This thesis titled

The Importance of Child Life Within the Neonatal Intensive Care Unit (NICU)

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Abstract

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The Importance of Child Life within the Neonatal Intensive Care Unit (NICU)

Director of Thesis: Jenny Chabot

Infant’s hospitalization soon after birth often causes the family system to adjust to new or different roles while typical routines may change. Medical professionals as well as Certified Child Life Specialists (CCLS) can assist children and their families who are navigating the hospital environment. Through questionnaires completed by CCLS and an interview with a parent who had a child in the Neonatal Intensive Care Unit (NICU), a deeper understanding was reached regarding what CCLS can provide children and their families in the NICU setting.
To my dad, mom, husband, brother, grani, grandfather, family, friends, and professionals

who have continually supported, loved and guided me along my academic journey.
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Chapter 1: Introduction

Background Information

Infants who are placed within the neonatal intensive care unit (NICU) are exposed to a wide range of sights, sounds, smells, and an environment that may be challenging for their adequate growth and development. Pearson (2005) discussed the wide use of Erikson’s theory of personality development in pediatrics. According to this theory, there are “eight predictable age-related stages”; newborns to infants 6 months of age are included in Erikson’s trust versus mistrust stage. Turner (2009) described the issues in this stage of development to be: separation from caregivers in addition to unfamiliar environments, routines and people, all of which are most likely to happen during an infant’s stay in the NICU. Stressors related to the hospital setting may negatively affect families and caregivers of infants in the NICU. Additionally, the uncertainty of the NICU environment may also elicit strain. Known stressors for parents/caregivers of children in the NICU include: an alteration of parental role, worrying about infants’ health, lack of parental sleep and/or parental depression, and anxiety (Busse, Stromgren, Thorngate, & Thomas, 2013). For an infant, the high level of light and sound common in the NICU has been found to be more unfavorable and longer lasting to developing infants as compared to adults (Walsh-Sukys, Reitenbach, Hudson-Barr, & DePompei, 2001). Pearson (2005) recognized the significance of protection, security, and intimacy for infants to form a level of trust with their families. For example Pearson (2005) explained that when the family was present and played an active role in their infant’s care, the infant almost always did better, showing that the family has the greatest impact on a baby’s health and
development. If these needs were not met, infants might develop depression, show signs of hospitalism (“used to describe the inability of infants to survive in institutional settings”) or develop failure to thrive (Pearson, 2005, p. 6). The present research focuses on how Certified Child Life Specialists (CCLS) can assist infants and their families in the NICU.

CCLS “promote effective coping through play, preparation, education, and self-expression activities. They provide emotional support for families, and encourage optimum development of children facing a broad range of challenging experiences, particularly those related to healthcare and hospitalization” (Child Life Council, 1998-2012). Due to the overwhelming atmosphere of the NICU, CCLS can be of assistance to infants and their families. CCLS can clarify unclear information and offer resources or tools to assist them while focusing on the recovery of the infant. In addition, CCLS are in a position to hear parents/caregivers concerns and try to meet the individual needs of each family.

Research has explored what parents find helpful while their child is hospitalized or their infant is in the NICU. Assurance (i.e., support, guidance), consistent information, parental participation, emotional, physical and spiritual support as well as proximity to their child (Obeidat, Bond, & Callister, 2009) were a few factors mentioned by parents to increase their satisfaction during their infant’s stay in the NICU. Obeidat et al. (2009) emphasized the importance of health care professionals’ understanding the experience from the parents’ view; when the parents’ needs and concerns are met their fulfillment
may improve. Therefore, CCLS can serve as individuals who bring other professionals together, working with the child and parents to reduce dissatisfaction.

Bell, Johnson, Desai, and McLeod (2009) described a CCLS’ role as one that recognizes the family as a child’s constant; these family members play a significant role in the patient’s health and well being in a healthcare setting. Preparing and supporting families can help them cope while supporting the child-family relationship and honoring family diversity. The collaboration of care approach opens up communication between the family and professionals by sharing information, providing support, and keeping in mind the child’s developmental needs during hospitalization. Current research based specifically on how CCLS can assist families within the NICU is minimal. There are just over 100 children’s hospitals out of roughly 410 that are providing child life services in the NICU across the United States (Child Life Council, 1998-2012). The present research examines what tools CCLS find most and least effective when working with families in the NICU. In addition, this study provides information on what tools or resources are used most in the NICU setting, as well as ideas these professionals have to assist future infants and their families within the NICU setting. Parents who had a child in the NICU also were included to see what they found to be helpful or not, how their voice was heard and ways to improve the NICU experience.

The results of this thesis will be used to educate professionals who work in the NICU, including nurses and doctors as well as current or future CCLS. Findings may also help hospitals begin a child life program in the NICU or assist current teams enhance existing programs. This research can provide opportunities for families to revisit their
experiences as parents with a child in the NICU, and allow them opportunities to share their experiences and be heard.

Limitations of this study include the design limitations of qualitative research and the data methods chosen by the researcher, a small sample size, and the narrow geographical location.

Delimitations of this study include CCLS working in the NICU and families/caregivers of an infant who is in the NICU. The CCLS were recruited from a post on the Child Life Council forum. CCLS participants were required to have at least 12 months of work experience in the NICU. Families/caregivers were recruited by flyers posted in copy rooms at Ohio University and by word of mouth (i.e., snowball sampling). In order for a family/caregiver to participate, their infant must have spent a minimum of 5-7 days in the NICU and the hospitalization must have been within the past 7 years.
Chapter 2: Review of the Literature

Family Centered Care (FCC)

With more than 450,000 babies born premature (born before 37 weeks gestation) each year (March of Dimes Foundation, 2013), the NICU is a vital environment not only for the infants but also their families. Bell et al. (2009) explained the significance of facilitating family centered care (FCC) when “fostered by mutual respect and founded on family strengths and priorities, this strong partnership enables every member of the healthcare team, with the family ‘in the driver’s seat,’ to create and implement a comprehensive and dynamic care of plan” (p. 95). FCC is defined as an “approach to healthcare that is based on mutually beneficial partnerships between patients, families and health care professionals” (Bell et al., p. 95). Bell et al., (2009) also spoke about the importance of communication, collaboration, and participation within the dynamics of FFC, giving families an active part in the care of their child. Staff members in the NICU are critical to the effectiveness of communicating with caregivers, talking with other staff, and then organizing the information to keep the key components of FCC present (Wigert, Dellenmark, & Bry, 2013). According to Wigert et al. (2013), FCC is when parents are “kept well informed and involved to a high degree in the care of their child and decisions affecting the child” (p. 12). This approach views parents as partners in the care of their fragile infant (Obeidat et al. 2009) rather than just seeing them as another person in the room.
Role of CCLS and Psychosocial Teams

CCLS are typically on psychosocial teams, consisting of but not limited to art therapists, music therapists, recreational therapists, teachers, or social workers. However, CCLS may be on medical teams and can include but are not limited to doctors, physical therapists, occupational therapists, speech therapists, nurses, medical professionals, psychologists, or chaplains. Therefore, collaboration among team members is essential in the care of infants in the NICU and all hospitalized children. CCLS are a referral source and can cotreat with other team members, psychosocial or medical. CCLS may be the professionals to recommend the services of other professionals or they may assist in the healing, coping, or developmental process of children in the healthcare or hospital setting.

Wojtasik-Pond and White (2009) stated that CCLS goals are “to help children engage and subdue fears, misconceptions, anger and profound sadness that hospital experiences provoke, to protect and enhance their developmental integrity, and, whenever possible, use the experiences of illness and hospitalization to build strengths rather than compromise them” (2009, p. 12). Thompson and Snow (2009) discussed research conducted in intensive care units, outpatient clinics, emergency departments, and community-based programs that found “the presence of child life professionals enhances the play behavior of children, increases parent-child interaction, reduces level of negative behavior of children, and may facilitate the adjustment of children and their families to a variety of medical settings and conditions” (p. 40). Klinzing and Klinzing (2009) emphasized communication as being an essential factor of the child life practice, stating
“It is through the effectiveness of communication that child life specialists facilitate interpersonal relationships with children, staff and family members and help to create and maintain family-centered care” (2009, p. 78).

Developmental education can be of help to parents and/or caregivers who are trying to care for an infant in the NICU setting. Physical therapists Dusing, Van Drew, and Brown (2012) found ways to educate parents of sick infants in the NICU by introducing developmental principles early on, providing a variety of ways to offer the education as well as having other professionals form teams to help promote developmental care during all care giving opportunities, all while making themselves available at set times for specific meetings or specific questions that parents or caregivers may have about their infant. In addition to providing services in the NICU, professionals provide brochures and assistance after the infant is discharged from the hospital.

With the assistance of professionals, parents can increase their knowledge of child development (Dusing et al., 2012). Looking at parental responses to the NICU environment such as fatigue, sleep disturbances, anxiety and depression, Busse et al., (2013) found “the philosophy of family-centered care in the NICU hinges on the parents’ involvement in care and support for parents” (p. 57). Bell et al., (2009) explained the role of a CCLS by stating, “They (CCLS) can assist them (families) in coping with hospitalization, chronic illness or disability. While they support the normal developmental tasks of independence, continuation in schooling, and the development of individuality, they can also support families and their relationship with their children” (p. 102).
Parental Stress and Importance of Attachment and Bonding

Understanding an infant’s development may not be the only knowledge a caregiver or parent can utilize. Jessee and Gaynard (2009) indicated that infants are in Piaget’s sensorimotor stage; they are learning and exploring life through their senses, such as vision or motor actions. For example, an infant may track or mouth (explore by mouth) an object that is presented to them by a caregiver during play. The importance of attachment and bonding between parents and newborns are significant and pose a concern during an infant’s stay in the NICU. The environment of the NICU is full of hard surfaces to make disinfecting easier, which increases the levels of noise from medical equipment to a high level; constant bright lights are also prevalent in a NICU environment (Walsh-Sukys et al., 2001). The unfamiliar and threatening NICU atmosphere may have negative consequences, such as delayed maternal attachment between the infant and his/her mother (Obeidat et al., 2009) According to Obeidat et al. (2009), “Parents need to be able to see, hold and touch their newborn in order to facilitate early attachment and bonding” (pp. 23-24). In addition, the sounds and sights of the NICU may be overwhelming to both parents and the infant, and add to the loss of bonding and care of the infant (Zimmerman & Bauersachs, 2012). Due to the atmosphere of the NICU, parents may become stressed and show an increase in anxiety, depression, or fatigue (Busse et al., 2013). Research shows that parental anxiety, which is defined as, infant’s health condition, financial worries, other children, occupation (Busse et al., 2013) and alteration of parental role (not primary caregiver, nurses and doctors are providing the care to their infant) showed negative outcomes for parents who had a child in the NICU. Similarly the lack of control,
defined as what one cannot always prepare for what happens next (Obeidat et al., 2009) was also associated with negative outcomes for parents associated with infants being hospitalized in the NICU.

Guillaume et al. (2013) discussed parents of hospitalized infants in the NICU who expressed the need for good communication between the medical staff and themselves. The desire to understand and be educated about the NICU environment (for example the monitors or various medical machines in the room) was also voiced as important. Further, families wanted to be informed of changes that may arise with their infant (Guillaume et al., 20013). Mundy (2010) found parents rated assurance needs to be high on their priority list when being admitted to the NICU, meaning that support and feeling of hope were important during admission. Upon discharge it was found that families’ transportation needs were rated as highly important (Mundy, 2010). Research illustrates that infants are in need of care, but their parents well being is just as important.

Wigert et al. (2013) took a deeper look into the relationship between parents, nurses, and healthcare providers while in the NICU setting. Overall, parents found that questions regarding their infant were answered. They were satisfied with communication and considered the professionals easy to communicate with. Half of the respondents felt their emotional situation was very well understood (Wigert et al., 2013). Conversely, “A few parents described situations where they felt it was best to follow the routines of the unit even if they as parents had another opinion” (Wigert, Dellenmark, & Bry, 2013, p. 10). Mundy (2010) described the importance of identifying the needs of each individual family, which can aid professionals in providing assistance for parents’ actual needs,
rather than assistance based on the nurses’ perception of what the family may need. Developing trusting, open, and therapeutic relationships that offer support have been described as the main foci when assessing parents of a premature infant (Zimmerman & Bauersachs, 2012). The family as a whole is affected by an infant’s stay in the NICU, yet each family member individually handles the stress in his/her own way.

**Infant Stress**

Infants in the NICU are exposed to sights, sounds, smells, pain, and feelings similar to other children in the hospital or health care setting. However, high light and sound levels in the NICU have been found to be “more detrimental and more long-lasting in the developing human than what has been described in the adult” (Walsh-Sukys et al., 2001, p. 230). Sleep deficiency and being in an environment with constant high light and sound levels like an ICU unit has been termed “ICU psychosis” (Walsh-Sukys et al., 2001, p. 230). Walsh-Sukys et al. (2001) explained how this psychosis affects hospital staff members in addition to the patients being cared for and their families by increasing the stress level of those caring for the ill patient. Pearson (2005) stated that security, intimacy and protection are essential in developing trust between an infant and his or her family. Advocating for parental presence may increase the bond between infant and his or her caregivers (2005).

**Siblings of Patients in the NICU**

Camhi (2005) observed 10 siblings (5 girls and 5 boys from 20 months to 6 years old) at play focusing on how they were affected by their brother or sister being hospitalized after birth. All 10 siblings were the youngest children at the time their
brother or sister was born. Four themes were observed during their play sessions, the first being temporary loss of the good object, meaning the children showed anxiety to find that something was lost or not available, similar to an object being unavailable internally (Camhi, 2005). Francisco, a 20-month-old boy who had a hard time dealing with his mother leaving often without explanation, illustrated this. Four-year-old Fatima’s play focused on bringing back her damaged/lost mother, as she was observed as a “mother’s repairer” and very in tune to her mother’s emotional state (Camhi, 2005). Francisco and Fatima’s play illustrated the loss of their mother’s presence and want for their “good object (their mother)” to return. A second theme was exploring a new identity in the family, meaning these siblings dealt with a sense of loss (no longer an only child, or mother/father were emotionally or physically absent), yet gained autonomy and new abilities in the family (Camhi, 2005). In an attempt to find their place in the family system, siblings role-played being a nurse, a child and/or a mother during play sessions. The third theme was attempts to internalize the new baby, and in this theme, siblings showed difficulty mentally understanding what was happening to their sibling. Siblings played with multiple babies because some of the rooms had multiple infants, even though their mother only gave birth to one. Others showed fears of an object after they named it to represent their baby brother/sister, while others found it hard to differentiate the baby from all the machines in the room (Camhi, 2005). Lastly, ambivalent feelings were expressed through an increase in anxiety with certain toys that were seen as harmful to their baby brother/sister. Other siblings’ anxiety rose when any infant cried and some siblings feared their baby brother/sister would not wake up and went to check on them.
frequently (Camhi, 2005). Often times these siblings are dealing with preoccupied parents who are less available due to their sick brother or sister (Camhi, 2005). Consequently siblings are affected too, often indirectly. However, their feelings and thoughts are valid and important.

With siblings in mind, DeVos Children’s Hospital Neonatal Services at Spectrum Health in Grand Rapids, Michigan developed a “Sibling Night” program (Munch & Levick, 2010). Munch and Levick (2010) realized how traumatizing and emotional the NICU environment can be for siblings as well as parents; consequently, they offer a night where siblings and parents can take time to sort through their thoughts and feelings. In addition to sorting through their feelings, parents can receive information about their sick infant while their older child or children are in another room actively filling out their *My Me Book* (Munch & Levick, 2010). This book allows for the sibling to think about what is going on within their family with reassurance that their baby brother’s or sister’s sickness is not their fault (Munch & Levick, 2010). The workbook is designed to offer social support in a nonthreatening environment and if needed, the siblings will be told to share the book with the parents and or a social worker with the child present. Their feelings are valid, and they will be encouraged to express feelings and emotions.

**Programs Implemented in the NICU**

**Help-Understand-Guidance (HUG) program.** In addition to keeping siblings and parents/caregivers involved in the care of an infant in the NICU, a program developed especially for parents/caregivers to understand their infant as an individual may also be beneficial. Tedder (2008) explains the importance of parents learning to
appreciate their baby and his or her cues or states. The HUG program stands for “Help-
Understanding-Guidance,” designed to help parents understand and interpret their
infants’ special way of communicating (Tedder, 2008). The HUG program is intended to
give parents confidence and increase their effectiveness in meeting their infant’s needs
appropriately and in a timely way. A goal of the HUG program is to increase parent’s
knowledge of the various states of infants as well as passion for their infants by knowing
how to read their cues (Tedder, 2008).

Three key skills were needed to develop confidence and effectiveness in caring
for an infant. The first is understanding a newborn’s state (see Table 1). By recognizing
an infant’s state, parents can ensure adequate feeding, promote interaction, or enhance
sleep for infants (Tedder, 2008). The second skill is reading the infant’s cues. To aid in
reading infant’s cues three newborn zones were described (zone one, resting zone; zone
two, ready zone; and zone three, rebooting zone). The resting zone is when an infant is
sleeping. Ready zone is an alert state where baby is ready to eat and interact with
caregivers. The rebooting zone is when an infant is fussing or crying, signaling a need for
caregivers’ help (Tedder, 2008). The third and final skill needed to develop confidence
and effectiveness is appreciating a baby’s capabilities, in other words, appreciating an
infant’s ability to engage and interact with caregivers (Tedder, 2008). By reading their
infant’s cues (e.g., changes in color or breathing, how content the infant is, and variations
of crying) parents can be more effective in learning how to care for their infant (Tedder,
2008). Lastly, teaching parents to appreciate an infant’s aptitude to connect with his/her
parent is a “greater the attachment and less frustration parents may experience” (Tedder,
2008, p. 19). As a result, the HUG program can increase parents’ confidence in knowing what their new baby needs.

Table 1

Skills and Zones Associated With HUGS Program

<table>
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<tr>
<td>• Understanding newborn’s state</td>
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<td>• Reading infant’s cues relative to zones</td>
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<td>Resting zone: When infant is sleeping</td>
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<tr>
<td>Ready zone: Infant is alert and ready to eat and/or interact with caregivers</td>
</tr>
<tr>
<td>Rebooting zone: Infant is fussy/crying and needs help from caregivers</td>
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<td>• Developing confidence and effectiveness</td>
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Kangaroo Mother Care (KMC)

According to Samra, Taweel and Cadwell (2013), KMC has been shown to be safe, effective, and feasible for low birth weight (LBW) infants in the NICU. KMC is when the mother or father is holding the baby on his/her chest with skin-to-skin contact where the ventral side of the mother/father is to the ventral side of the baby (Samra et al., 2013). Utilizing KMC provides multisensory stimulation as well as promotes physiological conditions (Samra et al., 2013) all while giving parents a chance to bond with their infant. Guillaume et al. (2013) stated, “Globally fathers and mothers described
interactions with their child as important steps in starting to feel a bond with him/her” (p. 6).

**Systems Theory and the NICU**

Systems theory is a helpful framework for understanding the impact the NICU environment has on a family unit. When infants are sick, their improvement or decline can affect the overall functioning of their family. For example, decline in an infant’s medical state may cause his or her parents to feel stressed or carry a heavy heart for their son or daughter. If there are older siblings within this family, they may see changes in their parents’ attitude or actions, thus affecting the family as a whole (Dupuis, 2010). In addition to affecting all who are within the family system, systems theory identifies family communication as an important dimension (Harris et al., 2010). Also examining how the system (in this case, the family system) interacts with its environment and how every system must be considered whole so that it can be distinguished from its environment is crucial (Dupuis, 2010). A NICU example of this may be how mothers or fathers choose to talk with their older children or other family members about the medical status of the infant. How communication takes place, what is said, and the atmosphere of the NICU may affect both the listener and the speaker. With regards to the environment, research shows that when parents are in the NICU setting their feelings tend to be negative, unless professionals inform them about and include them in the care of his or her infant. Each family system is unique and when their specific needs are respected their family relationships and bonds remain strong during the hospitalization process.
Another aspect of the systems theory is that of context. According to Jurich and Myers-Bowman (1998), “. . . a part can be understood only in the context of the whole” (p. 75). When families have a sick son or daughter in the NICU, it is different from a sick son or daughter at home. It is typical for a mother and/or father to provide most if not all the care for his or her child at home. However, the parental role differs when the infant is admitted to the NICU, illustrating the importance of context within systems theory. During the interview process, parents of hospitalized infants will be able to reflect back on the time they spend in the NICU.

A family who visits or spends a lot of time within the NICU is considered a subsystem within the hospital (Jurich & Myers-Bowman, 1998) when addressing this issue with systems theory. The family is not the only subsystem within the hospital; other subsystems include nurses, doctors, physical, speech and occupational therapists, social workers, child life specialists, and possibly music and art therapists. These professionals may all be viewed as one subsystem or organized as separate subsystems that work alongside the family subsystem. The overall larger unit in which both the professionals and the families are enclosed would be the system of the hospital (Jurich & Myers-Bowman, 1998). Jurich and Myers-Bowman (1998) broadened the description of these systems and added that a family may have a church, community, or ethnic group membership that may also have an impact on the overall family subsystem while an infant is being cared for in the hospital.
Bioecological Theory

Turner (2009) described Bronfenbrenner’s theoretical perspective as based on the interdependence of individuals and their environments. Specifically, it is the perceptions of, and transactions with, the environment that influences one’s development (as cited in Thompson, 2009, p. 32). Figure 1 illustrates the four systems that relate to one another and the person at the center of all the systems. Using the bioecological theory, the infant in the NICU would be placed in the center as the individual. The microsystem includes the people with whom the infant interacts with his/her immediate settings: mom, dad, sibling(s), doctors, nurses, and other professionals working in the healthcare setting. Next is the mesosystem, which incorporates how the infant’s microsystems interact with one another. For example, how their caregiver communicates with the medical or psychosocial staff impacts the infant’s development. The exosystem is further from the infant and can indirectly affect the infant, such as their parents’ needing to return to work in order to pay the bills. Lastly is the macrosystem, which is furthest from the infant and may be characterized by the family’s culture or how the health care system overall operates. Turner (2009) stated, “According to Bronfenbrenner, a balance between the individual and systems in the environment serves to support positive developmental outcomes” (p. 33). A CCLS can aid in building relationships while examining how the systems are influencing the child. The CCLS’ observations then lead to the appropriate level of intervention to promote positive development and coping for the child and his/her family.
Figure 1. Bioecological theory framework. This figure illustrates the system breakdown in the bioecological theory. Adapted from “Translating Multilevel Theory into Multilevel Research: Challenges and Opportunities for Understanding the Social Determinants of Psychiatric Disorders,” by E. C. Dunn, K. E. Masyn, M. Yudron, S. M. Jones, and S. V. Subramanian, 2014, p. 863. Copyright 2014 by Springer. Reprinted with permission.
Chapter 3: Methodology

Participants

Certified Child Life Specialists. Qualitative research was used in the design of this study to gain information from CCLS who have worked in the NICU for a minimum of 12 months. CCLS who were interested in participating but had not worked in the NICU for at least 12 months were excluded. CCLS were asked to complete an online questionnaire (see Appendix C). The questionnaire looked at tools or resources being utilized by CCLS in the NICU as well as what professionals saw to be beneficial or nonbeneficial for the infants and their families. CCLS were also asked if a sibling support program was in place and to describe the program. Seven demands were derived from common themes found in the literature. The CCLS were asked to rank the seven demands according to their observations as well as what mothers, fathers, siblings and other family members have actually struggled with during an infant’s stay in the NICU. Of the 13 participants, one was between 23-27 years of age, three were between 28-32 years of age, five were between 33-45 years of age, one was between 46-56 years of age, and three were 56 years of age or older (see Figure 2). All 13 participants were female; 2 of the 13 were Hispanic; the remaining 11 were white/Caucasian (see Figure 3). Two of the participants had 9 or more years as a CCLS in the NICU, 3 had between 7-9 years of experience, 1 had 4-6 years of experience, 6 had between 2-3 years of experience and 1 had 1 year of experience as a CCLS in the NICU (see Figure 4).
Figure 2. Age of CCLS respondents.

Figure 3. Race/ethnicity of CCLS respondents.
Parent/Caregiver

For the second part of this study, the aim was to interview parents/caregivers who had an infant admitted to the NICU in which CCLS were present for at least a 5-7 day period within the past 7 years. The researcher posted flyers, talked with professionals in the child life field, and tried snowball-sampling methods to recruit participants. After a few months and no participants, the researcher submitted an amendment to Ohio University Institutional Review Board to change the limitations to a parent/caregiver who had an infant admitted to the NICU for at least a 5-7 day period within the past 7 years, without CCLS present. Following this change, the researcher was able to interview one mother about her experience in the NICU. The parent interview conducted by the researcher was semistructured (see Appendix D). The interview explored the parent’s perspective and whether she felt her needs or concerns were met during her child’s hospitalization. The mother was also asked what she found helpful during her infant’s stay in the NICU. Additionally, the mother was asked to provide suggestions about how
CCLS could aid future infants and their families during their NICU admission. The participant interviewed was a white/Caucasian female who was 32 years of age. Her infant was hospitalized for 6 nights and 7 days in the NICU.

**Participant Recruitment and Research Methods**

**Certified Child Life Specialists.** The CCLS were recruited by emailing (see Appendix E) the Child Life Council forum, the list serve of the professional organization. The researcher emailed the list serves three times to gain the 13 CCLS participants. Word of mouth (i.e., snowball sampling) also aided in identifying more CCLS participants.

**Parent/Caregiver**

In order to gain family/caregiver participants, the researcher posted flyers (see Appendix B) in copy rooms of faculty and staff members at Ohio University. The researcher also utilized the snowball sampling to gain participants.

**Protection of Participant Identity**

To protect participant identity, the parent’s audio recording was kept in a locked drawer in a locked room and erased after transcription. The surveys completed by the CCLS were deidentified to protect their identity.

**Approach to Analysis**

**CCLS Questionnaire.** From the data collected through questionnaires using Qualtrics, an online survey source, themes were pulled from the results. The following procedure was used to organize the responses.

1. The author read through all the responses once;
2. The author read through the list of tools utilized in the NICU a second time and a list was assembled;

3. The author read through the sibling support program responses again and these were then added to the tools utilized list;

4. A clean diagram was used to tally the number of CCLS respondents perceived demands for each individual;

5. The author refined the coding system by identifying the top three demands for each individual;

6. An empty diagram was used to tally the number of CCLS respondents demands seen by individuals in the chart;

7. The author refined the coding system by identifying the number of CCLS who how each family member was affected by the seven demands;

8. “What child life tools are most and least effective” was read through again and a list was developed;

9. After reading through the “anything else you would like to add” a second time, another list was made.

**Parent Interview.** The following procedure was used to code the open-ended responses.

1. The author transcribed the interview word for word;

2. The author listened to the interview a second time to make sure transcription was accurate;
3. The author read through the transcription and coded the parent’s responses.

**Procedure**

**CCLS.** The author used the following procedure when recruiting CCLS participants:

1. When a CCLS responded to the list serve invitation to participate, s/he was emailed a link to a Qualtrics survey and the consent form was attached in the same email;
2. Participants that had questions emailed author to clarify if they met the requirements;
3. The author responded to questions;
4. The survey was administered to CCLS participants;
5. The author coded answers about nine months after posting survey to Qualtrics.

**Parent.** The author used the following procedure when recruiting the parent participant:

1. The participants phone number was given to the author;
2. The author called and left a message for the parent;
3. The parent called back and scheduled a time and location for the interview;
4. The interview was conducted.
Chapter 4: Results

Parent/Caregiver Interview

The mother who was interviewed is from a rural area. The hospitalized infant was her second child and she was married to her children’s father during the time her son was in the NICU. Her son was born at a hospital that was not equipped for complications after the birth of an infant; therefore, her son needed to be life flighted to the nearest children’s hospital for care. Because the nearest children’s hospital was over an hour away, the mother was unable to go immediately with her son.

The parent interviewed by the researcher reported that she and her husband were nervous and scared once they were notified that their son needed more oxygen shortly after birth. The mother explained, “So my husband and I were super nervous and scared just everything all wrapped up into one.” The mother also described an immediate disconnect when her son was taken from her after delivery and how the father had a hard time watching as medical professionals struggled to place an IV in their son. She also noted that she and her husband felt a sense of calmness when the emergency nurses arrived who were going to life flight their son to a pediatric healthcare setting: “So the NICU nurses in the helicopter came and when they did their assessment of my son it was like an immediate calmness that came over us. Like we instantly could tell the difference between the level of you know, training and professionalism and all of that.” The mother also reported how the NICU nurses took the milk that came out immediately following birth and packed it in a container to take with them to the pediatric healthcare setting. The
mother expressed how meaningful this was to her and how appreciative she was of the nurses to take the time to consider her wishes.

The mother was unable to go to the pediatric healthcare setting until 7 hours later due to the timing of her being discharged from the hospital following birth; however, the father drove there immediately. The mother reported how relieved the father was when he saw his son again in the NICU. Their son was clean, visibly looked well, and seemed calmer and less restless. Once the mother arrived, she also interpreted the NICU environment to be calming, and upon her arrival, they addressed her as her son’s mother. She expressed how she liked feeling like she was not just a guest, but also a mother.

During their son’s stay in the NICU the nurses and doctors were seen as very accommodating, and as parents they felt that they knew the status of their child’s condition. Specifically, the mother shared how it was a teaching hospital and that a number of professionals would enter her son’s room. She explained, “Like they had the whole team of people at his side/bedside and each person had to go and like talk about what was going on with their situation and their particular part of his care.” She said that this was “awesome for us to hear the whole process.” Additionally the mother reported how the nurses suggested she do Kangaroo Mother Care (KMC) (see Figure 1) with her son right away, so she spent most days with her son on her chest forming a bond. The nurses also took pictures for the family when they were not there to share with the family once they returned. The mother was very grateful and happy with the level of care provided for her and her son in the NICU. The mother described the sensitivity the staff had: “You know look back on it now I could tell, you know how in the moment it feels
like the worse thing and you don’t know what’s going to happen and even though, you know he had premature lungs so it was really like in their minds a very typical baby stay, you know. And they knew in 5-7 days you’ll be out of here. But like you could tell that they weren’t just like kind of downplaying it for us because you know, being a parent you don’t think that way.”

Two big stressors were described by the mother with respect to herself and her husband: financial worry from missing work and not being able to see their older child. The mother recalled seeing her older daughter once while her son was in the hospital, and this was in the waiting room. She still remembered how much she missed her daughter but knew she was in good hands; it was just hard to be away from her. She describes the challenge: “But not seeing her (daughter) was probably hard for me, probably the hardest thing.” With regards to how the hospitalization affected the sibling, it was noted that she was having fun and was not affected by the situation. However, distance from the hospital was expressed as a challenge for the infant’s grandmother. The rankings of demands for the mother, father, sibling and other family members are displayed in Table 2.

Following her son’s hospitalization, the mother described her doctor visits that followed as very eventful. The first three visits following his discharge from the hospital included one or more tests every time he went in for a check up. Finally, at the third visit all went well and no more tests were needed. She explains the overwhelming feeling: “But the experience of him being born, going to the, having him in the helicopter to the NICU, we didn’t fly because were not allowed to fly but. Driving there, and being in
hospital for 7 days and then hearing the doctors’ words and like everything and he had
the doctors at like 6 months, like he just had one a week ago and it was normal visit
checkup and a flu shot you know and I can’t get over it. Like a year later, you know.
With my daughter I was not like that.” She says how now she gets anxiety when either
one of her children needs to go to the doctor and that “it’s a hard thing to shake” after the
NICU and eventful doctor’s office experiences.

Table 2

Demands Ranked by Parent/Caregiver (1, Most Demanding; 7, Least Demanding; NR, No Rating)

<table>
<thead>
<tr>
<th>Demands</th>
<th>Mothers</th>
<th>Fathers</th>
<th>Siblings</th>
<th>Other family members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Job demands</td>
<td>7</td>
<td>6</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Financial worry</td>
<td>2</td>
<td>2</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Distance from home</td>
<td>2</td>
<td>2</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Other family members’ demands</td>
<td>1</td>
<td>2</td>
<td>NR</td>
<td>6</td>
</tr>
<tr>
<td>Family support</td>
<td>7</td>
<td>7</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Lack of information</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
</tr>
<tr>
<td>Medical jargon</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
<td>NR</td>
</tr>
</tbody>
</table>
Certified Child Life Specialists Questionnaire Results

From the online questionnaire filled out by CCLS, the top three perceived demands of mothers, fathers, siblings and other family members vary depending on the individual (see Table 3). The author used a clean diagram to tally the number of CCLS respondents perceived demands for each individual then refined the coding system by identifying the top three demands for each individual. A mother’s assessed top three demands are: a) job demands, b) financial worry and c) a tie between distance from home and other family member demands. A father’s top three perceived demands are: a) job demands, b) financial worry and c) distance from home. Siblings observed the top three demands: a) distance from home, b) family support and lack of information tied and c) other family member demands as their third demand. Other family members’ top three perceived demands were: a) other family member demands, b) job demands and c) distance from home. The least significant demands seen by CCLS for mothers and fathers were medical jargon; for siblings, job demands and financial worry; and for other family members, the least significant demand perceived by CCLS was financial worry.
Table 3

*Top Demands CCLS Perceived of Mothers, Fathers, Siblings and Other Family Members*

*Struggle Within the NICU*

<table>
<thead>
<tr>
<th>Mothers</th>
<th>Fathers</th>
<th>Siblings</th>
<th>Other family members</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Job demands</td>
<td>1) Job demands</td>
<td>1) Distance from home</td>
<td>1) Other family member demands</td>
</tr>
<tr>
<td>2) Financial worry</td>
<td>2) Financial worry</td>
<td>2) Family support &amp; lack of information</td>
<td>2) Job demands</td>
</tr>
<tr>
<td>3) Distance from home &amp; other family members</td>
<td>3) Distance from home</td>
<td>3) Other family member demands</td>
<td>3) Distance from home</td>
</tr>
</tbody>
</table>

The questionnaire also provided information about what CCLS actually saw mothers, fathers, siblings and other family members struggle with during an infant’s stay in the NICU (see Figure 5). Mothers have been seen to struggle with distance from home, other family member demands, and financial worry. Fathers are challenged with other family member demands, financial worry, and job demands. Siblings are seen to have a hard time with the distance from home, family support, as well as lack of information. Other family members tend to encounter trouble with lack of information, family support, other family member demands, and distance from home. The data show that what CCLS perceive to be stressful or demanding is what they have seen pose a challenge for mothers, fathers, siblings, and other family members in the NICU setting.
Some specific tools that CCLS utilize in the NICU setting are: KMC, infant massage, Newborn Individualized Developmental Care and Assessment Program (NIDCAP), comfort positioning, nonpharmalogical pain management, procedural support, developmentally appropriate care, assessment and intervention of patient- and family-centered care, memory making, milestone documentation, education for family members, as well as sibling support programs. Out of the 13 participants, nine stated that their NICU department has a sibling program. Supports or materials that are provided to the sibling(s) vary from hospital to hospital, but participants reported both informal and formal programs. Some NICU’s provide opportunities for siblings to engage in medical play, develop books with a picture of their baby brother/sister, and talk about the hospital environment. Others may have a play area designated for siblings to play safely and supervised while their parent(s) are tending to their brother or sister. Some formal
programs are summer camps, weekly programs, or having a sibling night where the siblings are visited by professional dancers, magicians or puppeteers.

Of the tools described, the NIDCAP, infant massage, parent education, positioning for comfort, nonpharmalogical pain management, preparation, developmental play, playrooms, sibling support, and milestone documentation were identified as being the most effective in the NICU by CCLS. What was seen to be least effective by CCLS in the NICU was infant massage for some, and mobiles. It was also noted that the needs of the family and/or sibling should be taken into consideration to meet their individual needs during hospitalization.

Some CCLS participants would like to see more sibling support, more family support groups, and more parental participation in the comfort positioning during procedures. Additionally, it was noted that procedural support education may be more beneficial for IVs, blood draws, or peripherally inserted central catheter (PIC) placements, along with a formal sibling center or more sibling visitation opportunities. A CCLS participant stated that the NICU is the “front door to the hospital for these families, many of which will spend years receiving services from our institution for their child. The impression and care that they get in the NICU will impact their attitude about health care and child life for years.” Another CCLS said, “Providing positive touch, normal baby experiences and developmentally appropriate stimulation is critical.”
Chapter 5: Discussion

This study adds to the literature regarding the role of CCLS, as well as parents, in the NICU. The data showed that incorporating the families’ desires into the overall care of the infant led to a more satisfied hospital experience. The belief in patients and FCC is highly valued by the field of child life and CCLS, as validated by this research. Also the tools and resources used by CCLS are viewed as effective and beneficial, keeping in mind the importance of viewing every family unit as unique, respecting their differences, and attempting to meet their needs/wants when possible. This is an additional goal of CCLS.

Suggestions for future child life programs in the NICU would be to utilize the tools/resources that were seen to be useful, as well as advocate for parental presence and comfort positioning (see Figures 6, 7 and 8) during procedures or treatments. Comfort positioning provides an infant/child eye contact and/or an opportunity to be physically touching primary caregiver/parent to provide a sense of comfort during potential stressful situations. Distraction can also be utilized to focus a child/infant’s attention onto an object/person rather than what medical professionals are doing (see Figure 9). Educating siblings, parents and other family members about the sights, sounds, smells, and feeling of the NICU atmosphere may also allow for decreased fears or misconceptions about the environment or procedures. Providing procedural preparation for treatments can additionally inform parents about what will happen and what outcomes to expect from the procedure. CCLS can offer families a reason why certain treatments or protocols are recommended, validate parents’ feelings or thoughts about their child’s hospitalization,
and let them know they are not alone. Child life professionals are able to empower families to feel a part of the team and notify them of how their presence, opinion, and needs are vital in the care of their child.

*Figure 6. Comfort position when medical professionals need to examine the infant’s leg/foot. Copyright 2014 Barb Fisher. Reprinted with permission.*
Figure 7. Comfort position when medical professionals need to examine the infant’s arm/hand. Copyright 2014 by Barb Fisher. Reprinted with permission.

Figure 8. Comfort position when medical professionals need to examine the leg/foot while holding the infant. Copyright 2014 by Barb Fisher. Reprinted with permission.
As reported by the mother, her son’s hospitalization affected the family system as a whole. As a mother, she was challenged by not seeing her other child, by the financial responsibility of providing for her family, as well as by the distance from home. Additionally, it was expressed how the distance affected the infant’s grandmother in a negative manner, showing how when one family member goes into the hospital this can affect the remaining family members. Along with members of the family system affecting one another, the bioecological theory was also evident in how the financial aspect of mom and dad’s jobs indirectly affected how the family unit functioned. The hospital’s services also played a role when the infant needed to be life flighted to a pediatric healthcare setting to receive more specialized care. This also played into the distance for the mother who was unable to develop an instant bond with her child right after birth.

The author was limited in finding family participants with NICU experience due to regulations of the Health Insurance Portability and Accountability Act (HIPAA).
Professionals in the hospital environment who have easier access to infants and their families could do further research. Single data set collection method was used for the CCLS survey and another single data set collection method was used for the family that was interviewed. Answers from the survey given to the CCLS are limited to the questions that are presented. Additionally, there was no follow up once the surveys were completed. Each group was limited to the questions being asked by the researcher. As a result, the findings of this study are not intended to generalize across the population. The intent was to gain a deeper understanding of CCLS being present in the NICU setting.

Research could be done with current programs that offer CCLS services in their NICU. For example, caregivers could be asked to fill out exit questionnaires reflecting on their experiences to see what more CCLS could provide for them. To add to this research, more parents/caregivers who experience the NICU setting could be interviewed to gain a better understanding of their perspective on the environment, their role in their infant’s care, and how effective they feel the staff is in meeting their family’s needs. Yet another project could look at how the medical staff feels about CCLS being added to their team. After educating medical professionals on the role of CCLS in the NICU it would be useful to ask them how they perceive the CCLS. The interview that took place for this study touched on aspects that CCLS would have been responsible for, yet CCLS were not present so nurses took on the role. Although, by having CCLS present, nurses would be able to focus their attention primarily on the medical needs of the infants, while allowing CCLS to work with the psychosocial components of the infant and his/her family’s care.
This method allows for a team approach while fulfilling the mission of FCC and the developmental goals of the infant.

This study provides justification for CCLS providing services in NICU as an added part of providing patient and FCC practices. These professionals are integral members of the psychosocial team and can offer added support for patients and their families in the NICU. There is clearly a need for a support system in the NICU for families of the infants who are hospitalized; CCLS has the knowledge and understanding to take the role.

**Proposal for Implementing the Role of CCLS in the NICU**

The prevalence of CCLS in the NICU is slim compared to the number of children’s hospitals with NICUs, therefore a proposal (see Appendix H) has been established to educate others about why CCLS have an important place in the NICU setting. The mission of CCLS in the NICU is to strive to provide support, coping strategies and education to the patient and his/her family during a child’s hospitalization. CCLS understand and value a child’s developmental needs and promote growth and developmental activities and interventions during their hospital stay. Play, FCC, procedural support and parental presence are appreciated by CCLS and are an integral part of child life interventions.

There are seven objectives to the role of CCLS in the NICU: a) education, b) promote attachment and bonding, c) enhance sibling involvement, d) encourage developmentally appropriate play, e) increase positive stimulation, f) utilize psychosocial team members and g) grow patient and FCC concepts. The education piece could be seen
by simply educating parents, siblings and/or family members about the equipment in the room or preparing them for procedures or treatments that may take place. Describing how to perform comfort positioning and its benefits can lead into the second objective, increasing attachment and bonding. When comfort holds are done by the parents/caregivers this can offer the infant a chance to trust and find comfort in their caregiver during pleasurable procedures. KMC also will increase the attachment needs between infants and their caregivers, while offering some one-on-one time. Siblings are often thought to be unaffected by their little brother/sister’s stay in the NICU, but this is not true. By educating and allowing for siblings to visit their younger sister/brother may provide them a way to cope and see their mother/father more regularly. Another resource is to have a sibling playroom off of or near the NICU unit that is staffed by professionals who can explain why their brother/sister is in the NICU and where their parents are. This area serves as a safe and open environment for communication and understanding about their feelings or misconceptions. The fourth objective is to encourage developmental play; this can offer the infant to be just that, an infant. Play is the universal language of children and can bring comfort to them during uncomfortable situations. For infants providing desensitization and allowing them to explore their environment through their senses can provide them with opportunities to meet their developmental milestones. Increasing positive stimulation like soft music, calming voices, and lower light and sounds will permit infants to be calmer and less stressed. CCLS are members of a psychosocial team and are able to consult art therapists, music therapists, social work, and/or palliative care specialists who can provide even more ways to care for infants’ and
their families’ holistic health. Lastly, CCLS have the ability to grow patient and FCC by advocating for their voices to be heard on the unit or in multidisciplinary rounds. CCLS professionals are able to intently listen to fears, concerns, misunderstandings or wants of patients and their families with the drive to meet their individual needs. When a CCLS does not have the answer, he/she can find someone who does to ease the family’s worries and advocate for the family. The family being seen as a child constant and allowing them to play an active role in their child’s care.

The program description for NICU child life services will entail education, direct care, advocacy, and FCC planning. The NICU child life program will emphasize the importance of parents as partners, developmentally appropriate play, and education, providing opportunities for each. The NICU was described as the “front door to the hospital for these families, many of which will spend years receiving services from our institution for their child. The impression and care that they get in the NICU will impact their attitude about health care and child life for years,” stated by a CCLS participant in a study that looked at the importance of child life in the NICU. In conclusion, with the addition of CCLS to the NICU staff, both the professionals as well as patients and their families will receive comprehensive individualized holistic care in the NICU.
References


Guillaume, S., Michelin, N., Amrani, E., Benier, B., Durrmeyer, X., Lescure, S.,…


Appendix A: Informed Consent

Ohio University Consent Form

Title of Research: The Importance of Child Life in the Neonatal Intensive Care Unit (NICU)

Researchers: Bethany C. Karl (student), Jenny Chabot Advisor

You are being asked to participate in research. For you to be able to decide whether you want to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to sign it. This will allow your participation in this study. You should receive a copy of this document to take with you.

Explanation of Study

This study is being done because the results will aid current as well as future Child Life Specialists who are working with infants and their families who are within the Neonatal Intensive Care Unit (NICU). The outcomes will also allow for your voice to be heard and suggestions to be considered in the future to help families and infants in the NICU setting.

If you agree to participate, you will be asked to answer some questions about the care you have provided for infants and their families who were within the NICU or questions will be asked regarding your infants stay in the NICU where Child Life was present.

Your participation in the study will last approximately 30-45 minutes. Time is dependent on the length of your answers.

Risks and Discomforts

Risks or discomforts that you might experience are feelings that were associated with the stressors or challenging times while your infant was hospitalized in the NICU.
These may arise as you revisit certain situations or interactions with some of the hospital staff.

Benefits

This study is important to science/society because you and your infant’s individual needs and thoughts should be taken into consideration in an attempt to decrease your stress or increase the amount of support/assistance provided for you.

Individually, you may benefit from this interview by revisiting your infants stay in the NICU; where you may have had some good memories or you may find this interview to be a way to cope or deal with your infants’ hospitalization. With regards to you as a Certified Child Life Specialists; you will be able to reflect back on your interactions and help future professionals working with infants and their families in the Neonatal Intensive Care Unit.

Confidentiality and Records

Your study information will be kept confidential by your surveys or recordings of your interview being locked up in a desk drawer in a locked room.

Additionally, while every effort will be made to keep your study-related information confidential, there may be circumstances where this information must be shared with:
  * Federal agencies, for example the Office of Human Research Protections, whose responsibility is to protect human subjects in research;
  * Representatives of Ohio University (OU), including the Institutional Review Board, a committee that oversees the research at OU;

Compensation

No compensation will be provided.

Contact Information

If you have any questions regarding this study, please contact: Researcher: Bethany C. Karl; 1-440-371-8424 or email: bethacf@bgsu.edu; Advisor: Jenny Chabot; 1-740-593-2871 or email: chabot@ohio.edu

If you have any questions regarding your rights as a research participant, please contact Jo Ellen Sherow, Director of Research Compliance, Ohio University, (740)593-0664.
By signing below, you are agreeing that:

- you have read this consent form (or it has been read to you) and have been given the opportunity to ask questions and have them answered
- you have been informed of potential risks and they have been explained to your satisfaction.
- you understand Ohio University has no funds set aside for any injuries you might receive as a result of participating in this study
- you are 18 years of age or older
- your participation in this research is completely voluntary
- you may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you and you will not lose any benefits to which you are otherwise entitled.

Signature ___________________________________________ Date __________
________

Printed Name ____________________________________________

Version Date: 03/03/2014
Appendix B: Flyer for Parent/Caregiver Recruitment

Are you a parent or caregiver who has had an infant who was admitted to NICU?

Are you interested in sharing your experience/interactions while your son/daughter was in the NICU?

I am currently looking to interview families who have had an infant in the NICU setting. I am looking at the benefits or areas that could use some improvement with regards to Certified Child Life Specialists being present to infants and their families in the NICU.

The interview should take roughly 30-45 minutes and I will be more than willing to work around your personal schedule. Thank you for your time 😊

For more info contact:
Bethany Karl
Bk762912@ohio.edu
Appendix C: Questionnaire for CCLS

Questionnaire for CCLS working in the NICU setting for at least one year:

Directions: Please answer the following seven questions regarding the child life practices in the hospital you are working.

1) How long have you worked in the NICU?
   ___ 1 year
   ___ 2-3 years
   ___ 4-6 years
   ___ 7-9 years
   ___ 9 or more years

2) Please list and describe specific tools that you utilize (e.g.: Kangaroo Care, HUGS program, Sibling support program(s), etc.). Please rate how often each tool is used (for example: 1 being your top choice, 2 being your next choice and so on…)?
   • ______________________________________________________________________
   • ______________________________________________________________________
   • ______________________________________________________________________
   • ______________________________________________________________________
   • ______________________________________________________________________
3) Do you have a sibling support program? (for example: specific tools, resources, or collaboration with other professionals, etc.)

___ yes
___ no

3a) If Yes, please explain the program in detail below:

__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
__________________________________________________________________
4) Use the diagram below to mark the boxes of stressors, issues, demands…etc. you have seen mothers, fathers, siblings or other family members struggle with.

<table>
<thead>
<tr>
<th>Demands</th>
<th>Mothers</th>
<th>Fathers</th>
<th>Siblings</th>
<th>Other Family Members</th>
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<tbody>
<tr>
<td>Job demands</td>
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<td>Financial Worry</td>
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<td>Other family members/demands</td>
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<td>Family Support</td>
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<td>Lack of Information</td>
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<tr>
<td>Medical Jargon</td>
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</tbody>
</table>

5) Using the diagram below please rank the demand for each member of the family.

(scale: 1; most significant and 7; least significant)

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</tbody>
</table>
4) What child life tools are most effective in the NICU?

5) What child life tools are least effective in the NICU?

6) What would you like to see done more often for family support while an infant is in the NICU?

7) Is there anything else you would like to add about child life services or infants and their families during their stay in the NICU?
Appendix D: Interview Questions

Questions for the families of infants who spent at least 5-7 days in the NICU:

1) How long was your infant’s stay in the NICU?

2) Looking back, what were your concerns and feelings? (Follow up: How were they addressed.)

3) What tools, support or resources were missing during the hospitalization process?

4) Do you feel that you were heard and listened to during your infants stay in the NICU?

5) Use the diagram below to mark the boxes of stressors, issues, demands…ect you have seen mothers, fathers, siblings or other family members struggle with.

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</table>
6) Using the diagram below please rank the demand for each member of the family.

(scale: 1; most significant and 7; least significant)

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7) Are there any additional comments you have about your experience with the NICU?
Appendix E: Email for Recruiting CCLS

Current CCLS working in the NICU,

    My name is Bethany Karl and I am currently a first year graduate student pursuing my masters in Child and Family Studies with a concentration in Child Life at Ohio University. As part of my master’s degree I am conducting research for my thesis.

    I am interested in what tools, strategies or techniques CCLS are currently using and if there are ideas of how to improve child life in the NICU. I am also collecting data from families who have had a child admitted to the NICU for at least one night where CCLS were present to see their perspective about how child life was beneficial or suggestions to improve the effectiveness.

    I am seeking out CCLS who have worked in the NICU for at least one year to complete a questionnaire. If you are interested or have further questions please feel free to contact me via email; bk762912@ohio.edu.

    Thank you very much for your time, have a great day.

    Bethany Karl
Appendix F: Demographics of CCLS

1) Age_____
2) Gender:
   Male_______ Female_____
3) Race/Ethnicity:
   White/Caucasian___ Black/African American___ Asian___
   Middle Eastern____ Hispanic____ Bi-Racial____ Other_______

4) How long have you worked in the NICU?
   __________________________________________________________
Appendix G: Demographics of Parent/Caregiver

1) Age____
2) Gender:
   Male______            Female_____
3) Race/Ethnicity:
   White/Caucasian ___   Black/African American ___   Asian ___
   Middle Eastern ___   Hispanic ___   Bi-Racial ___   Other _____
4) How long was your child in the NICU?
   ______________________________
Appendix H: Proposal for CCLS to be Added to NICU Staff

Proposal for Certified Child Life Specialists (CCLS) to be added to NICU staff

BETHANY C. KARL

Child Life

• CCLS, “promote effective coping through play, preparation, education, and self-expression activities. They provide emotional support for families, and encourage optimum development of children facing a broad range of challenging experiences, particularly those related to healthcare and hospitalization” (The Child Life Council, 1998-2012).

• Bell et al. (2009) describes a CCLS's role as one who recognizes the family as a child’s constant as these individuals play a significant role in the patient’s health and well being in a healthcare setting.

• collaboration of care approach opens up communication between the family and professionals by sharing information, providing support, and keeping in mind the child’s developmental needs during hospitalization (2009).
History of Child Life Profession

• 1920’s
  • Development began to improve healthcare for children
    • Play, preparation, educational programs
    • Emotional stability, health development
    • Decrease pain & fear
• 1965
  • Goal to create child & family friendly hospital environment
• 1970’s
  • Theoretical basis
• 1982
  • CLC established

History Cont.

• 1983
  • Research grant
  • *Psychosocial Care of Children in Hospitals: Clinical Practice Manual*
• 1998
  • Certification exam implemented
• 2000’s
  • Growth in traditional & non-traditional areas
    • Hospice, bereavement or support groups, dental facilities, courthouses, camps, early intervention programs
Child Life in NICU at…….  
(insert institution)

• What does child life fall under?
• Profile of CCLS at …… hospital
• Describe roles & responsibilities of CCLS (hospital specific)

Mission

Certified Child Life Specialist (CCLS) professionals strive to provide support, coping strategies and education to the patient and his/her family during a child’s hospitalization. CCLS understand and value a child’s developmental needs and promote growth and developmental activities and interventions during their hospital stay.

Play, FCC, procedural support and parental presence are appreciated by CCLS and are an integral part of child life interventions.

“It is through the effectiveness of communication that child life specialists facilitate interpretational relationships with children, staff and family members and help to create and maintain family-centered care.” (Klinzing and Klinzing 2009, p. 78)
Goals & Objectives

• Educate
  • Parents, siblings & other family members
  • Preparation for procedures
  • Procedural support
  • Comfort positioning

• Promote attachment & bonding
  • KCM
  • Comfort positioning

• Enhance sibling involvement
  • Sibling visits
  • Sibling playroom

• Developmentally Appropriate play
  • Exploring senses, people & environment

• Increase positive stimulation
  • Soft music
  • Decrease light & sounds
  • Advocate for soothing environment

• Utilize the psychosocial team
  • MT, AT, social work, palliative care

• Patient & FCC
  • Advocate for individual wishes/needs
  • Listen and hear concerns
  • Promote communication between families & professionals
  • Active family involvement

Program Description

• NICU child life services will entail education, direct care, advocacy, and FCC planning.

• The NICU child life program will emphasize the importance of parents as partners, developmentally appropriate play and education, providing opportunities for each.
Closing/Power Statement

CCLS participant in a recent study looking at the importance of Child Life in the NICU stated: the NICU is the

• “front door to the hospital for these families, many of which will spend years receiving services from our institution for their child. The impression and care that they get in the NICU will impact their attitude about health care and child life for years.”

References


