Addressing Parent Needs in the Neonatal Intensive Care Unit: A Survey of Music Therapists

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ADDRESSING PARENT NEEDS IN THE NEONATAL INTENSIVE CARE UNIT:
A SURVEY OF MUSIC THERAPISTS

By

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This thesis is dedicated to premature infants and their parents. I also dedicate this thesis to my parents, who navigated the uncertainties of my hospitalization as a premature infant. Your steadfast love and faith carried me then, and has helped mold me into the person I am today.
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ABSTRACT

Limited research exists exploring how music therapists address parent-related needs and concerns in the NICU. The purpose of the study was to expand existing knowledge and literature regarding how music therapists work with parents and their infants in the NICU, to address parent-related needs, and to provide suggestions for future directions for music therapy with parents of infants in the NICU. The principal investigator sent out an invitational email to music therapists who currently or have previously worked in the NICU. A total of 54 responses (n=54) were received—respondents (n=50) completed the survey entirely and 4 partially (n=4) via Surveymonkey.com®. Data were collected over a four-week period and were analyzed using descriptive statistical measures. Results support the use of music therapy to address both parent and infant goals and the expansion of ways in which music therapy/music therapists can serve as an extension of family-based NICU care. Results indicated that music therapists spend a relatively equal amount of time with parents and their infants (jointly and separately) and receive both medical and non-medical referrals for parent-related needs. Grief counseling, general counseling techniques, music therapy techniques specific to parent needs, and cultural sensitivity training were areas in which music therapists desired more training. Future implications for research include expansion of knowledge regarding how to work with parents of infants with neonatal abstinence syndrome and other complex medical issues.
INTRODUCTION

Hospitalization can be a stressful event for both the patient and the patient’s family. Patients and family members are seeking information regarding medical issues, assistance in symptom management, information regarding prognosis and/or recovery, and support in coping with these situations. Patient hospitalizations are on the rise, increasing by 11% between 2000 and 2010 (Hall, Levant, & DeFrances, 2013). With a growing emphasis on patient-centered care as well as the increasing number of people with chronic medical issues, increased attention has been placed on meeting patients’ psychosocial needs. According to Adler and Page (2008), in order for psychosocial care to truly be effective, there must be an emphasis on coping with psychological, behavioral, and social aspects of illness, and enabling patients’ families and health care providers to promote better health in themselves and their patients (Goodeg, 2014).

For parents of hospitalized premature infants, caring for and worrying about the health of their child or newborn with medical problems is greatly distressing (Pace, 1999; Cleveland, 2008). Infants are admitted to the Neonatal Intensive Care Unit (NICU) for a variety of reasons, including prematurity, sepsis, neonatal abstinence syndrome (NAS), and respiratory difficulty. Parents often struggle with the unknown in the unfamiliar and potentially threatening environment of the NICU and face challenges to the development of their parental roles (Fenwick, Barclay, & Schmied, 2001a, 2001b; Heerman, Wilson, & Wilhelms, 2005; Hurst, 2001a, 2001b; Lupton & Fenwick, 2001). Additionally, parents may feel as though they are ‘parenting from a distance’ and struggle with feelings of uselessness, while yearning to be helpful in the care of their infant (Higgins & Dullow). Being able to provide basic care and learning how to recognize signs of overstimulation are important in the development of the role of the parent (Heerman et al.) Being given an increasing role in providing care whenever possible as well as having opportunities for bonding are critical for parents of infants in the NICU (Lupton & Fenwick, 2001). Several studies also indicate that parents (particularly mothers) may at times feel frustration and stress due to the lack of opportunity to be near or have contact with their infant (Lupton & Fenwick, 2001; Higgins & Dullow, 2003; Ward, 2001; Whitlow, 2003). The research highlights that it is important for NICU staff to address parents’ needs during their infant’s medical treatment (Kazak & Barakat, 1996; Seideman et al., 1997),
while also providing applicable information to help parents understand their infant’s situation (Loo, Espinosa, Tyler & Howard, 2003; Seideman, et al., 1997).

The American Music Therapy Association (2013) defines music therapy as “the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program.” For each individual patient, a music therapist assesses, creates a treatment plan, and evaluates outcomes. Each patient’s music therapy goals and objectives are specific and related to the “medical diagnosis, course of treatment, and discharge timeline” (American Music Therapy Association, 2013). In the medical setting, research has shown music therapy provides positive benefits such as reducing anxiety, stress and pain, reducing nausea in chemotherapy or hemodialysis, reducing fear related to serious illness or injury, elevating mood and emotional states, increasing patient participation in treatment, shortening length of hospital stay, and providing emotional intimacy with families and caregivers (American Music Therapy Association, 2013; Standley et al., 2005). In addition, evidence demonstrates that music therapy is effective in various hospital units such as pre- and post-operative care, surgery, chronic pain management, oncology, orthopedic, neurology, heart and vascular care, obstetrics, emergency, physical rehabilitation, outpatient programs, pediatrics, and intensive care units, including the Neonatal Intensive Care Unit (American Music Therapy Association, 2013; Standley et al., 2005).

Over the past 30 years, music therapy in the Neonatal Intensive Care Unit with premature infants has been steadily growing in practice and research (Standley & Walworth, 2010). Evidence-based medical music therapy treatment in the NICU is centered on the needs of the infant, the medical and developmental goals of NICU care, and the protocols and interventions documented in the research literature. Reports in the existing literature demonstrate that music therapy addresses a large variety of needs and produces beneficial outcomes in the hospital. The issues and needs addressed in the NICU by music therapy include: potential interruption in neurological development (due to stress and sensory overstimulation of the infant’s immature neurological system) (Standley & Walworth, 2010), weight gain (Whipple, 2000), oxygen saturation levels (Standley, 2002), developing the suck-swallow-breathe reflex then transitioning
to nipple/bottle feeding, increasing the infant’s ability to tolerate increasing auditory and tactile stimuli, encouraging and facilitating parent-infant bonding, increasing the infant’s ability to self-soothe and self-regulate, and parent counseling (Standley & Walworth, 2010; Standley, 2012; Whipple J., 2008; Walworth, D., Standley, J., et. al., 2008). Additionally, music therapy has been shown to increase appropriate parent actions and responses to their infants, which may lead to decreased stress levels in parents (Whipple, 2000). Live singing of parent preferred lullabies enhanced parent-infant bonding and also significantly decreased the perception of parental stress (Loewy et al., 2013). Limited research exists exploring how music therapists address parent-related needs and concerns in the NICU. The purpose of this research study is to investigate the extent to which music therapists address the needs of parents of infants in the NICU.
Prematurity and the NICU Environment

Prematurity is defined as less than 37 weeks gestation, and low birth-weight (LBW) indicates the infant weighs less than 2500 grams (5 lbs., 8 oz). Infants born as early as 24 weeks gestation have a 56% probability of surviving in the U.S., while those born at 32.5 weeks have over a 95% survival rate (Centers for Disease Control [CDC], 1999). Prematurity and LBW are the second leading cause of infant mortality (birth defects are the leading cause of infant death). The incidence of infants born with LBW is increasing. In 2001, 7.6% of live births were considered LBW; by 2006, 9% of live births were LBW. Low birth-weight children are twice as likely to be hospitalized during early childhood and usually sustain longer hospital stays (Standley, 2003; Standley and Walworth, 2010). Many risks and complications are frequently associated with premature births, such as asthma, cerebral palsy, cognitive functioning below the normal level, poor academic achievement, and behavioral problems. Some health impairments may even lead to an increased predisposition to early mortality in adulthood (Gooding, 2010).

The average cost of hospitalization for infants in the NICU is $42,610 versus $2,830 for a term infant, and the average costs for health care through the first year of life for a premature infant is $32,000 versus $3,000 for full-term infants (Kornhauser, 2010; Standley, 2010). As LBW children grow and begin school, they are 50% more likely to be enrolled in special education. Medical treatment in the NICU can cause stress that disrupts neurological development, leading to future problems. Developmentally appropriate nurturing interventions may be able to offset some of the long-term trauma to infants from extended hospitalization (Standley, 2003).

During the third trimester while the infant is in the NICU, his or her brain is adding 250,000 neurons per minute. One hundred billion neurons will form, which is all a human being will receive throughout his or her lifetime (Chiron et al., 1997). The neural cells compete with each other and connect across synapses to link up with specific neurological functions (Fischer & Rose, 1994). In order to become permanent, these neural connections must be used regularly or
they will die off. During periods of stress and overstimulation, these neurons stop dividing. Thus, the premature infant who will spend the third trimester of fetal development in the NICU is susceptible to neurologic damage. Nurturing can offset some of this damage while promoting growth and development through cause/effect learning (Standley, 2012; Standley, 2003). The newborn’s brain is about one third the size of an adult’s but will triple in size by the age of 2 years (Standley, 2003).

Hearing develops quite early in fetal development. At 18 gestational weeks, hearing develops and the fetus responds to music during the third trimester of development (Lecanuet et al, 2000; Standley, 2003). At 30-35 gestational weeks, the fetus is hearing maternal and nearby environmental sounds and is beginning to respond. It has been shown that this auditory input while in the womb is assimilated and learned. The fetus begins to discriminate among speech sounds, especially concerning pitch and rhythm (Standley, 2003; Lecanuet, Granier-Deferre, & Busnel, 1995). The fetus also adapts to the mother’s voice when she speaks or sings and during her movements and breaths. It is established that, at birth, a term infant can distinguish a mother's voice, prefers women's over men's voices, recognizes stories and songs heard during the final trimester, and discerns his or her native language (DeCasper & Fifer, 1980; DeCasper & Spence, 1986; Kolata, 1984; Moon, Cooper, & Fifer, 1993; Polverini-Rey, 1992).

The premature infant’s neurological system is hypersensitive to stimuli (sound, light, touch, smell, and taste). Because stimulation across the senses is cumulative, the preterm infant’s exposure to stimuli should be restricted and controlled. Overstimulation disrupts neurological development and should be avoided as much as possible. The NICU environment has high ambient noise levels, which can increase the infant’s stress level, disrupt sleep cycles, cause startle responses shown in highly inconstant psychological measures, and reduce growth and development in preterm infants (Perlman, 2001). The American Academy of Pediatrics (APA) suggests that sound levels be maintained below an hourly loudness equivalent of 50dB, an hourly L10 (sound level exceeded 10% of the time) of the 55 dB and 1-second maximum of 70 dB using the A-weighted, slow response scale (American Academy of Pediatrics, 1997; Krueger, Wall, Parker & Nealis, 2005; Thomas, 2007).
It is known that male and female infants develop differently in the NICU. Female infants thrive more robustly and learn developmental skills more quickly, while male infants are bigger at birth, are more active, and are more easily overstimulated (Standley, 2003). Male infants also do not thrive as easily and may have longer hospitalization in the NICU before discharge. Cassidy and Ditty (2001) determined male infants' hearing to be less sensitive to frequency than female infants. In their post-hoc analysis of transient evoked otoacoustic emissions (TEOAE) scores, females showed consistent higher sensitivity to different properties of sound. In the protocols, the researchers included minimum gestational age, perceivable frequency spectrum, appropriate equipment, and appropriate decibel levels. They concluded that a "standardization of protocols regarding administration of auditory stimuli to infants" was crucial (Cassidy & Ditty, 2001; Peczeniuk-Hoffman, 2012).

**Parental Needs in the NICU**

The initial visit to the NICU can be very frightening for families of preterm infants. NICUs are very busy places with new noises, smells, and people. Although they are often full of other patients, parents may have a sense of being alone. Parents are inundated with information about their baby, the equipment, the unit, the staff, the visiting hours, etc. The staff, in an attempt to help inform the parents, often gives them too much technical information, which quickly overwhelms them. Hospital and unit policies can create significant road blocks for parents (Fenwick et al., 2001a, 2001b; Heerman et al., 2005). Other factors that may contribute to parental stress in the NICU include the lack of opportunity to interact with their infant, the sights and sounds of the NICU, the appearance and behavior of their baby, and alteration in their parental role (Miles, M. S., Funk, S. G., & Carlson, J., 1993; Vuong, 2013). Adjustment to the new family situation, the health status of the baby, the relationship to the infant and control of care, may also influence parental stress levels (Franck, Cox, Allen & Winter, 2005; Schappin, Wijnroks, Uniken Venema & Jongmans, 2013; Vuong 2013).

Shields-Poe & Pinelli (1997) conducted a descriptive study to identify sources of parental stress in NICUs. Pregnancy expectations, family income, social support, and the severity of
illness of their premature infant were all factors that were found to be associated with parental stress. Additionally, Shields-Poe & Pinelli (1997) found that mothers and fathers responded differently to the NICU experience. Miles, Funk & Kasper (1992) interviewed 23 couples of premature infants twice; the first time was within a week of their infant’s admission, and the second time was approximately one week later. Their findings indicated that both mothers and fathers perceived the change in parental role as the greatest source of stress. Mothers had higher stress scores associated with parental role alteration compared to fathers. Overall, research has shown that mothers tend to be more stressed and anxious, and tend to adapt poorly compared to fathers (Vuong, 2013; Doering, Moser & Dracup, 2000; Franck, Cox, Allen & Winter, 2005; Jackson, Ternestedt & Schollin, 2003; Miles, Funk & Kasper, 1992; Shields-Poe & Pinelli, 1997). Mothers tend to be stressed by the parent-infant relationship, which may be affected by their involvement with their child, the extended time spent in the NICU, and the biological or social role differences between mothers and fathers. Jackson, Ternestedt & Schollin (2003) found that mothers felt they had a need for control in the care of the baby, and therefore, participated more with baby care, yet they felt less confident providing care of their baby in the environment. However, fathers had difficulty leaving work, which resulted in fewer visits (Jackson, Ternestedt & Schollin, 2003). Fathers tended to feel stressed by trying to find a balance between work and family life and by the physical NICU environment (Bakewell-Sachs & Gennaro, 2004; Franck, Cox, Allen & Winter, 2005; Jackson, Ternestedt & Schollin, 2003; Miles, Funk & Kasper, 1992; Steedman, 2007).

Several studies have indicated that parental stress in the NICU has negative outcomes for the family (Doering, Moser & Dracup, 2000). The birth of a premature infant may create increased stress in a family, such as personal strain, financial burden, and family and social disruption (Doering, Moser & Dracup, 2000). Stress from the NICU experience is related to parenting behavior (Rodgers, 1998). Research has shown that stress from the premature birth can also affect parenting confidence, quality of the parent-child relationship and possibly the child’s outcomes (Loo, Espinosa, Tyler & Howard, 2003; Muller-Nix et al., 2004) in the forms of coercive parent-child interactions, inconsistent disciplining, inappropriate and unrealistic child expectations (Belsky, 1984; Rodgers, 1998). Additionally, mothers seem to be more distant in mother-child interactions, which may be due to the child’s immaturity, prolonged hospitalization,
early separation maternal emotional experience or alternations in parenting roles (Muller-Nix et al., 2004; Nair, Gupta & Jatana, 2003).

A study by Cleveland (2008) identified six areas of needs for parents who have an infant in the NICU. These needs include: (a) accurate information and inclusion in the infant’s care, (b) vigilant watching-over and protecting the infant, (c) contact with the infant, (d) being positively perceived by the nursery staff, (e) individualized care, and (f) a therapeutic relationship with the nursing staff. Additionally, Cleveland’s study highlighted four nursing behaviors to assist parents in meeting these needs: (a) emotional support, (b) parent empowerment, (c) a welcoming environment with supportive unit policies, and (d) parent education with an opportunity to practice new skills through guided participation (Cleveland, 2008). Cleveland concluded that, while strides have been made in research pertaining to parenting in the NICU, there is a need for continued study of this topic and parent needs in the NICU should remain a priority for researchers. Nursing (and other healthcare) staff “have a responsibility to provide evidence-based care that is effective and meets the needs of this vulnerable population of patients” (Cleveland, 2008).

In a study regarding the parents’ need to develop a therapeutic relationship with nursing staff, researchers found that the nurse’s interactions with parents can positively or negatively influence parent-infant relationship. Several researchers described a “power struggle” that developed between the parents (particularly the mother) and the nurse (Fenwick, 2001a; Lupton & Fenwick). This was often because of inhibitive nursing practices that included the nurse “protecting” the baby and directing the mother. This approach tended to alienate the mother and allowed the nurse to maintain his or her role as the expert (Fenwick et al., 2001a). Even subtle factors such as the nurse’s tone of voice and body language can have a positive or negative effect on parents’ anxiety (Cleveland, 2008). In a similar study by Hurst (2001b), mothers were found to be acutely aware of the struggle for power and the NICU staff. Researchers also suggest that parents generally want to collaborate with care providers, especially nurses (Bialoskurski et al.; Hurst, 2001a; Lee et al.; Mok & Leung; Taylor-Huber). Fenwick et al. (2001b) found that the nurse’s ability to “engage” the mother and develop a supportive relationship relied on the use of language. Sharing of personal information was found to occur through “chatting” and mothers
associated this skill with the nurse being a “good nurse.” Conversations often involved sharing about life outside of the nursery interspersed with information about the mother’s infant.

Heereman et al. (2005) found that supportive nursing care was helpful in facilitating meaningful empowerment of mothers as they moved from outsiders to engaged mothers in the NICU. As they became more engaged, they were more likely to become more active participants in their baby’s care routines. Heereman et al. (2005) also found that mothers who wanted to become more involved in their baby’s care sometimes stayed back and waited to be invited by the nurse, and some mothers felt so intimidated by the NICU environment that they were afraid to provide care. On the whole, nurses helped mothers feel more confident in these situations by giving them guided experience. Having the opportunity to practice new skills with assistance from nursing staff has been identified as important to NICU parents according to the literature (Browne & Talmi, 2005; Bruns & McCollum, 2002; Kowalski et al., 2006; Melnyk et al., 2001, 2006; Peterson et al., 2004).

Studies have shown that parents and caregivers may sometimes have difficulty with parent/infant attachment. Infants who are born ill or very premature may be taken out of the delivery room to stabilize, and the mother and family may not see the baby for several hours after delivery. Sometimes a baby may be transported to another NICU for a higher level of care. This delay in seeing or touching the baby can affect the attachment process. Seeing and touching are ways for the mother to immediately begin to feel positive maternal feelings toward her baby (Franklin, 2006). Mother/infant attachment is the single greatest predictor of future development of the child. Premature birth interruption of the pregnancy timeline and the considerable stress and fear that stems from distress about the infant’s wellbeing also interrupt the usual birth hormonal responses that contribute toward immediate attachment (Standley, 2014).

Several studies have demonstrated that early holding is one of the most important activities in promoting early attachment. Kangaroo care has been shown to be effective in promoting parent-infant bonding and reducing parental anxiety. A study by Gale (et al, 1993) found that kangaroo care was safe for the intubated infant and promoted parental attachment, even in parents who were at high risk for attachment impairments. It may also offer some parents an effective method to overcome some of the barriers to attachment imposed by the infant's
hospitalization. This skin-to-skin contact provides not only warmth but also tactile, olfactory, and auditory stimulation. Premature newborns are better able to maintain physiologic stability when compared to traditional holding, and it encourages a sense of closeness between the mother and the baby. Franklin (2006) also cites grief as another barrier that may delay or alter the attachment process. Parents may suffer profound grief over the loss of the “normal” baby. The events that occur are usually unexpected and parents will grieve the loss of the perfect pregnancy, labor and birth, the idea of their perfect child, and possibly the loss of the child's future. Franklin (2006) points out that some parents may purposefully delay attachment because they are afraid that their baby will not survive. In response to this, the parents may refuse to touch or hold the baby in an attempt to minimize their grief if the baby dies. The research suggests that NICU staff should encourage the parents to touch and talk to their infant, provide emotional support, and focus on the infant to help parents see past the medical equipment and begin to bond with their baby (Franklin, 2006; Cleveland, 2008; Mok & Leung, 2006).

In addition to providing opportunities for parent-infant bonding, it is also important that parents are given accurate information in a way that is easily understood, which will encourage them to participate in their baby’s care and decision-making (Cleveland, 2008; Franck, Cox, Allen & Winter, 2005; Holditch-Davis, Bartlett, Blickman & Miles, 2003; Nair, Gupta & Jatana, 2003; Shields-Poe & Pinelli, 1997; Zimmerman & Bauersachs, 2012; Vuong, 2013). Providing parents with opportunities for decision-making and baby care has been shown to reduce parents’ anxiety and confusion (Nair, Gupta & Jatana, 2003). When parents are taught how to read and respond to their premature infant’s behavioral cues, parents are able to understand the behavioral cues and become more comfortable with caregiving for their baby. Parent education has also been found to decrease stress and anxiety, and improve maternal confidence in caregiving (Bakewell-Sachs & Gennaro, 2004; Browne & Talmi, 2005; Franck, Cox, Allen & Winter, 2005; Loo, Espinosa, Tyler & Howard, 2003; Meyer et al, 1994; Vuong, 2013). Gomes-Pedro et al. (1995) implemented an early intervention to assist mothers and elicit responses from their infants. Results demonstrated better and more affectionate interactions and behaviors compared to the control group (Gomes-Pedro et al., 1995). In a similar study conducted by Matricardi et al (2013), an intervention of parents using an observation method of recognizing infant signs of stress and infant massage was found to reduce stress levels in the parents (Matricardi, Agostino,
Fedeli & Montriosso, 2013). Melyn et al. (2006) designed an intervention (Creating Opportunities for Parent Empowerment) to educate parents about the appearance and behaviors of preterm infants. Results showed that parents in the experimental group demonstrated more positive parent-infant interaction and stronger beliefs about their parental role, and mothers reported significantly less stress, depression and anxiety in the NICU compared to the control group. An intervention, the Mother-Infant Transaction Program, “consisted of seven daily sessions conducted during the week prior to the infant’s discharge from the hospital and four [subsequent] sessions conducted in the home 3, 14, 30 and 90 days after discharge,” enabled the mother to appreciate her infant, be sensitized and respond appropriately to the infant’s behavioral cues, and enhanced the mother’s enjoyment of her baby (Melyn et al., 2006).

Parental support groups have been shown to be helpful to families of infants in the NICU (Doering, Moser & Dracup, 2000; Holditch-Davis, Bartlett, Blickman & Miles, 2003; Preyde & Ardal, 2003; Wyly, 1995). These groups may be formal or informal support systems, such as social services and NICU parent support groups (Wyly, 1995) and may focus on coping strategies (Doering, Moser & Dracup, 2000; Holditch, Davis, Bartlett, Blickman & Miles, 2003; Wyly, 1995). Mothers reported having less stress, anxiety and depression after participating in a parent buddy program with mothers who already had a premature infant (Preyde & Ardal, 2003). Rodgers’ (1998) study suggested that interventions to help parents deal with multiple sources of stress should incorporate techniques such as problem-solving skills, guided imagery, self-talk, and progressive relaxation. Interventions used to enhance the “parenting role adaptation may improve the quality of the mother-infant interaction, decrease stress, and perhaps improve the outcomes for these infants and families” (Raines, 2013; Vuong, 2013).

Music Therapy in the NICU

Music therapy has been used in the NICU for the past 30 years and has demonstrated that premature infants thrive when provided with recorded or live musical auditory stimuli (Loewy et al., 2013; Standley, 2012). Music has also been shown to have positive effects on physiologic measures such as stabilization of heart rate and respiration rate and an increase in oxygen
saturation levels (Cassidy & Standley, 1995; Coleman et al., 1997; Standley & Moore, 1995). In a study by Caine (1991), premature infants who received recorded music set at 70-80 decibel levels for 30 minutes improved in feeding, increased weight gain, showed a decrease in stress levels, and were discharged sooner compared to those infants who did not receive music.

In a study conducted by Lai (2006), the experimental group received kangaroo care paired with recorded music for three consecutive days and the control group received routine incubator care (Lai et al., 2006). Although there were no differences in physiological variables, infants in the experimental group who received music showed more intervals of quiet sleep and less crying than infants in the control group who did not receive music. Infants in the experimental group benefited with more quiet sleep states and less crying, and mothers in this group had significantly lower scores for maternal anxiety compared to both infant and mother control groups. Other evidence-based uses of music in the NICU include: reduction in pain responses (i.e. frequency and duration inconsolable crying) and improved physiological measures of heart rate, respiration rate, oxygen saturation, and mean arterial blood pressure (Keith et al., 2000); improved behavior state and deeper sleep following painful medical procedures (Arnon, 2006); facilitation of a more rapid return to baseline heart rate, behavior state, and observed facial expressions following heel sticks to obtain blood samples (Butt & Kisilevsky, 2000); and reduction in length of stay (Caine, 1992; Baily & Kantak, 2005; Kaminsky, 1993; Cevasco, 2008). Furthermore, research shows that live music leads to greater reductions in heart rate and deeper sleep in stable preterm infants (Arnon et al., 2006).

Research supports the use of music contingently to reinforce non-nutritive sucking (NNS) assists with nipple acceptance and healthy sucking patterns (Gooding, 2010). Before being able to be discharged, the premature infant must learn to coordinate the suck, swallow, breathe responses while feeding and must independently take in enough nutrition during oral feeding to gain weight consistently and grow across time (Standley, 2014). NNS is a key activity for preterm infants because it stimulates the brain to release the necessary hormones that improve physiological measures and behavior states while also preparing them for oral feeding. The Pacifier Activated Lullaby (PAL) is an FDA-approved medical device that reinforces non-nutritive sucking with a short period of recorded lullaby music. Sustained sucking from the
infant triggers sustained music. Research results have demonstrated that the PAL increases sucking endurance, increases feeding rate, and develops sucking bursts of 10 to 12 sucks before pause, which greatly enhances feeding skill (Standley, 2014). According to research by Standley (2010), PAL trials greatly reduced gavage feeding length for infants at 34 weeks (AGA), with three trials superior to one trial. Also, female infants learned to nipple feed significantly faster than male infants (Standley, 2014; Standley & Walworth, 2010).

Music has also been used to increase the infant’s tolerance to stimulation through multimodal stimulation (MMS), an adaptation of the White-Traut and Tubeszewski auditory, tactile, vestibular, visual protocol by Standley (1998). The intervention is a sequence of stroking, rocking and eye-to-eye contact that is used to soothe and increase the infant’s tolerance to stimulation. Standley (1998) assessed the benefits of this intervention paired with music. The results of this study demonstrated that both genders increased tolerance for the stimulation, and females were discharged 11.9 days sooner compared to the no contact control group, while males in the experimental group were discharged 1.5 days sooner (Standley, 1998). Research has demonstrated that multimodal stimulation is not appropriate for infants younger than 30 weeks and should be carefully monitored for signs of overstimulation when administered (Standley, 2014.) Research has demonstrated that music has been effective in facilitating neurological growth and development by enhancing developmental gains and bonding between mother and infant through MMS (Standley & Walworth, 2010; Whipple 2000). This intervention is not appropriate for infants younger than 30 weeks and must be carefully monitored for signs of overstimulation when administered (Gooding, 2010).

According to a post-hoc analysis of a NICU-MT program by Standley and Swedberg (2011), infants receiving music therapy in the NICU gained more weight per day than did infants not referred for music therapy. Infants born between 24-28 weeks gestation were discharged sooner than non-music infants of the same age. Infants 30 weeks gestation and older receiving music therapy had a longer hospital stay, but were also diagnosed with more serious illnesses. Notably, the smallest, lowest birth weight infants were most often referred for music therapy (Standley & Swedberg, 2011). Additionally, the aims of music therapy in the NICU fit models
Parents who desire more opportunities to be involved in their infant’s therapy or who have been observed to overstimulate their child may be trained in the use of music to teach neurologic tolerance/habituation to stimulation procedure (MMS). Whipple (2000) examined the effects of parent training in music and multimodal stimulation on the quantity and quality of parent-infant interactions, weight gain, and length of hospitalization of premature and LBW infants in the NICU. Parents in the experimental group (n = 10) received one hour of instruction in appropriate uses of music, multimodal stimulation including massage techniques, and signs of infant overstimulation and avoidance by the infant. Parent-infant interactions, particularly parent actions and responses, as well as infant stress and non-stress behaviors were observed. Infant stress responses were significantly lower and the appropriateness of parent actions and responses were significantly increased for parents and infants in the experimental group compared to those subjects in the control group. Parents in the experimental group also reported spending significantly more time visiting their infants in the NICU than did the parents of infants in the control group. Additionally, length of stay in the hospital was shortened and average daily weight gain was greater for infants whose parents received the training. The results demonstrated that parents will effectively utilize the intervention and will visit their infant more regularly in the NICU (Whipple, 2000; Peczeniuk-Hoffman, 2012). Parents can also be trained to use music for soothing/bonding and developmental stimulation. For example, parents may use singing or lullabies to soothe their baby or use music during developmental play (Trehub & Trainor, 1998; Trehub, Hill, & Kamenetsky, 1997). Loewy et al. (2013) found that live singing of parent preferred lullabies enhanced parent-infant bonding while also significantly decreased the perception of parental stress. Data indicate that the NICU staff believe that music can also be beneficial for parents by decreasing stress and focusing or enhancing performance of required tasks, and that the use of music in the NICU could improve parent mood and increase overall comfort in the unit (Tarja et al., 2012).

Music therapists have the ability to assist families during the potentially difficult experience of the hospitalization of their infant in the NICU. The fragmentation and stress
caused by an infant’s hospitalization may be reduced by supportive care, thus facilitating better long-term coping in families (Prentice & Stainton, 2003). Parents’ understanding of and involvement in the care of their child is also critical and adds an additional need for music therapy service (Standley, 2014). Music therapy can be a “highly effective, nonthreatening methodology for expression of feelings, clarification of values, identification of choices and decisions, and inspiration to act” (Standley & Walworth, 2010). Parental counseling in music therapy with preterm infants encourages parent-infant bonding and meaningful interaction, teaches developmental skills and awareness of developmental delays, and provides emotional support for parents when dealing with infant related issues (Gooding, 2010). Music therapists have “the opportunity to ensure that the potency of the relationship with parents is not an incidental by-product of service to their infant, but a pivotal service to the parents themselves” (Shoemark, 2008b). However, in order to effectively serve parents of infants in the NICU, music therapists must possess a good understanding of their needs and how to address them.

Limited research exists exploring how music therapists address parent-related needs and concerns in the NICU. The purpose of this research study is to investigate the extent to which music therapists address the needs of parents of infants in the NICU. Aims of the study include the expansion of existing knowledge and literature regarding how music therapists work with parents and their infants in the NICU, to address parent-related needs, and to provide suggestions for future directions for music therapy with parents of infants in the NICU.
CHAPTER 2

METHOD

Survey Participants

The principal investigator contacted the Certification Board for Music Therapists (CBMT) office and obtained a list of email addresses of music therapists who had reported that they work in the Neonatal Intensive Care Unit. CBMT allows for individual reporting of work setting and populations, therefore, 48 individuals identified themselves as working in the NICU setting. In addition, professional music therapists who participated in the NICU-MT training through the Infant and Child Medical Music Therapy Institute at Florida State University and who completed at least one portion of the training were also invited to participate in this study. The Infant and Child Medical Music Therapy Institute (ICMMTI) at Florida State University requires three components (lecture, hands-on training, and take-home exam) in order to receive the designation in NICU Music Therapy (NICU-MT). The researcher contacted and received permission from Dr. Jayne Standley at Florida State University to use the list of e-mail addresses containing 286 potential participants. Once the two lists of names and email addresses were acquired, they were cross-checked for duplication. Twenty-three email addresses were duplicates and were therefore removed from the CBMT list. It was estimated that there were potentially 311 email addresses (N=311) that could qualify to participate in the study. This estimate included the number of e-mail addresses from CBMT (n=25) as well as those obtained from ICMMTI (n=286) after the duplicate email addresses were subtracted. In order to be eligible to participate in the study, respondents had to meet the following criteria: 1) Be a board-certified music therapist and 2) Be currently practicing (or have previously worked) in the Neonatal Intensive Care Unit.

Potential participants were sent an invitational email to take a descriptive survey entitled Addressing Parent Needs in the Neonatal Intensive Care Unit: A Survey of Music Therapists (See Appendix C). The survey invitation outlined the background information for the study and included a link to the survey instrument. The survey was used to investigate the extent to which
music therapists address the needs of parents of infants in the NICU. The internet-based survey consisted of a series of 28 multiple-choice questions with some questions featuring opportunities for participants to elaborate on their answers. The survey included questions regarding their current or previous experience working in the NICU and how they work with parents of infants. The internet web site Surveymonkey.com® was used as a web tool for this research study. Surveymoney.com® is a recognized web site that guarantees user confidentiality and security. The principal investigator monitored the survey closely over the course of the data collection period. The collected data was stored in the principal investigator’s account required a username and password to login electronically. All survey responses were reported in an aggregate or de-identified manner and was only accessible by the principal investigator and co-investigator. Additionally, documentation of informed consent was not collected to further ensure privacy (as it would link participants to their responses), and email addresses were stored separately from participant names.

**Procedure**

The principal investigator consulted the co-investigator prior to submitting the study proposal to The Florida State University Human Subjects Committee Institutional Review Board. After receiving approval from FSU HSIRB (see Appendix A for approval letter), The principal investigator contacted the Certification Board for Music Therapists (CBMT) to obtain a list of email addresses of music therapists who report that they currently work in a Neonatal Intensive Care Unit setting. Since CBMT allows for individual reporting of work setting and populations, individuals can identify themselves as working in the NICU setting and their email addresses can be obtained. Additionally, a list of names and email addresses of professional music therapists who have completed the NICU-MT training through Florida State University and who potentially have the NICU-MT credential were obtained by permission from Dr. Jayne Standley. The Infant and Child Medical Music Therapy Institute (ICMMTI) at Florida State University requires three components (lecture, hands-on training, and take-home exam) in order to receive the designation NICU Music Therapy (NICU-MT).
After cross referencing the two lists of email addresses, the principal investigator piloted the survey to two individuals not associated with the study and had the co-investigator look over the survey before making some necessary changes. Based on their feedback, minor changes were made to the survey instrument. The changes included adjustments in the wording of four questions, adding an "other" box to several questions, and changing the survey settings to allow participants to select more than one box for appropriate questions. Participants accessed the 28-question survey through Surveymonkey.com®, an online survey hosting company. An invitation and link to the survey (See Appendix B) were included in the e-mail invitation sent to all of the professional music therapists from the email lists obtained from Dr. Jayne Standley and CBMT. Music therapists were invited to participate in the study based on the notion that they may have met the following criteria: 1) Be a board-certified music therapist and 2) Be currently practicing (or have previously practiced) in the Neonatal Intensive Care Unit. The participants were asked to complete the survey within four weeks after receiving the initial e-mail. A week and a half after the initial e-mail was sent, the principal investigator sent a reminder e-mail to all potential participants. A second reminder email was sent a week and a half later, and a final email reminder was sent the day prior to the close of the survey. The survey remained open for four weeks to obtain as many data points as possible.
CHAPTER 3
RESULTS AND DISCUSSION

Data Analysis

Descriptive data were gathered to answer the research questions. Following the closing of the survey, data were analyzed using appropriate descriptive statistical analysis (e.g. mean, mode, median, etc). The principal investigator examined the raw data from each question, noting overall and per question response percentages, and subsequently formed conclusions based on the information yielded from the survey results.

Responses

A total of 54 responses were received. Of the 54 responses, 50 respondents completed the entire survey and 4 completed part of the survey. A total of 54 surveys (n=54) met the eligibility requirements and were included in the data analysis.

Survey Questions

The following section shows individual question by question summarized results of the responses for the 28-item survey for this study. The figures for data representation indicate the percentages of responses and the number of responses for each item. The figures for data representation show how many respondents completed questions and how many respondents chose not to answer certain questions.
Results

Question 1: *How long have you been practicing music therapy in the NICU setting?*

![Pie chart showing years of practice in the NICU setting.](image)

Figure 1: Number of Years Practicing in the NICU Setting

The average number of years music therapists (respondents) have practiced in the NICU was 3.06 years. While almost half of respondents have practiced less than 2 years, 10 respondents reported having practiced music therapy 10 or more years in the NICU.
Question 2: How many hours do you spend per week in the NICU?

Figure 2: Hours Per Week Spent in the NICU

Most music therapists indicated that they spend an average of 3 hours per week in the NICU, while some respondents indicated, “it varies” or “referral based per need” according to the free responses when “Other” was selected.
Question 3: How many infants on average do you work with per week? If you work with infants intermittently, please check “other” and specify.

Figure 3: Average Number of Infants Per Week

The majority of music therapists indicated that they work with an average of 3-4 infants per week or ‘it varies’ according to the free responses provided for “Other.”
Question 4: *What kind of NICU specific training do you have? (Check all that apply.)*

![Bar chart showing NICU specific training](image)

**Figure 4: NICU Specific Training**

The majority of music therapists possess the NICU-MT credential, however, other answers included: “First Sounds: Rhythm, Breath & Lullaby International NICU Training” and “Developmental Care Training.” Free responses for “Other” included: “training provided by my employer,” “trained by nursing staff on NIDCAP processes,” and “1st level of NICU-MT training; 26 years on Pediatrics.”
Question 5: *Do you receive referrals specifically for parent-related needs? If you answered “no,” skip to question 8.*

![Pie Chart]

**Figure 5: Referrals Specifically for Parent-related Needs**

The majority of music therapists responded that they receive referrals specifically for parent-related needs.
Question 6: If you answered “yes” to question 5, who provides referrals?

Figure 6: Provision of Referrals

The majority of music therapists responded “Other” and indicated referrals come from both medical and non-medical personnel. For medical staff, the nursing staff and MD were the most cited sources of referrals. After the survey was launched, it was determined that respondents were unable to select multiple answers for this particular question due to a technical issue, hence the majority of respondents answered “Other” and filled in their own responses. Answers regarding specific personnel included: “Child life specialist,” “Social worker,” “Chaplain,” “Psychology,” “Occupational Therapy,” and “Physical Therapy.”
Figure 7: Reasons for Referral

The distribution for percentages of responses regarding reasons for referrals for parent-related needs were quite even; however, the highest percentages of responses were for the following: Parent anxiety, to facilitate developmentally appropriate interactions, parent-infant bonding, extended hospitalization and bereavement.
Question 8: *Do you work with parents (i.e. address parent needs) even without referrals?*

![Pie chart showing the results of Question 8](image)

**Figure 8: Working with Parents**

The majority of music therapists reported that they work with parents in the NICU (i.e. address parent needs) even without referrals.
Question 9: What age(s) are the infants of the parents with whom you work? Please select the age of the infant at the time of parental referral (Check all that apply.)

Figure 9: Ages of the Infants in the NICU

The average ages of infants with whom music therapists work in the NICU is 33-37 weeks gestational age, followed by 38-41 weeks gestational age, and 28-32 weeks gestational age.
Question 10: *What infant issues are associated with parental referrals? (Check all that apply.*)*

**Figure 10: Infant Issues Associated with Parental Referrals**

The majority of music therapists reported that extended hospitalization, genetic conditions, and failure to thrive are the issues associated with parent referrals. The responses for “Other” included: “CDH,” “BPD,” “cardiac condition,” “Hospice/Palliative,” “addiction,” “attachment rejection,” and “IVH grade 3 and 4.”
Question 11: *On average, how often do you work with parents each week? If you work with parents intermittently, please check “other” and specify.*

![Bar chart showing the frequency of working with parents per week.](chart11)

**Figure 11: Average Number of Times Per Week Working with Parents**

On average, music therapists reported working with parents 1-4 times per week; however, the majority of respondents indicated “Other.” Several respondents for “Other” indicated that their referrals were not weekly based or were varied based on scheduling or “as needed.”
Question 12: On average, how many parents do you work with each week?

Figure 12: Average Number of Parents Per Week

On average, music therapists work with 1-4 parents per week; however, several responses for “Other” indicated that their referrals were not weekly based or “varied” based on scheduling or “as needed/according to parent availability.”
Question 13: *Which parent do you usually work with?*

![Pie chart showing the distribution of responses for Question 13.]

**Answered:** 53  **Skipped:** 1

- **Mother:** 79.25% (42)
- **Other (please specify):** 20.75% (11)

Figure 13: Parent and Music Therapy

The majority of music therapists indicated that they most often work with the mother in the NICU. Responses for “Other” included: “it varies,” “both and extended,” “all of the above,” and “mother and father.”
Question 14: *What type of interactions do you have with parents? (Check all that apply.)*

![Figure 14: Types of Interactions Music Therapists Have with Parents](image)

The majority of music therapists who responded to the above question indicated that their interactions with parents are generally with the parent and infant together, although some respondents indicated that they work with parent, infant and other family members at times, or with the parent only.
Question 15: *How do you interact with parents? (Check all that apply.)*

Figure 15: How Music Therapists Interact with Parents

The majority of music therapists responded that they interact with parents in person. Responses for “Other” included: “written note first, then in person,” and “depends on availability and referral/assessment.”
Question 16: Do you provide music therapy educational materials for parents?

The majority of music therapists who responded to the above question reported that they provide music therapy education materials for parents.
Question 17: If yes, check all of the types of materials that you provide.

![Figure 17: Types of Music Therapy Educational Materials](image)

Music therapists who responded to this question indicated that they provide music therapy educational materials for parents, such as a music therapy informational sheet, intervention handouts (i.e. “How to” sheets on specific interventions), song lyrics, and musical recordings (e.g., CDs given to parents). Responses for “Other” included: “a list of appropriate CDs to use after discharge” and “recordings of mother singing.”
Question 18: *What approach do you use when working with parents?*  
*(Check all that apply.)*

![Music Therapy Approach Used When Working with Parents](image)

The highest percentages of responses for this question indicated that music therapists reported using developmental, humanistic, and cognitive-behavioral approaches when working with parents in the NICU.

Figure 18: Music Therapy Approach Used When Working with Parents
Question 19: If you selected more than one approach above, list your primary approach. (Select one only.)

Figure 19: Primary Music Therapy Approach Used When Working with Parents

Music therapists identified primary approaches used when working with parents as developmental, cognitive-behavioral and/or humanistic.
Question 20: What type of interventions do you use when working with parents separately from their children? (Check all that apply.)

The majority of music therapists who responded to the above question reported that they use parental recordings (i.e. making recordings with parents to use with baby when parent is not present), parental counseling, and music-assisted relaxation when working with parents only. Responses for “Other” included: “bereavement support,” “patient education,” and “a parent group.”
Question 21: *When working with parents and their infant(s) simultaneously, what type of interventions do you use? (Check all that apply.)*

![Bar Chart: Interventions Used When Working with Parents and Their Infant(s) Simultaneously](chart)

**Figure 21: Interventions Used When Working with Parents and Their Infant(s) Simultaneously**

The majority of music therapists who responded to the above question reported using the following interventions when working with parents and their infants simultaneously: infant directed singing, developmental music play, multimodal stimulation, and music-assisted kangaroo care. Responses for “Other” included: “contingent singing,” “entrainment,” and “PAL.”
Question 22: *What questions/concerns do parents have about the use of music with their baby? (Check all that apply.)*

![Bar chart showing parent questions/concerns regarding use of music with their baby.]

Figure 22: Parent Questions/Concerns Regarding Use of Music with Baby

With regard to the questions/concerns parents have about the use of music with their baby, the majority of respondents indicated that parents have concerns about their own singing ability, questions about the best kind of music to use, questions about resources (i.e. songs, recordings, etc.), questions about overstimulating the baby, questions about how loud the music should be, and questions about the amount of music to use.
Question 23: *What non-musical questions/concerns do parents have when you work with them? (Check all that apply.)*

**Figure 23: Non-Musical Parent Questions/Concerns**

With regard to the non-music-related questions/concerns parents have when music therapists work with them, the majority of respondents reported that parents have concerns/questions about the environment, about parenting, about limiting/confusing/conflicting information, and about staff communication. Some of the responses for “Other” included: “questions about feeding,” “family issues,” “what my qualifications are as an MT,” “the baby’s health,” “how to engage siblings and family into care of baby,” “stimulation,” and “attachment.” Another respondent answered, “death, guilt, attachment, PTSD, relationship with siblings and spouse.”
Question 24: *What goals do you address when working with parents? (Check all that apply.)*

Figure 24: Goals Addressed When Working with Parents

The goals that music therapists address with parents (highest percentages of responses) include: anxiety reduction, promote developmental objectives, increase normalization, facilitate coping, improve quality of life, and bereavement care. Responses for “Other”: “appropriate levels of stimulation/education,” “care for transition into home,” “self-esteem,” “attachment,” and “facilitate bonding.”
Question 25: What barriers exist in working with parents at your facility? (Check all that apply.)

Music therapists identified parental responsibilities (work, other children, etc.) preventing visitation, parents living long distances away and not being able to visit, staffing issues (i.e. not enough MT staffing coverage), and parent visitation schedule not lining up with MT hours as barriers in working with parents. Responses for “Other” included: “working at different facilities depending on referral,” “parents having to work to keep health insurance,” and “inner city mothers being unable to leave home due to caring for other children or not having transportation available.”
Question 26: Do you feel like you are adequately trained to work with parents?

Figure 26: Music Therapists’ Training to Work with Parents

The majority of music therapists who responded to the above question indicated that they felt adequately trained to work with parents of infants in the NICU.
Question 27: If no, what would you like more training in? (Check all that apply.)

Figure 27: Areas in Which Music Therapists Would Like More Training

Respondents who answered “No” to the previous question shared that they felt they needed more training in the following areas: grief counseling, general counseling techniques, MT interventions specific to parent needs, and cultural sensitivity. Responses for “Other” included: “How to sensitively deal with parents of babies who have neonatal abstinence syndrome and who may themselves be drug abusers” and “infant neurophysiology.”
Question 28: *What else would you like to share with us about your work with parents in the NICU? Please share anything you feel comfortable sharing.*

Nine individuals provided free responses to the above question. Below are some of the responses that were shared:

“My work fluctuates based on patient needs and my obligations with other patients of the medical center.”

“I love it.”

“Sometimes not having children of my own may make my relating to parents difficult, however, it really hasn’t been an issue. It is something worth considering when training music therapists to work with parents.”

“Impossible to cover PEDS and NICU in a 30-hour week as a lone music therapist.”

“My hospital’s NICU is very closed off to change. They don’t understand how music therapy can be used and are afraid of over-stimulation. Even with education about how music can be used, some staff members are still resistant.”

“I provide Hospice Palliative care for children. Some of the basic MMS and procedure support music therapy has been transformational in the end of life care of the infant and has been another layer of engagement and empowerment for the parents, siblings, and extended family.”

“Good to call this ‘caregivers’- some do not have access to parents. Entrainment is key- and I do not see it mentioned here. Also, assessing PTSD and observing and working with fellow staff is critical.”

**Discussion**

Based on the responses of the individuals who participated in the survey, the demographic overview of music therapists practicing in the NICU yielded diverse information. While most music therapists possess the NICU-MT credential, other respondents possess other types of training, and the majority of music therapists have been practicing in the NICU for 1-2 years. Music therapists reported utilizing a variety of approaches, interventions, and goals when working with parents of infants in the NICU.
With regard to referrals, it is interesting to note the variety of referral sources for parent-related needs (both medical and non-medical). This reflects the continued need for patient-centered care and meeting patients’ psychosocial needs (Gooding, 2010). The percentages for responses regarding reasons for referrals for parent-related needs were quite evenly distributed. Results indicated that referrals for parent anxiety, facilitating developmentally appropriate interactions, parent-infant bonding, extended hospitalization and bereavement were of the highest percentages. These findings support existing studies that have identified parent-related needs in the NICU (Cleveland, 2008; Franklin, 2006; Heerman et al., 2005). Bereavement support (and grief counseling) is another area that warrants more research as it pertains to parent needs in the NICU. It is also interesting to note the variety of responses given for the issues that are associated with parent referrals (CDH, BPD, cardiac condition, Hospice/Palliative, addiction, attachment rejection, IVH grade 3 and 4). Additional research regarding working with infants with these conditions would be beneficial.

The answers given by respondents regarding the goals addressed with parents in the NICU support the use of interventions designed to increase the infant’s tolerance to stimulation, facilitate bonding with the parent, in addition to increasing/supporting developmentally appropriate interactions between infant and parent. Additionally, the goals that music therapists address when working with parents of infants support existing findings in the literature regarding the stressful nature of the NICU and the need to help parents reduce anxiety but also increase normalization, coping skills, and facilitate developmentally appropriate interactions.

Music therapists identified parental responsibilities (work, other children, etc.) preventing visitation, parents living long distances away and not being able to visit, staffing issues (i.e. not enough MT staffing coverage), and parent visitation schedule not lining up with MT hours as barriers in working with parents at their respective facilities. While some of these factors cannot be adjusted, the music therapist may be able to communicate with the parents via a written note/phone call letting them know that the music therapist has been seeing the infant.

The final question of the survey gave music therapists the opportunity to share anything about their work with parents in the NICU that they felt comfortable sharing. Overall, responses
were very positive (i.e. “I love it” and “good to call this ‘caregivers,’ since some do not have
access to parents”). One respondent shared that MMS and procedural support has been
“transformational” in her work with hospice and palliative care for children and their families. A
few music therapists shared that they found it difficult to cover their large caseload (including
NICU infants and parents) in a limited time frame per week.

While the majority of music therapists who took part in this survey indicated that they
felt adequately trained to work with parents of infants in the NICU, results indicated that there is
a need for additional training (particularly in the areas of counseling, bereavement, and cultural
sensitivity) and a need for more NICU training for music therapists in order to meet the demands
of increasing caseloads. Specialized, evidence-based uses of music therapy in the NICU are in
development, but acceptance within the medical community is still being generated by one NICU
at a time by each music therapist attempting to start a new program (Standley, 2014). Therefore,
it is important to continue to build upon existing specialized training to continue to meet the
demand for NICU music therapy, to continue to effectively serve parents of infants in the NICU,
and to enhance the dissemination of music therapy practice with this fragile population.

Limitations

The original intent of the study was to survey board-certified music therapists who are
actively practicing in the Neonatal Intensive Care Unit. Due to the inability to filter the email
address lists to only include board-certified music therapists who are currently practicing in the
NICU, it was not possible to send the survey exclusively to these individuals, therefore, there
may have been some respondents who completed the survey who are not currently practicing in
the NICU, but who have done so in the past. The size of the population of board-certified music
therapists currently practicing in the NICU is unclear, as CBMT and the Infant and Child
Medical Music Therapy Institute through Florida State University do not keep track of this
information. Also, it is possible that the contact emails on both lists have contact information for
individuals that are not completely current, since not all music therapists report current work
information to CBMT and the Infant and Child Medical Music Therapy Institute, therefore the
estimated number may not be an accurate representation. It is also possible that individuals
provided different contact information to the two databases. The primary investigator cross
referenced email addresses on both lists and updated them accordingly. Any automatic reply
received after the emailed survey invitation was sent that indicated a change in email address for
a participant was subsequently updated by the principal investigator and the invitational email
was sent to the participant’s new email address. In the future, being able to control for and more
specifically identify this population (currently practicing NICU music therapists) would be
greatly beneficial.

Implications for Future Research

Based on the findings of this survey, it can be inferred that there is a need for music
therapists to work with parents just as much as their infants in the NICU. Music therapists are
unable to change the NICU environment, nor are they able to change the equipment and tubes
connected to the infant and other factors surrounding the infant’s hospital experience. However,
music therapists have the ability to assist families during the experience of hospitalization of
their infant in the NICU by providing support (i.e. counseling), education (i.e. giving appropriate
and accurate information, helping parents understand their baby’s behavior/appearance, etc.), and
providing appropriate music interventions to address both parent and infant needs.

While this survey addressed several aspects of working with parents of infants in the
NICU, future studies should focus on areas in which there has been little documented research
thus far (i.e. music therapy in counseling and/or bereavement with parents of infants in the
NICU). Music therapists who reported they did not feel adequately trained to work with parents
cited grief counseling, general counseling techniques, music therapy techniques specific to
parent needs, and cultural sensitivity training as areas in which they desire more training. Also,
exploring how to work with parents of infants with neonatal abstinence syndrome or other
complex medical issues, working with adolescent parents, or parents of ethnically diverse
backgrounds warrant further research. Future studies regarding parent needs should perhaps
focus on these areas.
Premature infants are perhaps the most medically and developmentally fragile population served by music therapy. It should be noted that specialized uses of music therapy in the NICU are in development, but acceptance within the medical community is still ongoing (Standley, 2014). Therefore, it is of paramount importance for music therapists working in the NICU to assure that all work with infants in the NICU enhance medical treatment and do no harm to the infant. Individuals providing music in the NICU should be trained to know the medical standards and guidelines for NICU care of premature infants, recognize preterm infant responses to environmental stimuli by gestational age, and pay special attention to music selection, monitoring of dB level, and length of exposure are critical (Cassidy and Ditty, 1998). Volunteers, medical staff, or parents may bring music into the NICU without understanding the implications, so the music therapist should attempt to gently educate them regarding the research and guidelines for music use in the NICU. Additionally, without NICU training, the possibility exists that music therapists can do harm to the infant and potentially reduce music therapy acceptance by the medical profession, allied therapies, and developmental specialties (Standley, 2014).

Conclusion

Results of this study support the use of music therapy to address both parent and infant goals. Existing research demonstrates that family empowerment via support and guided parent training in caring for their infant is important to parent stress reduction as discharge approaches (Franck et al., 2005). Music therapy and music therapists can serve as an extension of family-based NICU care through the use of music and counseling to reduce parent stress, teaching parents and/or caregivers the importance of early intervention and the signs of overstimulation, and the use of music-assisted interventions (i.e. kangaroo care, relaxation, etc.) to promote bonding and engagement. As both the field of music therapy and medical advances in the NICU environment continue to evolve, music therapists must remain cognizant of the human needs of these small patients and their families, and continue to strive to provide evidence-based, patient-centered services appropriate to support this special population.
APPENDIX A

FLORIDA STATE UNIVERSITY
HUMAN SUBJECTS APPROVAL FORM

Office of the Vice President for Research
Human Subjects Committee
Tallahassee, Florida 32306-2742
(850) 644-8673 · FAX (850) 644-4392

APPROVAL MEMORANDUM

Date: 10/06/2014
To: Bethany Trainer
Address: 
Dept.: MUSIC SCHOOL
From: Thomas L. Jacobson, Chair

Re: Use of Human Subjects in Research
Addressing Parent Needs in the Neonatal Intensive Care Unit: A Survey of Music Therapists

The application that you submitted to this office in regard to the use of human subjects in the proposal referenced above have been reviewed by the Secretary, the Chair, and two members of the Human Subjects Committee. Your project is determined to be Expedited per 45 CFR § 46.110(7) and has been approved by an expedited review process.

The Human Subjects Committee has not evaluated your proposal for scientific merit, except to weigh the risk to the human participants and the aspects of the proposal related to potential risk and benefit. This approval does not replace any departmental or other approvals, which may be required.

If you submitted a proposed consent form with your application, the approved stamped consent form is attached to this approval notice. Only the stamped version of the consent form may be used in recruiting research subjects.

If the project has not been completed by 10/05/2015 you must request a renewal of approval for continuation of the project. As a courtesy, a renewal notice will be sent to you prior to your expiration date; however, it is your responsibility as the Principal Investigator to timely request renewal of your approval from the Committee.

You are advised that any change in protocol for this project must be reviewed and approved by the Committee prior to implementation of the proposed change in the protocol. A protocol change/amendment form is required to be submitted for approval by the Committee. In addition, federal regulations require that the Principal Investigator promptly report, in writing any unanticipated problems or adverse events involving risks to research subjects or others.

By copy of this memorandum, the chairman of your department and/or your major professor is reminded that he/she is responsible for being informed concerning research projects involving human subjects in the department, and should review protocols as often as needed to insure that the project is being conducted in compliance with our institution and with DHHS regulations.

This institution has an Assurance on file with the Office for Human Research Protection. The Assurance Number is IRB00000446.

Cc: Jayne Standley, Advisor
HSC No. 2014.13814
APPENDIX B

SURVEY INVITATION LETTER

Dear Music Therapist,

My name is Bethany Trainor and I’m a graduate student in the Music Therapy program at Florida State University. I’m currently conducting research for a thesis that will complete the requirements for my degree. I’m contacting you to invite you to participate in this study.

Limited research exists exploring how music therapists address parent-related needs and concerns in the NICU. The purpose of this study is to investigate the extent to which music therapists are addressing the needs of parents of infants in the NICU. Aims of the study include the expansion of existing knowledge and literature regarding how music therapists work with parents and their infants in the NICU, how music therapists address parent-related needs, and suggestions for future directions for music therapists in how they work with parents of infants in the NICU.

You will be asked to complete an online survey. The survey will include questions regarding your experience working in the NICU and how you work with parents of infants. The internet web site SurveyMonkey.com® will be used as the platform to administer the survey for this research study. SurveyMonkey.com® is a recognized web site that guarantees user confidentiality and security.

Risks: There are no anticipated risks in this study.

Confidentiality: All information collected will remain anonymous, secure, and accessed only by the principal investigator and co-investigator. All survey responses will be reported in an aggregate or de-identified manner, and all data will be coded, password protected, and only accessible by the principal investigator and co-investigator. Additionally, email addresses will be stored separately from participant names to further reduce risks. No identifiable personal information will be used in the final written study.

Participation: Your participation in the study is completely voluntary. You are allowed to skip any question that makes you feel uncomfortable and you can stop and exit the survey at any time. Your participation in the survey will indicate your consent.

Time required: The study will require about 15 minutes of your time. There will be multiple questions, but it is up to you how much you expand on some questions so the survey time may vary.

Payment: You will receive no payment for participating in the study.

If you have any questions or concerns about this research, please feel free to contact the Principal Investigator: Bethany Trainor (btrainor@fsu.edu), Co-Investigator: Dr. Lori Gooding (lgooding@fsu.edu), or Faculty Advisor: Dr. Jayne Standley (jstandley@fsu.edu).

*Please complete this survey only if you have actually worked in the NICU. If you do not currently work in the NICU but have in the past, please answer these questions based on your previous experiences.

By clicking the link below, you are agreeing to participate in this study.

The link to the survey can be found here:
https://www.surveymonkey.com/s.aspx

Your participation in this study is greatly appreciated!

- Bethany Trainor

This survey invitation was sent through SurveyMonkey. If you click the following link, you will no longer receive emails regarding this survey
https://www.surveymonkey.com/optout.aspx
APPENDIX C

SURVEY INSTRUMENT

Addressing Parent Needs in the Neonatal Intensive Care Unit: A Survey of Music Therapists

1. How long have you been practicing music therapy in the NICU setting?
   - Less than 1 year
   - 1-2 years
   - 3-4 years
   - 5-6 years
   - 7-9 years
   - 10 or more years

2. How many hours do you spend per week in the NICU?
   - 1-2
   - 3-4
   - 5-6
   - 7-9
   - 10 or more
   - Other (please specify)

3. How many infants on average do you work with per week? If you work with infants intermittently, please check “other” and specify.
   - 1-2
   - 3-4
   - 5-6
   - 7-9
   - 10 or more
   - Other (please specify)

4. What kind of NICU specific training do you have (Check all that apply.)
   - Infant Massage
   - First Sounds: Rhythm, Breath & Lullaby
   - International Neonatal Intensive Care Unit Training
   - NICU-MT
   - Developmental Care Training
   - Other (please specify)
5. Do you receive referrals specifically for parent-related needs? If you answered “no,” please skip to question 8.
   Yes
   No

6. If you answered “yes” to question 5, who provides referrals?
   MD
   Nursing staff
   Social worker
   Chaplain
   Parent care coordinator
   Other (please specify)

7. If yes to question 5, what are the referrals for? (Check all that apply.)
   Parental anxiety
   Parent-infant bonding
   To increase parent engagement
   To facilitate developmentally appropriate interactions
   To increase parental coping skills
   To improve communication between parent and staff
   Transition to home support
   Bereavement support
   Extended hospitalizations
   Other (please specify)

8. Do you work with parents (i.e. address parent needs) even without referrals?
   Yes
   No

9. What age(s) are the infants of the parents with whom you work? Please select the age of the infant at the time of parental referral. (Check all that apply.)
   < 23 weeks
   23-27 weeks gestational age
   28-32 weeks gestational age
   33-37 weeks gestational age
   38-41 weeks gestational age
   Post term infants (42+)
10. What infant issues are associated with parental referrals? (Check all that apply.)
   Genetic conditions
   Neonatal abstinence syndrome
   Failure to thrive
   Hypoxic-ischemic encephalopathy (HIE)
   Extended hospitalization
   Other (please specify)

11. On average, how often do you work with parents each week? If you work with parents intermittently, please check “other” and specify.
   1-2 times
   3-4 times
   5-6 times
   7-9 times
   10 or more times
   Other (please specify)

12. On average, how many parents do you work with per week?
   1-2
   3-4
   5-6
   7-9
   10 or more
   Other (please specify)

13. Which parent do you usually work with?
   Mother
   Father
   Grandmother
   Grandfather
   Legal guardian
   Other (please specify)
14. What type of interactions do you have with parents? (Check all that apply.)
   Parent only
   Parent and infant together
   Parent and infant separately
   Parent and other family members
   Parent, infant and other family members
   Parental groups (e.g., parent support group)
   Other (please specify)

15. How do you interact with parents? (Check all that apply.)
   In person only
   Via email
   Via phone
   Via Skype or similar technology
   Via written communication left for parents
   Other (please specify)

16. Do you provide music therapy educational materials for parents?
   Yes
   No

17. If yes, check all of the types of materials that you provide.
   Music Therapy Info sheet
   Song suggestion lists
   Intervention handouts (i.e., “How to” sheets on specific interventions)
   Suggested recordings list
   Song lyrics
   Sheet music
   Musical recordings (e.g., CDs given to parents)
   Other (please specify)
18. What approach do you use when working with parents? (Check all that apply.)
   Analytical
   Cognitive-Behavioral
   Creative/ Nordoff Robbins
   Eclectic
   Humanistic
   Psychodynamic
   Developmental
   Other (please specify)

19. If you selected more than one approach above, list your primary approach. (Select one only.)
   Analytical
   Cognitive-Behavioral
   Creative/ Nordoff Robbins
   Eclectic
   Humanistic
   Psychodynamic
   Developmental
   Other (please specify)

20. What type of interventions do you use when working with parents separately from their child(ren)? (Check all that apply.)
   Improvisation
   Life Review
   Parental Counseling
   Psychoeducation
   Music-assisted relaxation
   Parental recordings (i.e., making recordings with parents to use with baby when parent is not present)
   Other (please specify)
21. When working with parents and their infant(s) simultaneously, what type of interventions do you use? (Check all that apply.)

- Developmental music play
- Infant directed singing
- Multimodal stimulation
- Music-assisted kangaroo care
- Toning
- Music during pumping
- Improvisation
- Other (please specify)

22. What questions/concerns do parents have about the use of music with their baby? (Check all that apply.)

- Concerns about their own singing ability
- Questions about the best kind of music to use
- Questions about the amount of music to use
- Questions about how loud the music should be
- Questions about over-stimulating the baby
- Concerns about implementing music interventions without the MT present
- Questions about resources (songs, recordings, etc.)
- Questions about recording their own voice to be played when the parent is not present
- Other (please specify)

23. What non-musical questions/concerns do parents have when you work with them? (Check all that apply.)

- Concerns/questions about parenting
- Concerns/questions about the environment
- Financial concerns
- Concerns/questions about limiting, confusing, or conflicting information
- Concerns/questions about staff communication
- Other (please specify)
24. What goals do you address when working with parents? (Check all that apply.)
   - Bereavement care
   - Reduce anxiety
   - Facilitate coping
   - Improve quality of care
   - Increase engagement
   - Increase normalization
   - Promote developmental objectives
   - Other (please specify)

25. What barriers exist in working with parents at your facility? (Check all that apply.)
   - Staffing issues (i.e., not enough MT staffing coverage)
   - NICU schedule
   - Parent visitation schedule does not align with MT hours
   - Parents live long distances away and cannot visit regularly
   - Parental responsibilities (work, other children, etc.) prevent visitation
   - Lack of staff understanding re: MT impact on parent needs
   - Resistance from other healthcare providers
   - Funding for services
   - Other (please specify)

26. Do you feel like you are adequately trained to work with parents?
   - Yes
   - No

27. If no, what would you like more training in? (Check all that apply.)
   - General counseling techniques
   - Grief counseling
   - MT interventions specific to parental needs
   - Cultural sensitivity training
   - Staff education
   - Staff communication
   - Musical preparedness
   - Other (please specify)

28. What else would you like to share with us about your work with parents in the NICU? Please share anything you feel comfortable sharing.
REFERENCES


Baily, K., & Kantak, A. (2005). Music therapy in the neonatal intensive care unit, a multi-site study: A randomized control blind study of music therapy with high risk neonates cared for in Neonatal ICU. Presentation at Music Therapy in the NICU: A symposium on research and applications of music therapy in the neonatal intensive care unit, Cleveland, OH.


BIOGRAPHICAL SKETCH

Name:    Bethany Trainor

Date of Birth:    April 28th, 1985

Place of Birth:    New York, New York

Education:    Westminster Choir College of Rider University
Princeton, New Jersey
Bachelor of Music in Music Theory/Composition
Degree Awarded May 2007

New York University
New York, New York
Master of Music in Music Composition
Emphasis on Writing Music for Film/Multimedia
Degree Awarded January 2009

Florida State University
Tallahassee, Florida
Master of Music in Music Therapy
Degree Awarded May 2015


Experience:    Graduate Teaching Assistant, Florida State University
Tallahassee, Florida; August 2013-May 2014

Music Therapy Internship, University of Kentucky Healthcare
Lexington, Kentucky; September 2014-March 2015