they would spend doing each. The fact that each responsibility was ranked in first place by at least two of the participants indicates that there is confusion as to which responsibilities CCLS prioritize in the NICU and that the participants do not have a standard way of prioritizing their day. This may be because each patient and each day are different and CCLS must offer interventions on a case by case basis. One day a CCLS may spend most of the day providing developmental stimulation to the infants, and the next spend most of their time providing another intervention based on the needs of the patients and families in the NICU that day. Rankings may also depend on the individual participant's philosophy of child life or the policies of their institution. Though the CLC maintains that play, psychosocial support, and family support are the three main components of child life (CLC, 2000), each person will have their own interpretation of which is most important. Likewise, each facility, based on staffing and resources, may place greater focus on one of these components over the others. Research concerning the motivation behind performing each of the responsibilities may shed some light on why considerable differences in responses to this question exist.

Also interesting to note is that a majority (98.6%, $n = 68$) of participants agreed that sibling support is a responsibility of CCLS in the NICU. This responsibility was chosen by more participants than any other responsibility. However, just over 7% ($n = 5$) suggested that this was the responsibility that they would spend the most time doing. One would think that the amount of time spent performing a child life responsibility would correspond with the number of

participants who chose that responsibility as a part of the role of a CCLS in the NICU. This data suggests that participants are aware that sibling support is indeed a responsibility of CCLS in the NICU, however, there is question as to why they would not spend much time performing this duty.

Additional responsibilities of CCLS in the NICU could include communicating with the patients' families via phone or e-mail, making follow-up appointments, hosting NICU reunions, and making home visits. Participants with and without NICU experience varied significantly on communicating with families and hosting NICU reunions. Participants with NICU experience would most likely be involved in these activities more often than those without experience. Few participants reported making follow-up appointments (10.1%, $n = 7$) or making home visits (1.6%, $n = 1$) often or very often and there was no significant difference between the two groups for these two responsibilities suggesting that at this point in time, these are not responsibilities of CCLS who work in the NICU.

Education and Training

Specific Training

Formal workshops were the most commonly reported form of specific training participants receive pertaining to NICU infants. This will be discussed in the next section on continuing education. The reliability of the subscale concerning training specific to NICU infants was quite low ($\alpha = .547$). This indicates that the participants received varying types of special training concerning this population. More specifically, next to using the CLC online forum, participants were least likely to report receiving education about the eleven care items throughout their academic coursework. This suggests that the education received in college does not often provide information specific to NICU infants and that, perhaps, internship supervisors

are the first to educate novice child life students unless the student takes it upon themselves to gather information from other resources. Previous research (Jessee, 1990; Turner & Fralic, 2009) indicates that most of the training of new child life specialists occurs through a transfer of knowledge from certified child life specialist to student. It is not clear from this research whether this is so because academic coursework does not cover specific material or because students are more apt to learn in a hands-on environment.

It is impossible for a textbook or a college course to cover all of the intricacies of the field of child life, however, because there is a growing number of premature births (IOM, 2006) it is now becoming more important to educate all healthcare professionals on the needs of this population. For example, an OT, another member of the multidisciplinary team within the NICU has special guidelines for knowledge and skills necessary to work with this population. The OT certifying body, AOTA (2006), does not recommend that OTAs be involved in caring for NICU infants. Likewise, AOTA advises entry-level OTs to gain pediatric experience before beginning practice with NICU infants and suggests that any OT working in the NICU be well-versed in “pediatric occupational therapy with infants and young children, longitudinal follow-up of infants treated in the NICU, and collaboration with families” (AOTA, 2006, p.2). AOTA also emphasizes specific knowledge and skills an OT must possess prior to beginning independent clinical work in the NICU. Such detailed guidelines are beneficial to the practice of OTs in the NICU. Similar rules of practice for the education and training of CCLSs would be valuable for CCLS who want to work in the NICU.

Continuing Education

Formal workshops for continuing education credit were the overall most common form of special training reported. This may be because to maintain certification with the CLC, a child life

specialist must submit proof of a certain number of continuing education credits or they will have to retake the certification exam. Facilities may provide this type of training most often because it is an official way to ensure that their staff is maintaining a particular standard of education. The participants also most commonly reported wanting formal workshops rather than any other type of continuing education. This may be because this type of workshop will help them maintain certification whereas none of the other options would directly do so. Also, participants may feel as if they absorb and retain more information in a formal workshop setting. Though all of the other options (e.g. on-the-job training, updated literature) are viable methods for disseminating information, they might not be as effective as a formal workshop.

It is important to note, however, that only about half of participants indicated receiving each type of continuing education. One must ask why some participants reported that they do not receive continuing education or only receive a small amount. With limited time and resources, formal workshops may give the institution and the CCLS “more bang for their buck” as they can learn a lot of information in a little amount of time and also provide proof of education for re-certification purposes. It may also be true that the institution provides many types of continuing education, but perhaps not specific to infants in the NICU. Also, it may be the case that participants who do not work in the NICU do not take full advantage of continuing education about the NICU opting rather for education that is more specifically applicable to the unit in which they currently work.

Using Other Resources

Along with specific training and opportunities for continuing education, participants were asked how often they consult other healthcare professionals or other resources for information concerning working in the NICU. Few (11.5%, $n = 8$) indicated that they seek information from

their child life supervisor. This may be due to the fact that CCLS may not work in direct contact with their supervisor on a day to day basis depending on how their hospital is staffed. It is perhaps more convenient for a CCLS to consult a nurse who is likely readily available at the patient's bedside all day. Indeed almost 80% ($n = 55$) of participants indicated that they seek information from nurses often or very often. A good part (66.6%, $n = 46$) of the participants also reported consulting occupational and physical therapists for information. When CCLS have specific questions about an infant, it may be more advantageous to seek advice from another healthcare professional rather than their child life supervisor.

Integration into the Interdisciplinary Team

When asked to identify how they feel other healthcare professionals perceive their role as CCLS, the participants indicated that they are perceived as a fully integrated and very visible team member by nurses, occupational and physical therapists, social workers, and chaplains or other religious personnel. The participants report, however, that doctors perceive them as only somewhat visible and only being an included, but not fully integrated member of the team. For some reason, current CCLS believe that doctors do not perceive them as a full member of the healthcare team. This may have to do with the actual amount of time CCLS spend in contact with the doctors versus the amount of time they spend with the other healthcare professionals. With busy schedules and large case loads, doctors may be inaccessible to the child life staff who thus find it easier to contact a nurse or other healthcare professional with questions or when they need to provide information about a patient. Perhaps CCLS are intimidated by doctors and opt to contact who they perceive to be a more approachable member of the healthcare team. It may also be that doctors are not fully aware of the role of child life specialists and therefore do not

appreciate them as much as they could. More research is necessary before coming to a conclusion about this matter.

Is this Education and Training Adequate?

General ability to work in the NICU. In determining the adequacy of training/education CCLS receive to work with such a unique population most participants (89.8%, $n = 62$) agreed that they feel prepared to answer developmental questions that the infants' families might have. Likewise, most participants felt strongly that would answer these types of questions themselves rather than consulting a doctor or another healthcare professional. However, when it came to medical questions, most participants (69.5%, $n = 48$) indicated that though they are familiar with the basic medical procedures, terminology, etiology, and disease process of NICU infants, it is more comfortable to involve a doctor when a patient's family has medical questions (82.6%, $n = 57$). This finding is in line with the CLC and AAP's position statements (CLC, 2000; AAP Committee on Hospital Care & CLC, 2006) on the role of child life in healthcare settings. The job of a CCLS is to play and to provide psychosocial and family support. It is not within a CCLS' realm of expertise to answer medical questions, though they need to be thoroughly educated on medical procedures etc in order to provide accurate information and effective interventions to patients and their families. It is their responsibility to answer developmental questions, though, and the CCLS must know when it is appropriate to provide information to the family and when it is best to involve a more knowledgeable healthcare professional.

Overall, most participants agreed that they are adequately prepared to assess a NICU infant's developmental and emotional needs accurately (72.5%, $n = 50$), feel comfortable introducing developmentally supportive interventions to the baby (94.2%, $n = 65$) and feel

adequately prepared to advocate for the needs of the infants and their families (92.7%, $n = 64$) by maintaining an open dialog with health care staff. Despite the lack of specific education and continuing education, current CCLS feel informed and prepared when working with infants in the NICU.

Not surprisingly, there was a significant difference between participants with and without NICU experience when it came to their knowledge of the basic medical procedures, terminology, etiology, and disease process of NICU infants, but there was no difference in feeling prepared to accurately assess the developmental and emotional needs of NICU infants. This suggests that all CCLS, regardless of NICU experience feel equally prepared to correctly assess infant needs, but not all feel just as educated about the medical aspects of the NICU. Similarly, there was a difference between groups in their comfort level to provide interventions to the baby. Those participants who have experience may well be more knowledgeable and more capable of working directly with the infants and thus would feel more comfortable offering specific interventions.

Ability to provide specific interventions. For each of the eleven care items (e.g. auditory stimulation light stimulation, skin-to-skin contact), most participants agreed that they were adequately prepared to provide each to infants in the NICU. However, only 50.1% ($n = 35$) agreed that they are prepared to offer information regarding early intervention services. Why participants do not feel prepared to educate families about early intervention services is unclear. Participants did not report receiving much specific training related to providing information about early intervention services and would perhaps feel more prepared to do so if they had received more training on this topic. It may be the case that early intervention services fall within the job responsibilities of other healthcare professionals. For example, at some institutions, social

workers may be in charge of educating families about these services. However, CCLS can reinforce the benefits of early intervention with families. More research is necessary to determine if early intervention is a duty of child life specialists, and if it is, why current CCLS do not feel adequately prepared to provide such services.

There was a significant difference between participants with and without NICU experience for nine of the eleven care items. The two care items for which there was no difference were strategies for pain management and providing procedural support. This suggests that all CCLS, regardless of NICU experience, feel equally about their ability to provide these two types of interventions.

Standardized assessment tools. Standardized assessment tools can be a helpful resource to CCLS working in the NICU. They provide specific guides by which to measure infant development and can aid the CCLS in choosing the most appropriate and developmentally beneficial interventions for their patients. When looking at the percentages of participants who use standardized assessment tools, it is evident that many are aware of several of these tools, most do not know how to use each tool and do not routinely use it in their practice. Turner and Fralic (2009) note that the assessment process of child life specialists is an ongoing process that depends on relationships that the specialist builds with patients and their families. It may be that using a time-consuming standardized questionnaire proves to be cumbersome and impedes the formation of relationships with the families of NICU infants. However, Turner and Fralic (2009) also emphasize the importance of observation in assessment. Becoming familiar with standardized assessment tools may educate current CCLS on what to look for when assessing their patients and families and may thus help them make a better overall evaluation of the infants' and families' needs. Questions as to why these tools are or are not used were not asked,

so further research is necessary to determine why this type of resource is not often used by current CCLS.

Satisfaction with Education and Training

Unfortunately, many (71%, $n = 49$) of the participants did not have a rotation in the NICU during their internship. Only a small percentage of those participants with a NICU internship indicated that they were very satisfied with their education and training concerning the eleven care items during this time. Most participants did however indicate they were satisfied or somewhat satisfied with their education and training for most of the items. Early intervention services and transfer to home following discharge were the two care items with which participants reported being most dissatisfied. Specifically, 8.7% ($n = 6$) and 13% ($n = 9$), respectively, indicated neutral and 11.6% ($n = 8$) and 8.7% ($n = 6$), respectively, reported being dissatisfied with their education and training. Furthermore, participants were least likely to report being satisfied with their education and training concerning these two care items since becoming certified. This suggests that current CCLS are not well educated and trained on these two topics and may therefore not be able to adequately educate and train child life interns appropriately. This cycle of insufficient education needs to be broken by providing more effective and universal opportunities for learning for both already certified child life specialists and interns.

The CLC (2000) does have a standardized list of competencies for all CCLS. These competencies include a list of the knowledge and skills CCLS must be proficient in before completing their internship and must sustain competence in to maintain certification. As of today, these competencies serve as the basis of practice for all CCLS regardless of the environment in which they work. In other words, no specific competencies are outlined and no additional certification is required to practice in the NICU. This is similar to some other

healthcare professionals who work in the NICU. For example, nurses require no additional education to work in the NICU unless they wish to become a neonatal nurse practitioner (All Star Directories, 2010). However, it is recommended that music therapists learn specialized protocols (Gooding, 2010). Likewise, OTs have a specific list of NICU competencies (AOTA, 2006), and PTs must acquire a certification in pediatric physical therapy before beginning clinical practice with pediatric patients (APTA, 2011). CCLS may be more satisfied with their education and training and be more prepared to work with the NICU population if they knew specifically what knowledge and skills are necessary to begin clinical work in the NICU.

For the set of questions on the survey concerning satisfaction with education and training concerning the eleven care items during the internship, participants had the option of answering “Not Applicable.” This answer choice was intended for those participants who did not have a NICU rotation during their internship, however the number of participants who checked this option changed for each care item. This change may have occurred because participants who did have a rotation in the NICU but did not receive training or education about a particular care item also checked “Not Applicable.” It may be that some participants simply were not educated about certain care items at all. However, more specific research would be necessary to draw this conclusion.

A higher percentage of participants indicated being very satisfied with their training/education since becoming certified. Participants most commonly reported being very satisfied with their training and education concerning play since becoming certified (42%, $n = 29$). This finding complements the fact that participants also reported receiving the most forms of specific training and continuing education about play. Also, more participants (75.6%, $n = 52$)

indicated being adequately prepared to play with NICU infants than provide any of the other care items.

When a comparison was made between those participants based on their years of experience in the field of child life, there was a difference for play, early intervention, and discharge education. The value for palliative care also approached significance. This indicates that for these four care items, those participants with more experience were more likely to be satisfied with their training and education. Interestingly, for early intervention and discharge education, this difference only existed between participants with less than one year experience and those with more than 20 years experience. Those with a greater amount of experience would simply have more training or education and may thus be more satisfied with it, however this finding may also indicate that it takes upwards of 20 years to become truly comfortable providing these two care items to patient families. It may reflect that not much specific training or continuing education pertaining to those items is available, as reported by the participants of this study.

Most puzzling of all is the fact that though few participants indicated receiving specific training or continuing education for each of the eleven care items, most participants indicated that they are satisfied with their training since becoming certified and agree that they are adequately prepared to provide these types of care to NICU infants and their families. Only a third of the participants agreed that their training and education were not sufficient to work with the NICU population. There are a few plausible explanations for this result. First, it is possible that the limited amount of specific education provided is sufficient to properly train CCLS to work in the NICU. It is also likely that CCLS can adapt the skills they have acquired while working in other units to the NICU without acquiring any additional education specific to that

population. It is also important to consider that pure experience may be the best form of education in child life, rather than workshops or literature. Because each individual patient and their family will have different needs based on the patient's diagnosis, the family's background, etc, there may not be a "textbook" way of handling each patient. CCLS need to be flexible and able to modify textbook interventions to fit their particular patient. So, even though the CCLS may not have had much formal education, their experience and ability to transfer child life skills across units may be enough to prepare them to work in the NICU. There was a significant difference between those with and without NICU experience when it came to believing that their training and education were sufficient to work in the NICU. This result lends credence to the theory that experience may be the defining factor in truly being prepared to work with this population.

Lastly, it is necessary to mention the fact that some participants may not have been willing to admit that they are not prepared to work in the NICU or that they are dissatisfied with any of their training or education. Hopefully, this social desirability bias was not a factor in this research, but it must be considered as an explanation for this contradictory result.

Additional Education and Training

When asked to propose what type of additional training or education would be most beneficial to their practice, the participants most commonly suggested formal workshops for continuing education credit for each of the eleven care items. Again, this is likely due to the fact that this may be a more effective and efficient means of learning new information and is beneficial to CCLS working to maintain their certification. Some participants also wrote in additional options for further education including supplementary professional certifications such as the Certified Infant Massage Instructor (CIMI).

Open-Ended Questions

As mentioned above, the most frequently made suggestion ($n = 11$) for improving the education and training of CCLS who work in the NICU was clear and specific education about typical infant development and the specific developmental needs and medical issues of premature infants. It seems as if the participants feel as if there is a general lack of knowledge about NICU infants and want more formal education on their needs. Participants also noted that they want more opportunities to shadow and receive hands-on training from CCLS who currently work in the NICU. The idea of an internship experience as a way to gain this education and hands-on training was prevalent in many participant responses. These suggestions complement other findings of this research in that they establish the importance of hands-on experiences when learning about the NICU population. One participant said it best:

The level of child life involvement seems very different across all facilities. It would be very difficult to require specific internship training for a NICU position . . . While many basic child life skills were learned in my internship (working with siblings, bereavement, therapeutic play, family centered care), I have relied heavily on the expertise of the interdisciplinary team to improve my knowledge base. Consequently, not only has this improved my skills and abilities, but it has strengthened my relationships with interdisciplinary staff.

Again, we see that it would be a difficult task to teach each child life specialist about every nuance of working in the NICU prior to beginning their clinical experience, but a solid foundation of knowledge pertaining to the specific needs of NICU infants goes a long way. Furthermore, being able to rely on other healthcare professionals in hands-on learning experiences is invaluable.

Limitations

There are a few limitations of this study. First, although the sample size was adequate to garner meaningful results, there were many cases of missing data which persuaded the use of a smaller sample of participants who had completed the whole survey. On the same note, gathering information online may not have been the best way to collect data. It would be interesting to see if these results could be replicated using a different data collection method.

Also, the participants' variety of education and work experiences make it difficult to generalize the findings across all child life programs. The participants work in multiple facility types that likely range in their values and policies which makes determining the full implications of these results challenging. Question also still remains as to what motivates CCLS to prioritize certain responsibilities in the NICU and whether or not providing information about early intervention services is within the role of a CCLS in this hospital environment. Finally, there is still uncertainty about whether or not the amount of training and education current CCLS receive is truly sufficient to adequately prepare these professionals to work with the NICU population.

Implications

Because the CLC is in charge of certification for all CCLS, it may be beneficial for them to consider composing a list of competencies specific to the NICU. This list of competencies would be most valuable if presented in conjunction with a position statement specific to the role of CCLS in the NICU. A position statement would clarify exactly what child life's role and responsibilities are in the NICU and would provide each type of facility (e.g. freestanding children's hospital, general hospital) guidelines on how to expect CCLS to fit into their model of an interdisciplinary team. It could also incorporate recommendations for a standardized curriculum that includes specific knowledge to be obtained prior to beginning work in the NICU.

Explanation of how CCLS can contribute to early intervention services could also be offered in such a position statement. Likewise, clarification on child life's role in post-discharge services could be provided. With a standardized model of practice, doctors and other healthcare professionals who work in the NICU will also have a better understanding of how CCLS function in the NICU and will thus be able to become a more integrated team.

Conclusion

Overall, it seems as if today's child life specialists feel adequately prepared to work with the unique population treated in the NICU. This finding is somewhat peculiar considering the inconsistencies found in what the participants considered to be the role of a CCLS in the NICU and the variety of education and training they received prior to and since obtaining their certification. More specific education and training coupled with uniform guidelines on how CCLS should operate in the NICU could only enhance the value of a CCLS within a healthcare team.

Other healthcare professionals (e.g. occupational/physical therapists, nurses) receive specific education in order to work with premature infants in the NICU. More extensive training for child life specialists would improve their ability to provide beneficial interventions for both patients and their families. The Academic Task Force as well as the Internship Task Force of the CLC have recently published documents concerning education for child life interns and graduate students. Though this is a large step towards standardizing child life education and training, neither task force has included premature infants or the NICU as a component of their recommendations. As the number of premature births increases, it becomes more and more important for all healthcare professionals to know the specific needs of this population. In order to provide the best care possible, child life specialists need to be clear on their distinct role in the

NICU and must be properly educated on how to assess needs and carry out interventions for these unique patients.

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APPENDIX A: IRB APPROVAL LETTER



EAST CAROLINA UNIVERSITY

University & Medical Center Institutional Review Board Office
1L-09 Brody Medical Sciences Building* 600 Moye Boulevard •
Greenville, NC 27834 Office 252-744-2914 • Fax 252-744-2284
www.ecu.edu/irb

Date: December 2, 2010

Principal Investigator: Jessica Smith

Dept./Ctr./Institute: Dept. of CDFR

Mailstop or Address: ECU—Mailstop-505

RE: Exempt Certification

UMCIRB# 10-0694

Funding Source: Unfunded

Title: "Child Life Specialists in the NICU: Are they Prepared to Work with this Unique Population?"

Dear Jessica Smith:

On 12.1.10, the University & Medical Center Institutional Review Board (UMCIRB) determined that your research meets ECU requirements and federal exemption criterion #2 which includes research conducted in established or commonly accepted educational settings, involving normal educational practices, such as research on regular and special education instructional strategies, or research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.

It is your responsibility to ensure that this research is conducted in the manner reported in your Internal Processing Form and Protocol, as well as being consistent with the ethical principles of the Belmont Report and your profession.

This research study does not require any additional interaction with the UMORB unless there are proposed changes to this study. Any change, prior to implementing that change, must be submitted to the UMCIRB for review and approval. The UMORB will determine if the change impacts the eligibility of the research for exempt status. If more substantive review is required, you will be notified within five business days.

The UMCIRB Office will hold your exemption application for a period of five years from the date of this letter. If you wish to continue this protocol beyond this period, you will need to submit an Exemption Certification Request at least 30 days before the end of the five year period.

Sincerely,

Chairperson, University St. Medical Center Institutional Review Board

Cc: Natalia Sira

APPENDIX B: CHILD LIFE COUNCIL APPROVAL LETTER

Good morning Jessica,

Thank you for contacting CLC!

The Child Life Council welcomes and encourages research projects and data collection to help support child life academic and professional work. As a member of the Council, you have access to the membership through the CLC Forum. Your survey certainly meets the criteria for peer-to-peer outreach through this online network of child life professionals.

Once the survey link is ready, you may post a request through the Forum system requesting that your CLC colleagues complete the survey. You may also post follow-up request to the final posting to encourage participation before the deadline nears.

CLC does not sell or lend direct email addresses of members. However, a posting to the Forum will reach over 4,000 CLC members for potential inclusion in your research.

Good luck with this important project. When the thesis is completed, if you would like to share the results directly with CLC, we will welcome the opportunity to review and possibly share the results.

Best wishes,

Sharon

Sharon L. Ruckdeschel
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APPENDIX C: THE ROLE OF CHILD LIFE SPECIALISTS IN THE NICU SURVEY

Please read the informed consent information that follows. If after doing so you agree to participate in this study, please click on the corresponding button below.

ONLINE INFORMED CONSENT DOCUMENT INTRODUCTION You have been asked to participate in a research study being conducted by the principal investigator Jessica Smith who is a Master's student at East Carolina University. The purpose of this research study is investigate the role of child life specialists who work in the neonatal intensive care unit (NICU) and to explore what education and training are needed to sustain this role. **PLAN AND PROCEDURES** If you agree to participate in this study you will be invited to complete the online survey that follows. The questions concern your function as a child life specialist working in the NICU and the type of formal and informal education you have received pertaining to this role. The questionnaire will be administered through online survey software, Qualtrics. This questionnaire should not take more than 20 minutes to complete. The information that you provide will be transferred into a database. All information will be stored in password-protected files on a computer in the principal investigator's office. You may request a copy of the consent form for your records by contacting Jessica Smith at smithjessi09@ecu.edu. **COSTS OF PARTICIPATION** There are no costs to you for participating in the study. **Title of Research Study:** The Role of Child Life Specialists in the NICU **Principal Investigator:** Jessica Smith, BS **Institution:** East Carolina University **Email:** smithjessi09@ecu.edu

- I have read and understood this consent form and willingly agree to participate in this study.
- I do not agree to participate in this study.

If "I do not agree to participate in this study." is Selected, Then Skip to End of Survey

For this set of questions, please provide information about your position as a certified child life specialist.

What type of unit is your current position located in or was located within the last year? (Choose all that apply).

- Pediatrics
- Pediatric Intensive Care Unit
- Neonatal Intensive Care Unit
- Hematology/Oncology
- Rehabilitation
- Emergency Department
- Other _____

How long have you worked in pediatric/neonatal health care?

- Less than 1 year
- 1 to 5 years
- 6 to 10 years
- 11 to 15 years
- 16 to 20 years
- More than 20 years

How many hours of direct patient care do you have in a typical work day?

- None
- 1 to 3 hours
- 4 to 7 hours
- 8 to 10 hours
- More than 10 hours

Has your primary work assignment ever been in the Neonatal Intensive Care Unit (NICU)?

- Yes
- No

In an average week, how much time do you spend in the NICU?

- Less than 8 hours
- 9 to 16 hours
- 17 to 24 hours
- 25 to 32 hours
- 33 to 40 hours
- More than 40 hours

How many NICU patients have you cared for in the last month?

- Zero
- 1 to 10
- 11 to 20
- More than 20

Since becoming a certified child life specialist, which of the following areas have you worked in as your primary work assignment? (Choose all that apply)

- General Pediatrics
- Rehabilitation
- Hematology/Oncology
- Pediatric Intensive Care Unit
- Neonatal Intensive Care Unit
- Emergency Department
- Other (Please Specify) _____

Since becoming a certified child life specialist,

- I have never worked with infants in the NICU.
- I sometimes work with infants in the NICU.
- I regularly work with infants in the NICU.
- I used to work with infants in the NICU, but I no longer do.

In your opinion, how do you think your role as a child life specialist in the NICU is perceived by....

| | I am perceived as a fully integrated member of the interdisciplinary team. | I am perceived as an included, but not fully integrated member of the interdisciplinary team. | I am NOT perceived as a fully integrated member of the interdisciplinary team. | I do not work in the NICU. |
|---|--|---|--|----------------------------|
| doctors? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| nurses? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| occupational/physical therapists? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| social workers? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| chaplains or other religious personnel? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

In your opinion, when working in the NICU, how visible are you to....

| | Not Visible At All | Somewhat Visible | Very Visible | I do not work in the NICU. |
|---|-----------------------|-----------------------|-----------------------|----------------------------|
| doctors? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| nurses? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| occupational/physical therapists? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| social workers? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| chaplains or other religious personnel? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

For the next set of questions, please provide us with information about the NICU in your facility.

What level is the NICU in your facility?

- Level II
- Level III
- There is not a NICU in my facility

What type of facility/hospital is your NICU located in?

- Freestanding Children's Hospital
- General Hospital
- Children's Hospital within a Hospital
- Adult Hospital with Pediatric Services
- There is no NICU in my hospital/facility.
- Other (Please Specify) _____

How many pediatric inpatient beds does your hospital/facility have (not including neonate beds)?

- 0-50
- 51-100
- 101-150
- 151-200
- More than 200

How many inpatient neonate beds does your hospital/facility have?

- 0-10
- 11-20
- 21-30
- 31-40
- 41-50
- More than 50

What type of coverage does child life provide to the NICU in your facility?

- Full Time
- Part Time
- On-Call or As Needed
- We do not provide services in to the NICU.

Is the NICU in your hospital/facility NIDCAP (Newborn Individualized Care and Assessment Program) certified?

- Yes
- No

For the following question, please provide us with information about the role of a child life specialist in the NICU.

Which of the following are part of the role of a child life specialist working in the NICU?

- Providing developmentally appropriate auditory stimulation.
- Providing developmentally appropriate light stimulation.
- Providing skin-to-skin contact (e.g. Kangaroo Care or Infant Massage).
- Providing comfort positioning (i.e. swaddling and nesting).
- Providing developmentally appropriate play.
- Providing music therapy.
- Providing strategies for pain management.
- Providing procedural support.
- Providing palliative care and bereavement services.
- Providing support to siblings of the patient.
- Providing education to the family of the patient.
- Educating the patient's family about the infant's transition to home after discharge.
- Incorporating the principles of family centered care into your interventions for the patient and family.
- Providing information about early intervention services.

Please rank the following responsibilities of a child life specialist in the NICU in order of how much time you spend doing (or think you would spend doing if you do not currently work in the NICU) each responsibility (1 being the most amount of time and 8 being least amount of time).

- _____ Providing developmentally appropriate stimulation to the baby.
- _____ Providing procedural support to the baby.
- _____ Providing strategies for pain management to the baby.
- _____ Providing support to the infant's siblings.
- _____ Providing education about procedures to the infant's parents or other family.
- _____ Providing information about early intervention services.
- _____ Providing education for the baby's transition to home after discharge.
- _____ Incorporating family centered care principles into interventions for the infant and family.

For the following questions, please provide us with information about the training you received to become a certified child life specialist.

During my child life internship, I completed a rotation in (Choose all that apply)

- general pediatrics.
- rehabilitation.
- hematology/oncology.
- the pediatric intensive care unit.
- the neonatal intensive care unit.
- the emergency department.
- I did not complete a child life internship.
- Other (Please Specify) _____

At the facility in which you currently work, what type of continuing education do you receive related to infants in the NICU? (Choose all that apply)

- Formal workshops for continuing education credit
- Informal workshops NOT for continuing education credit
- Informal training from doctors, nurses, or other professionals
- Updated literature
- Internet based resources
- I do not receive continuing education or special training.
- Other (Please Specify) _____

The next set of questions focus on your ability to provide developmentally supportive interventions to infants in the NICU.

Please indicate your level of agreement with the following statements concerning working with infants in the NICU.

| | Strongly Disagree | Disagree | Neither Agree nor Disagree | Agree | Strongly Agree |
|---|-----------------------|-----------------------|----------------------------|-----------------------|-----------------------|
| I am adequately educated on the basic medical procedures, terminology, etiology, and disease process of NICU infants. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I feel adequately prepared to assess a NICU infant's developmental and emotional needs accurately by using appropriate tools. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

When working with infants in the NICU, I feel adequately prepared to provide...

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
|--|-----------------------|-----------------------|----------------------------|-----------------------|-----------------------|
| developmentally appropriate auditory stimulation. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| developmentally appropriate light stimulation. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| developmentally appropriate touch through skin-to-skin contact (e.g. Kangaroo Care or infant massage). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| comfort positioning (i.e. swaddling and nesting). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| developmentally appropriate play. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| therapeutic play using music. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| strategies for pain management. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| procedural support. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| information about early intervention services. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| education to the family about the infant's transition to home after discharge. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| palliative care. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please indicate your level of agreement with the following statements concerning working with infants in the NICU.

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
|--|-----------------------|-----------------------|----------------------------|-----------------------|-----------------------|
| When asked MEDICAL questions about a NICU infant by children/families, I feel adequately prepared to address those questions. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| When asked DEVELOPMENTAL questions about a NICU infant by children/families, I feel adequately prepared to address those questions. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| It is more comfortable to refer children/families who have MEDICAL questions about their infant to the nurse or doctor. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| It is more comfortable to refer children/families who have DEVELOPMENTAL questions about their infant to the nurse or doctor. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I feel adequately prepared to advocate for the needs of children and families by maintaining an open dialog with health care staff. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am comfortable introducing developmentally supportive interventions to the baby. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

The following questions focus on the training you have received to work with NICU infants. For each of the following categories, please indicate the type of special training you received to work with infants in the NICU. (Choose all that apply) If you have received other types of special training not included in the chart below, please indicate so in the next question.

| | Auditory Sensitivity | Light Sensitivity | Skin-to-Skin Contact | Comfort Positioning | Developmentally Appropriate Play |
|---|--------------------------|--------------------------|--------------------------|--------------------------|----------------------------------|
| I attended a FORMAL workshop or lecture for continuing education credit. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I attended an INFORMAL workshop or lecture NOT for continuing education credit. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I received up-to-date literature. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I used self-teaching methods such as reading a manual or watching a video. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I received on-the-job training from nurses or other NICU professionals. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I received information through academic coursework (i.e. college classes). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I received information through the Child Life Council's online list-serve. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I did not receive special training in this area. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| | Music Therapy | Pain Management | Procedural Support | Discharge Education | Palliative Care |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| I attended a FORMAL workshop or lecture for continuing education credit. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I attended an INFORMAL workshop or lecture NOT for continuing education credit. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I received up-to-date literature. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I used self-teaching methods such as reading a manual or watching a video. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I received on-the-job training from nurses or other NICU professionals. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I received information through academic coursework (i.e. college classes). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I received information through the Child Life Council's online list-serve. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I did not receive special training in this area. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

If you have received other types of special training for the following categories as they pertain to infants in the NICU, please indicate what additional training you have received.

- Auditory Sensitivity
- Light Sensitivity
- Skin-to-Skin Contact (e.g. Kangaroo Care or Infant Massage)
- Comfort Positioning (i.e. Swaddling and Nesting)
- Developmentally Appropriate Play
- Music Therapy
- Strategies for Pain Management
- Procedural Support
- Information about Early Intervention Services
- Education to the Family about the Transition to Home after Discharge
- Palliative Care

For each of the following categories, please indicate what type of special training you would like to receive.

- Auditory Sensitivity
- Light Sensitivity
- Skin-to-Skin Contact (e.g. Kangaroo Care or Infant Massage)
- Comfort Positioning (i.e. Swaddling and Nesting)
- Developmentally Appropriate Play
- Music Therapy
- Strategies for Pain Management
- Procedural Support
- Information about Early Intervention Services
- Education to the Family about the Transition to Home after Discharge
- Palliative Care

For each of the following categories pertaining to infants in the NICU, please indicate your evaluation of the training you received during your INTERNSHIP:

| | Very Satisfied | Satisfied | Somewhat Satisfied | Neutral | Somewhat Dissatisfied | Dissatisfied | Very Dissatisfied |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Auditory Sensitivity | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Light Sensitivity | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Skin-to-Skin Contact (e.g. Kangaroo Care or Infant Massage) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Comfort Positioning (i.e. Swaddling and Nesting) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Developmentally Appropriate Play | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Music Therapy | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Strategies for Pain Management | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Procedural Support | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Information about Early Intervention Services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Education to the Family about the Transition to Home after Discharge | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Palliative Care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

For each of the following categories pertaining to infants in the NICU, please indicate your evaluation of the training you have received since becoming CERTIFIED:

| | Very Satisfied | Satisfied | Somewhat Satisfied | Neutral | Somewhat Dissatisfied | Dissatisfied | Very Dissatisfied |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Auditory Sensitivity | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Light Sensitivity | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Skin-to-Skin Contact (e.g. Kangaroo Care or Infant Massage) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Comfort Positioning (i.e. Swaddling and Nesting) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Developmentally Appropriate Play | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Music Therapy | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Strategies for Pain Management | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Procedural Support | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Information about Early Intervention Services | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Education to the Family about the Transition to Home after Discharge | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Palliative Care | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please indicate your level of agreement with the following statements pertaining to your overall training to work with NICU infants:

| | Strongly Agree | Agree | Neither Agree nor Disagree | Disagree | Strongly Disagree |
|--|-----------------------|-----------------------|----------------------------|-----------------------|-----------------------|
| Education for child life professionals should include information specific to NICU infants. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| The training I have received has NOT been sufficient in teaching me how to work with NICU infants. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I would enjoy working with NICU infants more if I were better trained to do so. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I wish that I had more training to work with NICU infants. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I would feel more confident working with NICU infants if I had received more training on the needs of this population. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

When you have questions pertaining to a NICU infant, how often do you seek additional information from the following resources?

| | Never | Rarely | Sometimes | Often | Very Often |
|----------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Child Life Supervisor | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Library/Internet Sources | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Nurses | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Occupational/Physical Therapists | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Doctors | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Other Professionals | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Please indicate how often the following occurs while you are working in the NICU.

| | Never | Rarely | Sometimes | Often | Very Often |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| When working in an interdisciplinary team, the nurses, doctors, and other professionals provide me with enough information and appropriately explain equipment and procedures. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I feel informed and prepared when working in the NICU. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

If you previously worked in the NICU, but no longer do, what was your reason for leaving?

What suggestions do you have to improve training for child life specialists who work in the NICU?

Please tell us a little bit about yourself by providing demographic information.

What is your gender?

- Male
- Female

What is your race/ethnicity? (Choose all that apply)

- White
- Black
- Hispanic
- Asian
- Native American/ Alaska Native
- Other _____

What is your relationship status?

- Single, Never Married
- Engaged
- Married
- Separated
- Divorced
- Other _____

How many children do you have?

- 0
- 1
- 2
- 3
- 4
- 5
- More than 5

Thank you for taking the time to complete this survey!

