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DEVELOPMENTAL CARE IN THE NICU: BEST PRACTICES FOR PRETERM INFANTS, EXPECTATIONS OF HEALTHCARE PROVIDERS, AND IMPACT ON PARENTS AND FAMILIES

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Abstract

Infants born prematurely experience a variety of medical complications, which can impair their growth and development. These complications can result in permanent disabilities and medical conditions that could necessitate a lifetime of medical treatment. Neonatal Intensive Care Units (NICUs) offer specialty units for infants born prematurely to receive excellent medical care to help them survive after being delivered at as soon as 23 weeks of gestation. A complementary form of care offered in some NICUs is developmental care, which focuses specifically on modifying the neonate’s physical environment to ensure proper growth and development. As developmental care is a relatively new practice, it is still being incorporated into standard NICU care. In this project, the offerings of top US NICUs were reviewed to determine their incorporation of developmental care. Additionally, NICU providers were interviewed to gather their opinions on the quality of care infants and their families receive in the NICU, developmental care and its impacts, and how NICU care can be improved in general. Results of these interviews indicated that while developmental care has proven to be very successful, it is not a standard of care in many NICUs and is not used as frequently as it should be. NICU providers also found that parents often are negatively impacted by a lack of support in the NICU, and should receive more specific care. Through attending conferences on developmental care, NICU providers can encourage the use of developmental care in the NICUs that they work in. Additionally, engaging parents in developmental care and keeping them informed of their infant’s treatment can help to offer them further support during their time in the NICU.
Introduction

Every year, over 14.9 million children are born prematurely (World Health Organization [WHO], 2018). Preterm birth, also referred to as preterm parturition syndrome, is defined as birth that occurs before 37 weeks of gestational age (Bieleninik & Gold, 2014). Many factors contribute to the occurrence of preterm birth, such as the mother’s age at pregnancy, multiple pregnancy (e.g., twins or triplets), maternal health (both medical and psychological), and genetics (Bieleninik & Gold, 2014). The burdens associated with preterm birth, ranging from developmental delays to death, strike families across the world (Bieleninik & Gold, 2014). In 2015, preterm birth accounted for 17% of infant deaths (Center for Disease Control [CDC], 2018) and was the leading cause of death in children under five years of age (WHO, 2018). In the United States alone, one in ten infants are born prematurely, which is about 450,000 babies each year (March of Dimes, 2015).

Even when preterm birth does not result in the death of an infant, infants are susceptible to breathing and feeding problems, vision and hearing loss, and cerebral palsy (CDC, 2018). These complications can be severe, and even if the infant does survive the birth, could lead to death in the following weeks (WHO, 2018). Other long-term consequences of preterm birth include specific physical effects, neuro-developmental and behavioral effects, and moderate to severe global developmental delay (Bieleninik & Gold, 2014).

The scope of consequences associated with preterm birth extends even further beyond these health-related concerns to effects on the US economy and the child’s education and ability to work. March of Dimes, a nonprofit organization dedicated to researching and providing quality healthcare for mothers and babies, describes the long-lasting financial effects that premature birth has on society. In 2007, the cost associated with preterm birth in the US was
$26.2 billion. The breakdown of these costs was $16.9 billion in medical costs for the baby, $1.9 billion in labor and delivery costs, $611 million in early intervention services, $1.1 billion in special education services, and $5.7 billion in lost work pay for people born prematurely (March of Dimes, 2015). Due to the widespread scope of consequences resulting from preterm birth, it is essential to develop effective methods to treat and care for infants born prematurely in order to help them function and develop to the best of their abilities.

**The NICU Environment**

To minimize these consequences and address any birth complications, medical interventions are essential. Medical interventions include supportive care and devices, such as incubators, catheters, and mechanical ventilators, which are used to decrease infant morbidity and mortality (March of Dimes, 2015). The purpose of these medical interventions is to keep the infant alive and growing at as close to a normal rate as possible. These interventions are the primary focus of Neonatal Intensive Care Units (NICUs) and are provided by nurses and physicians. NICUs are intensive care nurseries for infants born prematurely or with complex medical conditions, such as anemia, apnea, respiratory distress, and sepsis (March of Dimes, 2015). Neonatologists and other specialists work to provide these medical interventions to infants in the NICU. Medical interventions are essential in treating the immediate consequences of preterm birth, such as incomplete development of major organs, brain injury, and feeding difficulties.

The early development taking place in the NICU as opposed to in the womb is concerning due to the generally inhospitable environment of the NICU. Prior to the development of the NICU, infants who were born prematurely or with various illnesses were usually treated on open pediatric floors or in isolated intensive care rooms within hospitals (Gluck, 1992). In the
1880s, the first infant incubator was developed, which was a major step forward in neonatal care. Infant incubators were modeled after incubators for baby chicks, and were designed to maintain a sterile and warm environment, which proved to be favorable in the neonate’s growth (Gluck, 1992). In the 1960s, the first NICU was developed in the Yale-New Haven Hospital, which included stations with incubators for infants to be treated (Gluck, 1992). While the use of incubators and other equipment to care for premature infants had been used prior to the 1960s, there was no central intensive care unit for these premature infants to be cared for. Due to fear of bacterial infections, there was a concern about keeping a high quantity of sick and/or premature infants in the same area, but in the NICU each infant was kept to his/her own temperature-controlled incubator. Most infants in the NICU were kept in a large room all together, where they received treatment using experimental techniques including ventilators and electrocardiogram (EKG) machines that were traditionally designed for adult use (Gluck, 1992).

Over time, the NICU environment started to develop to be more efficient for health professionals to use and therefore do a better job of serving the premature infant population. Different stations were organized for each patient including monitors, ventilators, and other equipment to prevent nurses from having to run across the entire NICU room to get supplies for their patients (Gluck, 1992). Once the framework for NICU care was established, physicians were able to focus on advancements to improve care. By the 1970s, a higher emphasis was being placed on family involvement in the NICU, starting with incubators being made of Plexi Glass for parents to see their children, allowing families to stay overnight in the NICU with their children, and the use of skin to skin care, in which parents provided direct skin to skin contact with their infants (Payne, 2016). In the 1990s, improvements in temperature management,
nutrition, and proper ventilation allowed infants to survive when delivered at as young as 23 weeks gestation (Payne, 2016).

Currently, nurseries and NICUs are ranked from a level I-IV, based on the intensity of the treatment infants require. A level I unit is also known as a well newborn nursery, and hosts the most stable infants, usually those born between 35 and 40 weeks. A level II unit, or a special care nursery, treats infants born at or after 32 weeks, or infants who may need short term assistance with breathing. A level III unit, the standard NICU, treats infants who are born before 32 weeks, are critically ill, or who need special equipment to help them survive and grow. Finally, a level IV unit, otherwise known as a regional NICU, is the highest level of care and treats infants who have birth defects or disorders that would require surgery (March of Dimes, 2015).

The current survival rate for infants in the NICU is 18% at 22 weeks gestation, 29% at 23 weeks gestation, 56% at 24 weeks gestation, 84% at 25 weeks gestation, and 90% at 26 weeks gestation (Stensvold et al., 2017). Infant survival at these very early ages can be attributed to the equipment used in the NICU and the skill of neonatal health professionals. This equipment consists of many machines, tubes, monitors, bright lights, uncomfortable temperatures, and an array of medical staff, all with the primary goal of keeping the infant alive. However, this differs greatly from the warm, dark, quiet environment of the womb where these infants are supposed to be growing. The environment of the womb is favorable to the NICU environment because the womb provides the infants with the nutrition, oxygen, a waterproof coating to protect the baby’s skin, and appropriate stimuli for the senses (March of Dimes, 2015). Not only is the NICU a less than favorable option for the infant to develop in, but it can be an uncomfortable environment for parents and families as well.
Effects of the NICU on Parents and Families

The NICU itself is a high stress environment, with various medical professionals working to care for preterm infants fighting serious and potentially life threatening conditions. For new parents to see their infants hooked up to these monitors and machines could cause them a great deal of stress, grief, and other unpleasant emotions. The general expectation following labor and delivery is to return home safely and promptly with a happy, healthy baby. However, parents with children in the NICU may not be able to bring their children home for weeks, or even months.

Mothers of preterm infants experience higher levels of tension and anxiety, depression, anger, hostility and fatigue, and lower levels of vigor and energy than mothers of full-term infants (Iono et al., 2016). Fathers of preterm infants also experience a change in emotions, with reportedly higher levels of anger and lower levels of vigor than fathers of full-term infants (Iono et al., 2016). The high stakes environment of the NICU, not getting the chance to physically bond as much with their child and the variability of their child’s health causes parents of preterm infants to experience unpleasant emotions more intensely than parents of full-term infants.

An additional cause of stress in both mothers and fathers in the NICU is their change in parental role (Baía et al., 2016). Change in parental role relates to the traditional assumption that a couple will go to the hospital, endure labor and delivery, and return home with a new baby to care for. However, parents in the NICU do not get to be the direct care providers for their child following birth. Instead, they are leaving their child’s care up to a team of health professionals. Not being able to assume the role of the primary care provider for their child can leave parents feeling stressed and even incompetent. Other factors that can contribute to this stress include
physical barriers that may be preventing parents from being in direct contact with their child and the feeling that as parents, they are not able to protect their child from harm (Baia et al., 2016).

Due to the high stress that parents in the NICU may be experiencing, along with increases in anxiety, anger, depression, and fatigue, it is important to provide care not only to the infant in the NICU, but to parents and families as well. Medical techniques and interventions are constantly being created and used to keep preterm infants alive, but a form of caring for preterm infants that focuses on their long-term development and the emotional health of their parents and families is developmental care.

**Developmental Care**

Developmental care focuses on healthy long-term growth and development of the infant in the NICU. Developmental care is defined as interventions taken to support the behavioral development and organization of the infant and to create an environment that minimizes the stress of the infant and his/her family while in the NICU and after discharge (Royal Women’s Hospital, 2018). Developmental care works by controlling the environment of the NICU to maintain it as close to the intrauterine environment as possible, thus ensuring more successful development for the infant (Malloch et al., 2012).

Developmental care is particularly important in helping premature infants develop in an environment that is conducive to their behavioral needs. The NICU can be a hostile environment, with clamoring machines, blinking lights and extreme medical procedures. However, developmental care interventions aim to create a more suitable environment for the neonate to develop, while also incorporating the family unit in many forms of care. Developmental care helps families by teaching them useful skills and techniques for raising and caring for a baby with developmental or physical complications and also providing an opportunity for parents to
bond with their newborn children. While having a child in the NICU is a frightening and emotional experience, developmental care provides comfort by supporting the development of the baby and of the family unit as a whole.

Studying and implementing developmental care is essential in serving the population of preterm infants because it is used to prevent long-term consequences of premature birth. Examples of developmental care include music therapy, “kangaroo care,” Newborn Individualized Developmental Care and Assessment Program (NIDCAP), and massage therapy (Bieleninik & Gold, 2014). Various studies have been conducted on these forms of developmental care to determine their effectiveness and the long-term developmental effects that they have on the infant (e.g., McAnulty et al., 2010, Bieleninik & Gold, 2014 and Malloch et al., 2012). However, the use of developmental care is very new in the broad scope of treatments for preterm birth, beginning in the late 1990s to early 2000s, which is why further research is necessary to determine how these forms of care affect both the infant and the family unit as a whole.

**Music therapy**

Music therapy is a primary form of developmental care used in the NICU in which a certified music therapist and/or the neonate’s caregiver performs music with the goal of comforting the neonate, normalizing the neonate’s physiological functions, and creating a soothing and calm atmosphere. Parents of infants in the NICU are at a high risk of stress, anxiety, and depression, and these factors can significantly hinder the early parent-infant relationship (Ettenberger, 2017). Through the use of family-centered music therapy, parents can be integrated into the therapeutic care of their infants, which will help to strengthen the bonds with their children. Depending on the needs of both the parents and infants, family-centered
music therapy can be used to help integrate siblings into the family system, develop methods for bonding with infants after leaving the hospital, and help soothe parents’ anxiety while their children are in the NICU (Ettenberger, 2017).

Infants in the NICU are often prone to developmental impairments or chronic disease, and the chaotic environment of the NICU can also lead to impaired auditory development. Due to the fact that once the infant is in the NICU he is no longer protected by the sound barrier of his mother’s womb, he is more susceptible to damage of the auditory system. Combined with the high-frequency, noisy environment of the NICU, the processing of auditory circuits is disturbed (Lahav & Skoe, 2014). By using music therapy, the neonate is distracted from the potentially damaging noises in the NICU, while also growing accustomed to familiar melodies and the intonations of family member’s voices, providing the grounds for a healthy parent and child attachment to develop. By providing soothing, low frequency noises for the infant to listen to, he or she will be less susceptible to auditory system damage (Ettenberger, 2017).

Music therapy has also been studied for its effectiveness in reducing resting energy expenditure in preterm infants. Resting energy expenditure (REE), also referred to as resting metabolic rate, is a way to measure metabolic efficiency, or the body’s capability of using energy efficiently. REE measures the amount of calories the body burns naturally while at rest. A high rate of REE is associated with a higher amount of calories burned, resulting in faster weight loss. However, in preterm infants, the goal is usually to gain weight quickly, as preterm infants are often underweight. To gain weight more quickly, a lower REE is preferred.

Researchers hypothesize that reducing REE will increase infants’ metabolic efficiency, therefore leading to a faster and healthier rate of weight gain. In a randomized clinical trial conducted by Lubetzky et al. (2009), 20 healthy preterm babies were randomly assigned to be
either exposed to Mozart music or no music at all for 30 minutes at a time on two consecutive days to observe if listening to Mozart reduces REE. Each infant was given his specific intervention on two consecutive days while he was sleeping, and REE was recorded by using a Deltatrac II Metabolic monitor. Infants in the music therapy group experienced a 10-13% reduction in REE from the baseline measurement, which was a statistically significant reduction, while infants in the control group without music therapy experienced either no change or an increase in REE over the 30-minute periods of observation, suggesting that music may be an effective means of lowering REE. The effects of REE on metabolic efficiency and weight gain were unclear, due to the fact that lower levels of REE were only experienced by the experimental group during the intervention, and returned to baseline levels shortly after. However, these findings can be used to identify music therapy as a potential intervention to improve metabolic efficiency. Additionally, REE is only one component of several factors that contribute to total energy expenditure. To determine whether lower levels of REE cause an increased weight gain, REE must be studied in conjunction with the other factors that contribute to total energy expenditure. This necessitates further research to link decreasing levels of REE to an increase in weight gain (Lubetzky et al., 2009).

The effects of various forms of music therapy have also been investigated in conjunction with other neurobehavioral and physiological effects. Communicative musicality, unlike standard music therapy, includes singing, music, and facial and body gestures used in order to fully engage the infant in the intervention. A pre/post between subjects study by Malloch et al. (2012) explored a communicative musicality model and its effects on calming and soothing infants in the NICU. Infants were randomized and given either the communicative musicality-music therapy intervention or no music intervention at all. The communicative musicality
intervention included a trained music therapist singing to the infant, while manipulating the use of various musical dynamics, such as tempo, melody, and the use of silence (Malloch et al., 2012). Infants receiving the intervention had music therapy three times a week for sessions that varied in length, but averaged to 52 minutes per session. Results of the intervention were measured based on the Neurobehavioral Assessment of the Preterm Infant (NAPI) and Alarm Distress Baby Scale (ADBS), and infants were measured on these scales both pre- and post-intervention. The results of this study show that the rating on the NAPI scale for infants who received music therapy was significantly higher (better) following the intervention than for those who did not receive music therapy. Specifically, infants who received the music therapy intervention were less irritable and coped with a series of handling and orientation movements without becoming deregulated (Malloch et al., 2012).

Communicative musicality has also been found to improve the emotional connection between parents and infant in the NICU. Building on Malloch et al.’s (2012) research, a similar study (McLean, 2016) explored the role of communicative musicality in the NICU in relation to intimacy and connection between parents and their children in the NICU. In this study, the use of communicative musicality bridged a gap between parents and their infants, forming a stronger bond. These results support the conclusion that music therapy is an effective method of supporting the neurobehavioral development of infants in the displeasing environment of the NICU and further enhancing the parent-infant bond.

Other varieties of music therapy include the use of different rhythmic sounds, like lullabies, the ocean, heartbeat sounds, and harp music being played in the NICU. A study conducted by Loewy et al. (2013) observed the effects of different forms of music therapy on different physiological functions in preterm infants. Three different forms of music therapy were
used. The first form, the lullaby intervention, was selected based on whether the parents of the infant had a preferred lullaby, and if not, “Twinkle, Twinkle” was used. During this intervention, parents were encouraged to sing the lullaby to their infant, but if they were not comfortable, the music therapist sang to them. The second form of the intervention was ocean noises, as researchers believe ocean noises are effective in soothing premature infants because they mimic the fluid noises of the womb, and were simulated using a Remo ocean disc. The third form of the intervention was to mimic the way that infants hear their mother’s heartbeat in the womb, using an instrument called a gato box. Of the 272 infants in the study, each infant received each of the three music therapy interventions on different days of the two weeks they participated in the study. The infants’ vital signs, feeding behaviors, and sleeping patterns were recorded before, during, and after each intervention. To serve as a control, the infants’ physiological parameters were also recorded while they received no intervention (Loewy et al., 2013).

The results of this study suggests that the use of music and rhythmic patterns help infants to self regulate their physiological functioning, which include regulated sucking patterns, a higher percentage of active sleep, and a decrease in heart rate. Overall, the rhythmic and soothing components of various forms of music therapy have been proven to stabilize and improve functioning in premature infants, allowing for more effective growth and positive development (Loewy et al., 2013).

Pentatonic live harp music is also hypothesized to improve physiological functions in the neonates while also reducing anxiety in parents. To measure the effects of pentatonic live harp music on the physiology of preterm infants and the anxiety of their mothers, live music was played on a children’s harp and physiological responses of the infant and anxiety levels of the mother were compared both while the harp was and was not being played (Ranger et al., 2018).
The use of pentatonic live harp music had few statistically significant effects on the infants’ physiological reactions. However, mothers who were present for the infant interventions reported that they felt significantly less anxious after the music therapy intervention than before the intervention or without it (Ranger et al., 2018). While no significant results were found regarding the effects of pentatonic live harp music on the improvement of infant physiological functions, the intervention significantly reduced maternal anxiety. This is an important and relevant conclusion as reduced anxiety will help comfort parents and allow them to engage more with their children, providing for a healthier parent-child attachment (Ranger et al., 2018).

Music therapy comes in various different forms, including communicative musicality, ocean noises, heartbeat sounds, lullabies, harp music, and even Mozart. Among these forms of music therapy, some impact the infant’s physiological regulation, some enhance and encourage the infant’s development, and some can even help strengthen the emotional bond between parents and their infant while in the NICU. Overall, music therapy has been proven to have positive impacts on parent-infant attachment, sleep, heart rate, neurodevelopment, temperament, and weight gain.

Kangaroo care

Another form of developmental care that stimulates neonates’ senses and helps to provide a comforting environment is kangaroo care. While music therapy aims to provide a hospitable environment for the infant through adjusting noise, kangaroo care stimulates the infants’ sense of touch and provides a comfortable environment through physical contact. Kangaroo care is a form of therapy often used in the NICU that promotes skin-to-skin contact between the infant and a
caregiver in order to help the infant maintain physiological functions similar to those targeted by music therapy, including regulated breathing patterns and reduced energy consumption.

Studies on kangaroo care examine variables of both parents and infants, including maternal-infant attachment, maternal stress, and physiological functions in preterm infants. A study conducted by Cho et al. (2016) observed the effects that engaging in kangaroo care had on the physiological functions of preterm infants, the level of maternal-infant attachment, and levels of maternal stress. Pre- and post-tests were utilized in the study to compare an experimental group, which received kangaroo care, and a control group which did not. The experimental group received kangaroo care during 30-minute sessions, three times a week for 10 sessions (Cho et al., 2016). Another study conducted by de Castro Silva et al. (2016) evaluated the effects of kangaroo care on preterm infants between 36 and 41 weeks post-conceptual age. Infants in the experimental group received kangaroo care for seven consecutive days while infants in the control group did not. Following these interventions, variables such as attention, quality of movements, asymmetry, and stress and abstinence signals were observed using the Neonatal Intensive Care Unit Network Neurobehavioral Scale (NNNS; de Castro Silva et al., 2016).

Cho et al. (2016) used a parent stress scale, maternal-infant attachment questionnaire, and basic physiological measurements to conclude that kangaroo care significantly stabilized the respiration rate of infants during the intervention, led to higher maternal-infant attachment scores, and was effective in reducing maternal stress when compared to the control group (Cho et al., 2016). de Castro Silva et al. (2016) found that the infants who received the seven-day kangaroo care intervention had higher quality of movements, better attention and orientation to external stimuli, and fewer signs of stress and abstinence during examination than the infants who did not receive the kangaroo care intervention (de Castro Silva et al., 2016). These findings
indicate the importance and effectiveness of kangaroo care in improving physiological functioning of the infant and improving the parent-infant attachment relationship.

Kangaroo care has been studied for other effects as well, such as if it benefits infant temperature regulation, infection resistance, mortality, sleep regulation, growth, and length of stay in the NICU. To synthesize various studies which analyze the effects of kangaroo care on various domains in infant development, several meta-analyses have been completed.

A meta-analysis conducted by Boundy et al. (2016) included 124 studies on the effects of kangaroo care on infant outcomes in the NICU. Kangaroo care was considered in the context of mortality among 7 studies, in which the results showed that infants in groups receiving kangaroo care as opposed to infants not receiving kangaroo care had a significantly lower mortality rate at 3, 6, and 12 months. Another interesting conclusion drawn from 12 studies in the meta-analysis looking at infection was that infants receiving kangaroo care had a 47% lower risk of sepsis as opposed to infants who did not receive kangaroo care (Boundy et al., 2016). Additionally, follow-up studies have determined the long-lasting impact of kangaroo care, with increased autonomic stability being measured up to 10 years after birth. Kangaroo care between an infant and his mother has also been found to have an effect on the duration, time of initiation, and exclusivity of breastfeeding (Campbell-Yeo et al., 2015). Kangaroo care has been proven to help preterm infants maintain homeostasis in systems such as body temperature and cardio-respiratory stability (Campbell-Yeo et al., 2015). Overall, the NICU environment is often prohibitive of parent-infant attachment, due to infants’ frequent needs of medical devices and interventions, which can put a barrier between healthy bonding. Kangaroo care allows for this bonding to occur while also improving the regular functions of the infant.
**Massage therapy**

Massage therapy is another intervention similar to kangaroo care, which aims to provide premature infants with the tactile stimulation that they may be lacking due to no longer being in the womb and not having as much physical contact with their caregivers because of restricting medical interventions. However, massage therapy differs from kangaroo care as it is primarily performed by a physical therapist, while kangaroo care is preferably performed by a parent. Additionally, massage therapy focuses on providing tactile stimulation to different parts of the body, while the aim of kangaroo care is to provide overall skin-to-skin contact. Premature infants are often at risk for experiencing negative physical side effects, particularly in their gastrointestinal system functioning, from not receiving the physical stimulation that they require (Choi et al., 2016). They are also at risk for having hypertonic or hypotonic muscles, which is a common side effect of preterm birth. Massage therapy, either performed by a trained massage therapist or a caregiver, can give infants the tactile and kinesthetic stimulation necessary that can counteract either tense or loose muscles, as well as improve physiological functions in a manner similar to kangaroo care.

While massage therapy and kangaroo care are often used complementarily, kangaroo care is unacceptable in some cultures, due to either the modesty of mothers or the lack of privacy in NICUs (Abdallah et al., 2013). Massage therapy does not promote infant-parent attachment the same way that kangaroo care does due to the fact that it is most frequently performed by a massage therapist, but the physiological benefits for the infant, such as stabilizing growth and respiration rates, remain fairly consistent. A specific aim of massage therapy is to decrease pain levels in infants. Pain in premature infants is measured by the Premature Infant Pain Profile (PIPP), which takes into consideration behavioral and physiological responses after an infant is
exposed to a painful stimulus. As infants are often exposed to painful stimuli in the NICU, whether it be an IV, an invasive procedure, or an uncomfortable machine, it is important to find ways to decrease the pain that these infants experience. Drawing blood via a heel stick is a common procedure in the NICU, so researchers Abdallah et al. (2013) utilized the heel stick to simulate a painful stimulus in studying the effects of massage therapy on decreasing pain in preterm infants. Of the 66 infants in the study, a heel stick was done on the intervention group both before and after receiving massage therapy sessions and on both the intervention and control group before discharge from the NICU. Massage therapy was administered during 10-minute sessions once a day, for a total of 10 sessions. The results indicated that pain, as measured on the PIPP, was significantly lower both after massage in the intervention group, and at discharge in the intervention group (Abdallah et al., 2013).

Massage therapy has also been studied in its relation to physical growth and improved gastrointestinal functioning. A study conducted by Choi et al. (2016) examined massage therapy in this context, measuring variables such as height, weight, volume of milk feeding and frequency of bowel movements, both before and after the massage intervention took place. The massage therapy intervention in this study consisted of applying moderate pressure to preterm infants for a 15-minute duration approximately an hour before they were supposed to feed. The variables were measured at the beginning of the study, and after both one and two weeks in the control group and the experimental group. During the time span in which the study took place, Choi et al. observed a significant increase in height, chest circumference, and number of bowel movements in the experimental group, as well as a decrease in the frequency of pre-feed gastric residual, or in other words, a remainder of food from the previous feeding found at the start of the next feeding. The positive results of massage therapy can be attributed to increased secretion
of growth hormones, stimulation of insulin release, and release of food absorption hormones (Choi et al., 2016).

Weight gain is a topic of interest among many researchers in regards to massage therapy, due to the belief that massage therapy may stimulate certain receptors that are critical in infant weight gain (Diego et al., 2014). Weight gain is important for preterm infants because increased weight gain has been linked with sooner NICU discharge. Additionally, most preterm infants are born underweight (Diego et al., 2014). Diego et al. compared the effects that massage therapy, both through applying moderate pressure and flexing and extending the limbs, had on infant weight gain and whether these results could be correlated to underlying physiological functions. In the study, infants were split into two groups, one group receiving moderate pressure application and the other groups receiving stimulation through the flexion and extension of various limbs over a five day span with interventions occurring three times a day for 10 minutes each. While both of the interventions led to increased weight gain, the moderate pressure application was associated with increased activity in the vagus nerve and the limb movement exercises were associated with increased calorie consumption (Diego et al., 2014).

The improvements in development that are typically associated with kangaroo care and music therapy are more internal, such as sleep regulation, consistent breathing rate, and stable heart-rate regulation. The effects that are correlated with massage therapy, however, are more related to externally visible changes in the infant, such as increased growth and maintenance of gastrointestinal functions. Massage therapy helps to decrease infants’ senses of pain, regulate their hormones, and help them to gain weight.
Newborn Individualized Developmental Care and Assessment Program (NICDAP)

NICDAP is a form of developmental care that was created to provide a specifically designed environment and care routine to respond to the infants’ behavior and to support infant biological and brain development (McAnulty et al., 2010). NICDAP focuses on altering the environment of the NICU to prevent harmful or damaging effects on the immature brain of preterm infants. Specifically, NICDAP works by accounting for the observable behaviors of infants that may be unwanted or negative and altering the environment in order to prevent these undesirable behaviors. There is no specific or standard protocol for using NICDAP, which is how it differs from massage therapy, kangaroo care, and music therapy. This makes NICDAP unique among these other forms of developmental care because it is individualized to meet the needs of each infant. Altering the environment using NICDAP can occur through adjusting light, sound, temperature, or activity level. For example, if an infant is fussy while awake and has difficulty sleeping, a lower level of light may allow for more appropriate states of arousal. Through observing each infant’s individual behavior, NICDAP allows for clinicians to individually assess each infant and format a plan of treatment to minimize stress in the neonate and optimize healthy growth and development.

McAnulty et al. (2010) conducted a study in which they performed a long-term follow up of 8-year-old children who were born prematurely and either had or had not received NICDAP when they were in the NICU. In the first phase of the study, NICDAP professionals sought to understand the comfort and stress signals of the infants in the experimental group and worked to alter the environment by providing accessories such as hammocks, hugging pillows, and specialized pacifiers. This phase was conducted when the participants were first admitted to the
NICU and included an experimental group that received NIDCAP and a control group that did not.

At the conclusion of the first half of the study (when infants were 2 weeks old) the experimental group presented a significant reduction in incidence of intraventricular hemorrhage, better weight gain, earlier independent feeding, and earlier discharge (Als et al., 1994). Once the participants were eight years old, the follow-up portion of the study was conducted where the original experimental group showed better spatial visualization, mental control, attention, integrative processing and had a better Performance IQ than the original control group (McAnulty et al., 2010). This suggests that the NIDCAP intervention that infants received had long lasting beneficial effects that continued to impact the experimental group through childhood.

Other studies have investigated the effects of NIDCAP during infants’ time in the NICU alone. Meeting motor performance milestones is a very common area for preterm infants to struggle with after birth, mainly due to their lack of time spent developing in the womb. The effects of NIDCAP implementation on the motor performance achievements in preterm infants were studied by Ullenhag et al. (2009). In the study, researchers were interested in determining whether there was a difference in the motor performance of infants depending on whether they were treated with NIDCAP before or after evaluation of their motor performance. The NIDCAP determined modifications in this study included altering the physical environment of the NICU, modifying caregiving activities, and facilitating infant self-regulatory efforts. The 126 infants in the study were split into two different groups, one that received NIDCAP before their motor performance was assessed and one that received NIDCAP after (Ullenhag et al., 2009).
Of the two groups in the Ullenhag study, the group which received NIDCAP prior to motor performance assessment had a significantly higher level of motor development in the arms, hands, and trunk. Through these observations, the conclusion can be drawn that NIDCAP implementation has a positive influence on the motor performance of preterm infants (Ullenhag et al., 2009). Both of these studies illuminate the positive effects of NIDCAP on the physical growth and development of the preterm infant.

These studies on music therapy, kangaroo care, massage therapy and NIDCAP demonstrate the importance that developmental care has on improving the overall function and well-being of the preterm infant. Developmental care is not used to cure anatomical defects or other physiological system malfunctions, however it can help basic development in areas such as maintaining homeostasis, regulating sleep/wake cycles, motor performance, general growth, and neurobehavioral functioning. Due to these reasons, it is important that developmental care be used in practice in the NICU alongside basic life support and medical interventions.

**Developmental care in the family system**

Not only has it been proven that developmental care has plentiful benefits for the growth and development of preterm infants, but its effects have been studied in relation to the family unit as well. The NICU environment can be very stressful for parents and families. The whirring machines and medical supplies can cause parents to feel anxious and fearful about what may happen to their child and what the child is experiencing. Watching physicians care for their child and not being able to fully understand what is happening can be an anxiety-producing experience. Additionally, the expectations of most parents upon going to the hospital to have a baby is that they will be able to take that baby home after and care for him themselves. For this reason, it is a difficult transition when parents feel a lack of control over what happens to their
Developmental care gives parents and families the ability to actively participate in their child’s care even while he is in the NICU.

When parents actively participate in music therapy sessions, they are given a chance to relax, be distracted, and bond with their child (Ettenberger, 2017). Additionally, they can learn skills to utilize music therapy for their child even after discharge from the hospital. This can help parents feel empowered to care for their child and learn techniques to foster their child’s development (Ettenberger, 2017). Music therapy has also been proven to have an effect on reducing maternal anxiety (Ranger et al., 2018).

Due to the intimacy of kangaroo care, this intervention has positive effects on parents as well, particularly parent-infant attachment. Skin to skin contact between a mother and her child serves as a very important bonding experience, especially when the infant has to spend such a large percentage of the day in an incubator. Kangaroo care has not only been proven to increase parent-infant attachment, but to decrease maternal stress and increase maternal affection as well (Cho et al., 2016).

Not many studies investigate the effects of massage therapy on the parent-infant attachment, as massage therapists are usually the ones providing this intervention. However, for cases where kangaroo care may be culturally unacceptable, massage therapy can be administered by mothers and serve as a manner for mothers to interact with their infant. Through administering massage therapy, mothers may also become more confident in their parenting skills and more attuned to their child’s needs (Abdallah et al., 2013). Developmental care does not just positively impact the infants who receive it, but parents and families as well. Parents involved in developmental care can experience a decrease in stress and anxiety, increase in attachment and affection, and can become more confident in their parenting.
Nurses’ perspectives and other influences on developmental care

While many studies have highlighted the positive impact of developmental care on both infants and parents, it is still a relatively new method of care. Because it is so new in the medical community, it is not a standard of care in some hospitals. In hospitals that do not offer developmental care, or that do not offer it to every patient, there are many limiting factors, including parent preferences, hospital leadership, physicians, and nurse’s perspectives. As nurses are primary providers for infants in the NICU, both for medical care and developmental care, their opinions on developmental care are essential to determine the frequency of developmental care being used in practice. In a study including 23 NICU nurses, participants were asked to complete a questionnaire regarding the impact of kangaroo care on the mother-infant attachment. All of the nurses in the study reported that they believed that kangaroo care had a significant impact on mother’s affection, increased maternal presence in the NICU, and higher involvement in care of their infant in the NICU (Valizadeh et al., 2012).

However, not all nurses are supportive of developmental care. Some believe that it is too time consuming and difficult. A study by Park and Kim (2019) sought to understand the factors affecting the implementation of developmental care by NICU nurses. Most nurses in the study reported that the variables that had the largest influence on their use of developmental care were a strong professional efficacy and a high sense of optimism. Others felt a lack of confidence in administering developmental care correctly, and therefore chose not to. Some believed that developmental care was not really an integral part of nursing care, and was just an optional way to treat patients. Thus, nurse beliefs alone can have an immense impact on whether developmental care in the NICU is actually being used, or whether it is just a technique that researchers support and encourage (Park & Kim, 2019).
Other factors that affect the implementation of developmental care include a power imbalance among physicians and other medical staff. Even though nurses are the primary caregivers to infants in the NICU, physician orders are regarded to be unquestioned and ultimate (Mirlashari et al., 2019). Therefore, if a nurse is in support of developmental care, but a physician is not, the physician may not allow the nurse to implement developmental care techniques with the patient. Additionally, some parents are afraid to implement developmental care due to the high stress atmosphere of the NICU and the fear that they might do something to harm their infant. Finally, physicians describe that organizational limitations prevent them from implementing developmental care due to the lack of family-centered values by specific hospitals as a whole. If higher-ups in the hospital do not advocate for developmental care, policy will not be put into place, and the practice will not become routine (Mirlashari et al., 2019). Several limitations from nurses, physicians, hospital leadership, and even parents prevent the practice of developmental care to flourish in the NICU setting.

**NICU follow-up programs**

NICU follow-up programs, while different from developmental care in the NICU, also aim to foster the growth and development of preterm infants after their NICU discharge. Both follow-up programs and developmental care have the same goal: to enhance and encourage the appropriate behavioral development of the infant. NICU follow-up programs are generally associated with specific hospitals and are recommended for infants to attend on a recurring basis. Generally, preterm infants who are referred to NICU follow-up programs will attend the program every three or four months for the first year of life, and then every 6 months for the following year. NICU follow-up programs are comprised of several different healthcare professionals who aim to target the specific needs of each infant in the program. The professionals often consist of
neonatologists, child development specialists, psychologists, dieticians, physical therapists, and speech language pathologists. Each of these professionals observes a certain domain of the infant’s development, and provide interventions to strengthen the facet of development when necessary (BWH NICU Follow-Up Program, 2019).

As NICU follow-up programs are a new advancement, there is little research on the effectiveness of these programs in the long-term development of children born preterm. However, these programs have a specific focus in monitoring the development of infants post NICU discharge and referring them to early intervention services when necessary. The goal of NICU follow-up programs is to study and evaluate the long-term outcomes of infants born prematurely with the hope of learning what changes to make in the care of future infants (Sauve & Lee, 2006). Additionally, NICU follow-up programs provide education to training medical professionals, and provide growth and feeding or developmental interventions when necessary. Most follow-up programs also have some sort of research component in which neonatologists compare interventions that infants received in the NICU with their growth and development over the next several years (Sobaih, 2012). Some even train neonatology fellows to give them a sense of the challenges that infants still face after their NICU discharge (Sobaih, 2012).

While infants that attend follow-up programs are often referred to early intervention services if there is a developmental delay or concern, follow up programs that are staffed with psychologists can provide developmental testing and recommendation, and programs with feeding therapists can teach parents how to improve their child’s eating habits (Sauve & Lee, 2006). The key for a successful follow-up program is if the staff can efficiently identify a developmental delay or disability and appropriately refer the patient to either a specialist or early intervention service (Sobaih, 2012). Currently, most major children’s hospitals are associated
with a follow-up program for their NICU, and those that do not have one are in the process of founding one. The growing trend in NICU follow-up program establishment is due to the fact that they are the most convenient and effective way to track the long-term development of high-risk infants and to provide interventions and referrals necessary for the infant’s well-being (Sobaih, 2012).

**Implications of this study**

The NICU offers life saving care to infants born prematurely or with other birth defects and complications. While the NICU has advanced technologies and equipment that can help infants in crisis to survive, this care can interfere with the overall development of the infant. This is why the use of developmental care in conjunction with the medical care provided by the NICU is essential to optimal infant growth and development. Additionally, the experience of having a child in the NICU can be traumatizing for parents, and can also interfere with the parent-infant attachment, so developmental care can additionally help to foster the relationship between parent and child and to incorporate parents into their child’s care. While developmental care has been proven to have positive effects on the growth and long term development of infants, the bond between parent and child and the mental health of the parent, it is still not a standard of care in all NICUs.

This study is designed to assess the beliefs of NICU care providers on developmental care in the NICUs where they work and identify current NICU practices. As a great deal of research on developmental care in the NICU is conducted or carried out by PhD graduates and research assistants as opposed to practicing medical personnel, the view of developmental care can often be biased. Since the researchers in these studies are not providing developmental care
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themselves, they may be unaware of the effort it takes to initiate developmental care and other various requirements that go along with it.

Through the collection of data from the interviews with NICU providers and the assessment of the top NICUs, this project aims to evaluate the use of developmental care in practice at top children’s hospitals, assess health care provider’s opinions on the effectiveness and feasibility of developmental care, and provide recommendations regarding best practices for preterm infant care and suggestions on how to improve NICU care.

Method

Participants

Four health care providers that work in the NICU (a neonatologist, a dietician, a feeding therapist, and a nurse) were chosen to be interviewed to review their opinions on developmental care and its use in their places of work. These providers were selected through convenience sampling based on their employment in the NICU, and their varying perspectives on the use of developmental care. While they all work directly with patients in the NICU, each has a different view to offer based on his/her unique career.

Procedures

Interview procedure

Interviewees were invited to participate via an email informing them of the study and what I hoped to gain from the interview. Interviews were scheduled via private email with each participant, and informed consent forms (see Appendix A) were distributed to participants via email. Prior to each interview, participants emailed the completed informed consent form to me, which were stored in a folder on my password-protected personal computer. Interviews were conducted by speaker phone in a private room and were recorded using the Photobooth video
recording feature on an Apple Macbook Air to record the audio of the interview. Each interview began with a description of the purpose and aims for the research, along with a definition of developmental care and examples of developmental care that the interviewee may be familiar with. Interviewees were made aware of the emotional experiences that some of the questions may bring about and were invited to pause the interview at any time. In each interview, questions regarding the participant’s familiarity with developmental care, use of developmental care at their place of employment, and opinions on neonatal care in general were asked. A pre-written script was used for interviews, which consisted of an introduction to the study, given by me, and specific interview questions used across interviewees (see Appendix B). Audio recordings of each interview were stored in a folder on the password-protected Macbook Air.

**Table procedure**

A table was created to summarize information regarding the use of developmental care in practice at US hospitals with top-rated NICUs. The US News Report’s list of top hospitals for neonatal care was used to identify the top 10 NICUs to be included in the table. In addition to these facilities, Brigham and Women’s Hospital was also included due to its affiliation with the majority of the interviewees and as the location of my summer research on outcomes of infants who attend the NICU follow-up program there. To construct the table, each hospital’s website was searched for information pertaining to developmental care in their NICUs, and in the cases when information was not found online, phone calls were made to these hospitals to confirm details. The parameters of the table consisted of sections including the level of the NICU, the number of beds available, the presence of a follow-up program associated with the hospital, the developmental care offerings available, and the members of the multidisciplinary team employed in the NICU.
Data Analysis

*Interview analysis*

Following the interviews, data were analyzed by listening to the recording of the interviews and identifying key words and themes apparent across interviews. Key themes and ideas from each interview were recorded in a document for comparison across interviews. Following my careful analysis through listening to each individual interview, notes from the interviews were compiled to generalize reoccurring patterns and themes across all four interviews.

*Table analysis*

After complete construction of the table, patterns across hospitals and their developmental care offerings were identified. Additionally, results on the average number of beds the NICUs had, the average level of the NICU, and whether or not they had an associated follow-up program were reviewed.

Results

*Interviews*

Interviews were conducted via a telephone call to healthcare professionals. Of the four healthcare professionals who had volunteered to participate in the study, interviews were only conducted with three of them due to complications in scheduling with the feeding therapist. Thus, these results are based on the interviews with the neonatologist, NICU nurse, and dietician.

Each of the providers interviewed had been working in the NICU (either at the hospital they are currently employed at or a NICU at another hospital) for a range of 8 to 9 years. The three providers have had positive experiences working in the NICU. The neonatologist endorsed that most of the time, the babies she has seen are able to get better, and she is able to track their
growth through the follow-up program affiliated with the hospital. The NICU nurse started
working in the NICU immediately after graduating nursing school, and said that over the past 9
years she had gone from a new grad, to a resource nurse, to a charge nurse and currently to
training as a nurse educator. The dietician expressed that she enjoys delivering exciting news to
parents about the growth and development of their children.

NICU environment

In regards to the environment of the NICU, the neonatologist found that it was very
“intense.” Difficult decisions about infant care are constantly being made, which makes the job
challenging yet rewarding. The NICU nurse described the environment of the NICU at which she
is employed as a more surgically-based infant ICU, and that the infants she treats are recovering
from complex surgeries. The dietician stated that the NICU she works at has experienced many
improvements in the past few years. It was remodeled to allow space for parents to stay over
night with their infants, and it offers privacy for families. However, she acknowledged that the
environment feels very sterile, and she wished it were “warmer.”

Developmental care

One of the three providers said that developmental care was a standard form of care in the
NICU she works in. The neonatologist admitted that it was not a standard of care, and that
learning about what is developmentally appropriate is a “new frontier” that health professionals
and researchers are beginning to explore. She, among other physicians in the hospital she is
employed at, is exploring the question of “how do we recreate a womb-like experience?” She
said some of the hospitals she has been employed at have had developmental care committees,
but developmental care often falls to the wayside when the baby’s life is at risk. On the other
hand, developmental care is a standard of care where the NICU nurse works. Any baby in her
NICU who is stable enough receives kangaroo care and music therapy, and a child life specialist caters to the needs of children and educates parents and nurses on how to provide developmental care. Developmental care is not a standard form of care where the dietician works, but she acknowledged that the nurses work to make kangaroo care a priority as long as the infant can be moved from his or her incubator. Additionally, the physical and occupational therapists work on promoting massage therapy.

When asked if she had ever witnessed developmental care being provided or had provided developmental care herself, the NICU nurse stated that she had, as the nurses are typically the providers that perform developmental care forms such as NIDCAP, modifying lighting, cuddling, and providing developmental supports. She has also witnessed physical and occupational therapists provide developmental care, and kangaroo care is generally provided by parents, not NICU staff. On the other hand, the dietician revealed that in the growth and development unit of the NICU where she works, there is a rehab team, including occupational and physical therapists, a feeding specialist, social workers, dietitians, and lactation specialists, with a specific focus to provide developmental care, and she has witnessed their work. Additionally, nurses at the hospital where she works have been to conferences and trainings on providing developmental care in the NICU.

Both the NICU nurse and the dietician have witnessed infants benefit from developmental care. The NICU nurse elaborated to say that kangaroo care is known to improve oxygen saturation, help infants grow better, and be clinically more stable. Additionally, reading and talking to infants helps them to reach developmental milestones.
**Infant and parent care**

The NICU nurse, dietician and neonatologist also expressed that they believe infants in the NICU receive adequate care. The NICU nurse said that while they receive top-level care, the infants with more involved parents typically have more support than those whose parents are not involved. The dietician said that the use of evidence-based techniques allows for infants in the NICU to receive the best possible care. The neonatologist said that in regards to developmental care, some NICUs can do better in promoting it and putting it into practice, but that the babies are much more than adequately cared for.

In regards to the question of whether parents receive adequate support in the NICU, the NICU nurse said she believed they do, but the dietician and neonatologist said that parents are not as supported as they could be. The dietician added that parents of infants in the NICU are going through trauma and crisis, and that they could use more social support, family support, education, and resources. To improve care of parents in the NICU, she suggests that there could be more structure for parents, such as having sit down meetings regarding their child’s care, as well as more open discussion and updates on their child’s progress.

**Preterm birth and society**

The neonatologist was asked how she believed preterm birth affected society as a whole. She said that there is a very high rate of prematurity in the US, but physicians do not know why. However, babies deserve the dignity of being given a chance to survive, because NICUs have the technology to do so. In the long run, babies who are born prematurely may need physical therapy or extra help in school, but so could any child, even one who was born full term. For this reason, she believes that prematurity is not putting an unnecessarily high burden on society.
**Improvements to NICU care**

Each of the three providers stated different ways in which they believed overall NICU care could be improved. The neonatologist suggested that creating artificial placentas is something that scientists are working on, and could take away the necessity of any invasive procedure by recreating a womb-like environment. Additionally, she believed that parental mental health needed to be focused on more, as the mental health of parents can trickle down to impact the infant and the family. Finally, she suggested that NICUs need to find better ways to developmentally care for babies, such as giving them noise cancelling headphones or a piece of cloth that smells like their mother.

The NICU nurse suggested that private rooms in her NICU could improve care, and the dietician said that the transition from the NICU to home could go much smoother. The dietician elaborated to add that doing housekeeping tasks like preparing formula, setting up follow-up appointments, and meeting as a team with the parents could help to make the transition more intentional.

**Additional experiences**

At the conclusion of the interviews, the providers were asked to share any experiences that they deemed relevant and thought would be helpful in completing this project. The neonatologist acknowledged that it has been a privilege to help families through what may be the darkest time in their lives, and it is an honor to care for the babies. The NICU nurse found that parents who are actively involved in their children’s care, by reading or singing, see more progress in their children than parents who are not actively involved. She also acknowledges that parents being on their phones while holding their children is not an effective way of bonding. Overall, it is important to educate parents and families on how to best care for their children in
the NICU. Finally, the dietician stated that it is important to keep learning about infant development and how to optimize it, and that providers need to be more intentional with their interactions with families to make the parents feel more supported.

**Top US NICUs**

Information gathered from phone calls and website searches of the 11 NICUs reviewed were compiled into a table (Table 1). In regards to the physical layout of the NICU, the number of beds in each NICU ranged from 24 to 125 with the average number of beds being 66.73 beds. In respect to the level of the NICU, 9 of the 11 are level IV NICUs, one is a level III, and one is a level III/IV. Of the 11 NICUs, all (100%) had a NICU follow-up program affiliated with their respective hospital.

Each of the 11 NICUs had a different assortment of health care providers, with the average number of different types of providers per NICU being 6 types of providers. The scope of providers consisted of physical therapists, occupational therapists, music therapists, child life specialists, feeding therapists, lactation consultants, speech-language pathologists, dieticians, art therapists, developmental specialists, chaplains, patient support assistants, social workers, and neonatal clinical specialists. Of these providers, the most common were physical therapists, occupational therapists, and child life specialists.

The forms of developmental care among these NICUs consisted of music therapy, kangaroo care, massage therapy, family centered care, play therapy (using toys at the bedside), art therapy (offers creative outlets to families), modified lighting, developmental supports (environmental modifications, supportive positioning), modified feeding techniques, NIDCAP, cuddler programs (similar to kangaroo care, but without a focus on skin to skin contact), positioning of head (providing physical support), and reading programs (reading to infants). The
most common forms of developmental care were family centered care, kangaroo care, and music therapy.

**Discussion**

Overall, developmental care has been proven to have several positive impacts on the infants who receive it, even if it is a fairly recent development and is not a standard of care in many NICUs. Developmental care can help infants to maintain steady breathing and heart rates, gain weight, regulate sleep cycles, and foster appropriate neurobehavioral development. Developmental care not only benefits infants, but has positive impacts on parents and families as well. Various forms of developmental care have been proven to reduce parent stress and anxiety, increase parent confidence in care for their infant, and enhance the bond between parent and child.

However, while developmental care may be beneficial to parents, a common theme among the interviews was that parents in the NICU do not receive enough support. Being in an Intensive Care Unit can be a traumatizing experience, and it is also traumatizing for parents to watch their children receive intensive care. While many top NICUs offer social work and chaplain services to help parents cope with the stress and trauma they are experiencing, the providers interviewed acknowledged that they believe parents still do not receive enough support. The neonatologist even went so far as to say that a way to improve NICU care as a whole would be to focus more on parental mental health, as it trickles down to affect the infant and the whole family.

Another common theme among the interviews was that while providers have seen the positive impacts of developmental care, it still fails to be put into practice. While two of the three providers interviewed said that they had witnessed the positive impacts of developmental care,
only one of the three providers said developmental care was a standard of care in the hospital where she works. Developmental care is not a standard of care where the neonatologist works, but she insisted that one of the ways to improve NICU care is to incorporate more developmental care for the infants.

Among the hospitals reviewed in this study, each of them had an associated follow-up program. This shows that the top NICU hospitals in the US are interested in tracking and fostering the long-term development of the infants they see. Additionally, each of the hospitals has at least one form of developmental care that is used in the NICU, so even though developmental care may not be standard in all of these hospitals, it is still used in some cases.

**Recommendations**

In order to improve infant care, developmental care should be a standard of care in all NICUs. The benefits of developmental care are vast for both infants and parents, and the variations of care are easy to implement. Of the hospitals reviewed, each of the NICUs have the staffing necessary to implement at least one, if not more, forms of developmental care. One of the most straightforward forms of developmental care, kangaroo care, can even be administered by parents. Given that this form of developmental care can be easily implemented, all NICU nurses should recommend the use of kangaroo care for families with infants who are physically stable enough to receive it.

Additionally, parents in the NICU need to receive more care. As the providers discussed in their interviews, parental mental health is something important to pay attention to, as it can affect the whole family. They described that one of the biggest improvements they think is necessary for the NICU is to focus more on caring for parents and communicating with them. By providing parents with education, resources, and support, parents can feel more included in their
infant’s care and can take part in it as well. To increase parent involvement, both further interaction with providers and the use of technology can be implemented. Ideally, it would be beneficial for parents to have weekly meetings with providers to discuss their infant’s progress and future directions for care. However, due to the busy schedule of NICU providers, this is not always feasible. In these cases, technology can be used for providers to update parents on interactions with their infants, discuss future actions, and provide parents with educational resources to learn more about their infant’s conditions and the care he/she is receiving. To increase the emotional support that parents receive, social workers should be required to meet with parents weekly to discuss the parents needs and create/update a support plan for the parents. This could include referrals to outside therapy/psychology services, support groups, or recommendations to seek additional support from family and friends. Additionally, parents can engage in the developmental care of their infant, as the available literature suggests that this is very beneficial in supporting parental mental health.

Another roadblock to implementing developmental care is the varying opinions of NICU providers regarding its use. As reflected in the interviews, many providers believe that developmental care is helpful, even if their hospitals do not use it in practice. As the dietician mentioned, nurses at the hospital where she is employed have been to conferences on developmental care and how to implement it in the NICU. To help implement developmental care in practice, various providers from NICUs should be encouraged to attend these conferences, and then to share their findings with all NICU providers. By sharing the valuable information learned at these conferences with their colleagues, NICU providers can help to foster an environment that is supportive of developmental care and strives to implement it.
Limitations and future directions

One of the major limitations of this study is the small number of participants. With only three participants, two of them coming from the same hospital, the results are limited and it would be difficult to generalize them to all NICUs. Additionally, participants in this study were not randomly selected, but chosen by the researcher. In future studies, participants should be selected from top NICUs across the country. Gathering data from hospitals nationwide can help to provide a more complete view as to what NICUs across America offer in regards to developmental care. If researchers were able to gather one or two participants from various NICUs across the country, there would be an increased amount and wider variety of data from the interviews, from which more general conclusions could be drawn.

Another limitation of this study was the difficulty that occurred in contacting participants and interviewing them. One of the participants had to be removed from the study because she was unable to find time to participate in an interview. Due to not having this participant in the study, the data that would have been collected from her was not included in the study, leaving three participants to share their experiences instead of the expected four. To prevent this kind of participant dropout, future studies should require participants to provide times when they are available to be interviewed when they are initially recruited for the study. Regarding the development of the table, one limitation was the lack of information on some of the NICU’s webpages. However, this information was able to be easily obtained by calling the NICUs directly and speaking to a staff member there. To make this information more widely accessible to the public, NICUs should keep their websites more up to date with care offerings, and consider providing a page on their website specifically devoted to developmental care if they do not have one already.
Future directions for research in developmental care include variations to clinical studies to determine long-term impacts of developmental care, such as studying a particular group of infants who receive developmental care and observing their development over time with comparison to a control group. Other future studies can compare forms of developmental care to determine which has more benefits for the infant and parents, and to determine which forms hospitals should be actively implementing for all infants.

Conclusions

Developmental care, in its various forms, offers many benefits to infants, parents, and even hospital providers who are able to see the infants they are treating grow and meet developmental milestones. As a fairly new field of research, there is a great deal of data regarding the effectiveness of developmental care, but further research is still necessary to study the long term outcomes of specific forms of developmental care and to determine which forms of developmental care should be necessary for all NICUs to provide. This project aimed to survey current developmental care practices, gather opinions of NICU providers in regards to developmental care, and provide recommendations for the use of developmental care in the future of NICU medicine.
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Appendix A

INFORMED CONSENT

CONSENT TO PARTICIPATE IN RESEARCH PROJECT ENTITLED: Developmental Care in the NICU: Best Practices for Preterm Infants, Expectations of Nurses, and Impacts on Parents and Families

Principal Investigator(s): Alicia Burrows

Participant’s Name: _______________________

KEY INFORMATION:

1. Consent and Voluntary Nature of Research: You are invited to give your consent to participate in a research study. Your participation is completely voluntary.

2. Purpose, Duration, and Procedures: The purpose of this research is to gather firsthand information on the implementation of developmental care in the NICU, the comfort-level of the NICU environment, and the quality of care delivered in the NICU. If you choose to participate in the study, you will be asked 10 questions via Skype, FaceTime, or a phone call. These questions will be recorded to collect themes and summarize interview findings. The interviews should take approximately 30 minutes to conduct.

3. Reasonably Foreseeable Risks and Discomforts: There are no inherent physical or financial risks in the procedures themselves. You will not be exposed to any more risk of harm or discomfort than those ordinarily encountered in daily life. It is possible that you may experience emotional distress from talking about your experiences in the NICU, which is an often emotional and high stakes environment. The risk of emotional distress will be minimized by only addressing topics related to care provided in the NICU and not specific cases of infants being treated in the NICU.

4. Reasonably Foreseeable Benefits: This study may be of no direct benefit to you, but the long-term benefits of the proposed study are to provide a document that outlines and reflects upon various forms of developmental care in the NICU, which are used to improve health and overall development in premature infants.

Confidentiality: The information from the surveys will be used for research purposes only. Your survey will only include a participant ID number and not your name. Any records with your name, including this informed consent form, will be stored separately from your responses in a locked file cabinet, and all data will be stored without your identity in a password-protected computer. The researchers will keep your participation confidential - your name will not be used in any reports or publications of this study and only summary findings will be shared in presentations or publications of this study. The data will be kept for three years following publication and then destroyed.

Freedom of Choice to Participate: You are free (1) to decide whether or not to participate, (2) to skip questions and (3) to withdraw from the study at any time. A decision not to participate will
not adversely affect any interactions with the investigator or any representative/employee of Assumption College.

Future Research: Information collected for this project will not be stripped of identifiers and used in other research in the future.

Questions: Before you sign this form, please ask any questions on any part of this study that is unclear to you. You may take as much time as necessary to think this over. At any point in the study, you may question the Principal Investigator about the study (Alicia Burrows, 617-543-3054, alicia.burrows@assumption.edu) or the faculty advisor (Alison Stoner, am.stoner@assumption.edu). In addition, you are free to contact the Institutional Review Board Chair about any concerns (Sarah Cavanagh, scavanagh@assumption.edu, irb@assumption.edu).

Consent: This project has been explained to me to my satisfaction and in language I can understand, and I have received a copy of this consent form. I understand what my participation will involve, and I agree to take part in this project under the terms of this agreement. I understand that I am not giving up my legal rights by signing this form.

Signature of Participant __________________________

Date __________________________

Printed Name of Participant _______________________________________________________

Signature of Investigator _________________________________________________________

Date __________________________
Appendix B

The dialogue for interviews were as follows: “Hi, and thank you for volunteering to interview with me. My name is Alicia Burrows and I am Health Science major at Assumption College in Worcester, Massachusetts. Following my graduation this coming May [2020], I plan to attend an accelerated program to earn my Bachelor’s Degree in Nursing. After this, my goal is to become a nurse either in the NICU or in the labor and delivery unit. As a part of Assumption’s Honor’s Program, I have designed a thesis project and will be executing research until December when I defend my thesis to a panel including my mentor, the Director of the Honor’s Program, and other faculty and students at the college. The goal of my project is to investigate various form of developmental care and determine their effects on preterm infants as well as the family unit as a whole. Developmental care is defined as interventions taken to create an enivronment that minimizes the stress of the infant and his/her family while supporting the behavioral development and organization of the infant. Developmental care works by controlling the environment of the NICU to maintain it as close to the intrauterine environment as possible, thus ensuring more successful development for the infant. Some examples of developmental care include music therapy, kangaroo care or skin-to-skin care, massage therapy, and Newborn Individualized Developmental Care and Assessment Program. With this in mind, I invite you to share your experiences with the NICU and developmental care.”

Following this overview, I asked each provider the following questions, and allowed them to elaborate on their experiences as they saw fit.

The questions I asked the NICU nurse, feeding therapist, and dietician included:

1. How long have you been working in the NICU?
2. What has your experience been like working in the NICU? Any highlights?
3. How would you describe the environment of the NICU?

4. Is developmental care a standard form of care in the NICU where you work or does it have to be referred? If it has to be referred, who makes these referrals?

5. Have you ever administered any forms of developmental care? If so, what forms?

6. Have you ever witnessed anyone else administer developmental care?

7. Have you witnessed or heard of any preterm infants benefit from forms of developmental care? If yes, can you explain?

8. Do you believe parents receive adequate care and support in the NICU? Why or why not?

9. Do you believe infants in the NICU receive adequate care? Why or why not?

10. What improvements could you suggest for the care of infants in the NICU?

11. Do you have any other experiences you would like to share that you believe would be helpful as I continue to work on my thesis?

The questions I asked my mentor from my summer internship included:

1. How long have you been working in the NICU?

2. What has your experience been like working in the NICU? Any highlights?

3. How would you describe the environment of the NICU?

4. Do you believe infants in the NICU receive adequate care?

5. Is developmental care a standard form of care in the NICU where you work or does it have to be referred? If it has to be referred, who makes these referrals?

6. What does the extent of your research include?

7. What improvements do you believe are necessary for effective neonatal care?

8. How do you believe the scope of preterm birth affects our society?
9. Do you have any other experiences you would like to share that you believe would be helpful as I continue to work on my thesis?
## Table 1

*Top US NICUs developmental care data*

<table>
<thead>
<tr>
<th>NICU</th>
<th>Members of Multidisciplinary Team</th>
<th>Developmental Care Offerings</th>
<th>Level of NICU</th>
<th>Associated Follow-Up Program</th>
<th>Number of Beds</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boston Children’s Hospital (US NEWS #2)</td>
<td>Physical therapists, occupational therapists, feeding therapists, child life specialists, music therapists</td>
<td>Music therapy, family-centered care, play therapy, reading to infants</td>
<td>III/IV</td>
<td>Yes</td>
<td>24</td>
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<td>Children’s Hospital of Pennsylvania (US NEWS #3)</td>
<td>Child life specialists, music therapists, art therapists, feeding therapists, physical therapists, social workers, psychologists, occupational therapists, lactation consultants, speech-language pathologists, dieticians</td>
<td>Music therapy, modified lighting, art therapy, play therapy</td>
<td>IV</td>
<td>Yes</td>
<td>95</td>
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<td>Cincinnati Children’s Hospital Medical Center (US NEWS #4)</td>
<td>Child life specialists, physical therapists, dieticians, occupational therapists, developmental specialists</td>
<td>Developmental supports (environmental modifications, supportive positioning), massage therapy, kangaroo care, NIDCAP, modified feeding techniques</td>
<td>IV</td>
<td>Yes</td>
<td>70</td>
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<td>Texas Children’s Hospital (US NEWS #7)</td>
<td>Child life specialists, lactation consultants, dieticians, social workers, occupational and physical therapists, neonatal clinical specialists</td>
<td>Music therapy, family centered care</td>
<td>IV</td>
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<td>76</td>
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<td>NICU</td>
<td>Members of Multidisciplinary Team</td>
<td>Developmental Care Offerings</td>
<td>Level of NICU</td>
<td>Associated Follow-Up Program</td>
<td>Number of Beds</td>
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<td>University of California San Francisco Benoiff Children’s Hospitals (US NEWS #5)</td>
<td>Physical and occupational therapists, patient support assistants, chaplains, social workers, child life specialists</td>
<td>Family centered care, music therapy, cuddling program</td>
<td>IV</td>
<td>Yes</td>
<td>50</td>
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<tr>
<td>Lucile Packard Children’s Hospital (US NEWS #6)</td>
<td>Social workers, chaplains, child life specialists, music therapists, physical therapists, occupational therapists</td>
<td>Family centered care, music therapy, kangaroo care, positioning of head</td>
<td>IV</td>
<td>Yes</td>
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<td>Rainbow Babies and Children’s Hospital (US NEWS #8)</td>
<td>Physical therapists, respiratory therapists, dieticians, developmental care specialist, occupational therapists</td>
<td>Family centered care, massage therapy, positioning of head, modified lighting, music therapy, kangaroo care</td>
<td>IV</td>
<td>Yes</td>
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<tr>
<td>Children’s Hospital Los Angeles (US NEWS #9)</td>
<td>Social workers, child life specialists, chaplains, dieticians, occupational and physical therapists</td>
<td>Family centered care, massage therapy, music therapy</td>
<td>IV</td>
<td>Yes</td>
<td>58</td>
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<tr>
<td>NICU</td>
<td>Members of Multidisciplinary Team</td>
<td>Developmental Care Offerings</td>
<td>Level of NICU</td>
<td>Associated Follow-Up Program</td>
<td>Number of Beds</td>
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<td>St. Louis Children’s Hospital (US NEWS #10)</td>
<td>Dieticians, social workers, speech therapist, physical and occupational therapists</td>
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<td>Brigham and Women’s Hospital</td>
<td>Speech language pathologists, physical and occupational therapists, dieticians, social workers</td>
<td>Kangaroo care, reading program</td>
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<td>Children’s National Hospital (US NEWS #1)</td>
<td>Dieticians, social workers, chaplains, child life specialists, developmental specialists</td>
<td>Modified lighting</td>
<td>IV</td>
<td>Yes</td>
<td>54</td>
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</table>