Caregiver/Speech-Language Pathologist Communication in the Neonatal Intensive Care Unit

by

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Abstract

Purpose: The purpose of the current investigation was to determine caregiver satisfaction with Speech-Language Pathologist's (SLP) communication in the Neonatal Intensive Care Unit (NICU), as well as the impact this communication has on caregiver stress.

Method: Primary caregivers of infants who endured a NICU stay in the past twelve months were invited to take a 48-item, web-based, nationally distributed survey. Eight caregivers met the inclusion criteria and completed the survey.

Results: The majority of participants indicated they were satisfied with their communication with their child's SLP and that communication with their child's SLP decreased their stress levels; however, areas for improvement were noted, such as availability and explanation of information in an understandable manner.

Conclusions: Findings from the current investigation are positive; however, they do reflect areas in which SLPs should focus their efforts. These include making efforts to coordinate their availability with caregiver visits as possible, as well as making every effort to explain information in caregiver-friendly language.

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List of Abbreviations

NICU Neonatal Intensive Care Unit

ASHA American Speech-Language and Hearing Association

AAP American Academy of Pediatrics

SLP Speech Language Pathologist

PT Physical Therapy

OT Occupational Therapy

VLBW Very Low Birth Weight

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Chapter 1: Introduction

Recent advances in neonatal care have increased survival rates in the Neonatal Intensive Care Unit (NICU; Stensvold et al., 2017). While the medical aspects of preterm infants' health and well-being are certainly still at the forefront of the minds of parents and healthcare providers, the increase in survival rate of preterm birth increases the need for high-quality care from healthcare providers that impacts the infants' wellbeing long-term. As infants born preterm are at an increased risk for developmental delays, therapy services such as physical therapy (PT), occupational therapy (OT), and speech language pathology (SLP) are part of a number NICU teams that service the infant during their stay in order to decrease the impact of the delay and the risk of onset (Jacobs et al., 2013; Jansson et al., 2004; Vohr, Coll, & Oh, 1988). These teams help the infant to not only survive, but also improve developmental outcomes.

Parents of preterm infants experience psychological distress which negatively influences the mental health of not only the mother and/or father, but the family as a whole (Shaw, Bernard, Storfer-Isser, Rhine, & Horwitz 2013). Primary caregivers, especially the mother, experience decreased interactions with their infant due to NICU hospitalization. This can have costly effects on the infant's development in early life as well as the mother's psychological well-being (Shaw, Bernard, Storfer-Isser, Rhine, & Horwitz 2013). Caregivers in the NICU report feeling confused about their role in their infant's care due to communication breakdowns between themselves and healthcare providers, and they are often uncomfortable visiting their infants for fear that they may cause them distress, leading to both stress and depression (Orzalesi & Aite, 2011). It is important that the caregivers know that while they may not be healthcare providers, they

can be provided with strategies to interact with their infants in a way that helps them developmentally. In order to provide caregivers with this information, it is vital that there is an open line of communication between healthcare providers and the caregivers.

As specialists in communication, SLPs are in a unique position to use their areas of expertise not only to treat their clients, but also to ensure that communication between themselves and their client (or the client's caregiver) is clear and understood. NICU SLPs are in an increasingly unique position in that their communication to the caregivers of infants in the NICU can hold a wealth of important medical information regarding the infants' health status and well-being. While it is not a requirement for SLPs to be present in NICUs (even the higher levels of NICUs), it is reported by the American Speech-Language Hearing Association (ASHA) that NICU care is within the SLPs' scope of practice. The role of the SLP in this setting involves not only the feeding and swallowing therapy, but also advocacy. SLPs are equipped to provide strategies that the caregivers, family members, and healthcare providers can use in the NICU to improve the infants' feeding/swallowing development as well as speech and language development. SLPs are also able to educate parents and family members about the impact the current environment and health status may have on preterm infants' swallowing, speech, language, and cognition development later in life and provide them with resources to reduce the effects of the potential delay, including recommendations for early intervention services.

Previous research has explored the communication that occurs between caregivers and doctors/nurses in the NICU, as well as the communication between both school-based SLPs and caregivers and SLPs who provided care to young children with language

disorders and their caregivers (Wigert, Dellenmark, & Bry, 2013; Tambyraja, Schmitt, & Justice, 2017; Porter, 2015). In each of these studies between all populations, it was reported that while communication was mostly satisfactory, there were some weaknesses that would have improved communication between the caregiver and the healthcare professional (Wigert, Dellenmark, & Bry, 2013; Tambyraja, Schmitt, & Justice, 2017; Porter, 2015). This relationship has yet to be explored between SLPs and caregivers in the NICU setting. Communication with caregivers plays an important role in family-centered care. Could clear communication potentially decrease the stress experienced by caregivers in the NICU? This research study will evaluate the current state of communication between SLPs and caregivers in the NICU from the caregiver perspective via a survey administered to caregivers who have recently undergone the NICU experience.

Chapter 2: Review of the Literature

This chapter describes literature relevant to the research purposes of the thesis. It is organized in the following sections: 1.) The Neonatal Intensive Care Unit (NICU); 2.) NICU Outcomes; 3.) Intervention and the Role of the SLP in the NICU; and 4.) Family-Centered Care.

The Neonatal Intensive Care Unit (NICU)

The NICU provides specialized medical services to newborns at high risk for medical complications. This includes infants who were born prematurely, infants with very low birth weight (VLBW), infants with respiratory distress, and infants with other birth defects that endanger their lives. In the United States, nearly eight percent of infants are admitted into the NICU (Harrison & Goodman, 2015). In the NICU, infants receive intensive care for immediate medical needs, such as respiration and maintaining proper vitals, and receive services from a multitude of healthcare professionals. In the United States, all NICUs Level III and above are required to provide medical doctors, nurses, and a physical therapist or occupational therapist. Additional services are available in some higher level NICUs but are not required by the American Pediatric Association (American Pediatric Association, 2015). The two most common medical reasons for NICU admission are prematurity and low or VLBW and are further discussed in the following sections.

Prematurity

Annually, approximately 15 million infants are born preterm worldwide (Liu et al., 2016). According to the CDC's National Vital Statics Report on Births, preterm births account for approximately 1 in 10 of all United States births (2018). This trend has been

continuing upward since 2014 (CDC, 2018). Most of these infants are cared for in NICUs. An infant is considered preterm if born before 37 weeks' gestation. Infants born premature have a number of health complications because they have not had the opportunity to fully develop in the womb prior to birth. Health risks include irregular heart rate, respiratory malfunction, irregular body temperature, increased risk of infection, and much more (World Health Organization, 2018). These fragile infants require constant monitoring and care.

Many factors contribute to the risk of preterm birth. Certain maternal populations such as mothers under the age of 18, mothers who have delivered previous pregnancies preterm, mothers with multiple gestations (twins, triplets, etc.), use of assisted reproductive technology, and women with certain reproductive abnormalities are at a higher risk of delivering preterm (Martin, Hamilton, Osterman, & Driscoll, 2018). Medical conditions during pregnancy may also increase risk of preterm delivery, such as the presence of sexually transmitted infections, high blood pressure, developmental abnormalities of the fetus, non-normal weight, short time period between pregnancies, and diabetes (Martin, Hamilton, Osterman, & Driscoll, 2018 Other contributing factors for a high risk preterm birth include smoking, drinking alcohol, use of illegal drugs, domestic violence, and stress (Martin, Hamilton, Osterman, & Driscoll, 2018).

Very Low Birth Weight (VLBW)

Babies are considered VLBW if they weigh under 3 lbs, 4 oz at birth. The leading cause for VLBW is prematurity; typically, the earlier the gestation the infant is born at, the lower the infants' weight will be. However, prematurity is not the only cause of VLBW; other populations are also at risk. Risk factors for VLBW include race (African

American populations are more likely to have VLBW infants), age (teen mothers are more likely to have VLBW infants), multiple births due to increased risk for prematurity, and maternal health (Martin, Hamilton, Osterman, & Driscoll, 2018). Infants who are VLBW have a variety of concerns that result in their NICU stay, including increased risk of infection, hypothermia, hypoglycemia, respiratory problems, asphyxia, impaired nutrition, and many more medical factors (Martin, Hamilton, Osterman, & Driscoll, 2018). While risks and symptoms are similar to those of premature infants, VLBW infants are not necessarily premature, but still high risk.

Outcomes Associated with NICU Stay

The time spent in the NICU is very stressful for both parent and infant. NICU stays are associated with increased risks of negative outcomes for both the infant and caregivers. The following section will explore the relationship between NICU stays and outcomes for infants as well as parents, both in the NICU and after discharge.

Infant Outcomes

There is a strong connection between NICU stays and outcomes in a child's development. Many milestones including weight gain, cognitive development, and language development are impacted by an extended period of time in the NICU (Blackburn, 1998). While a number of factors may impact how severely these outcomes are delayed, early intervention may decrease the impact of the NICU stay on development (Yoshinaga-Itano, 2003; Nordhov et al., 2010; Spittle & Treyvaud, 2016). The amount that early intervention may assist is also dependent on factors such as age at which therapy began, amount of time spent in therapy, and therapy techniques used (Orton, Spittle, Doyle, Anderson, & Boyd, 2009; Harding, Levin, Crossley, Murphey, &

Engel-Hoek, 2019; Paul & Roth, 2011). This section will explore the natural outcomes following discharge from the NICU as well as how the NICU environment affects those outcomes.

Post-Discharge Outcomes. Following discharge from the NICU, infants continue to face a number of challenges. However, these challenges may be impacted (positively or negatively) by factors during their NICU stay. Throughout the early developmental stages, children who stayed in the NICU show a number of delays or deficits when compared to their peers. Most notably (and often of most concern to doctors and parents alike), is the child's nutrition.

Feeding. Feeding after NICU discharge is a challenge not only for the parent, but for the infant as well. In a 2013 systematic review of 10 studies focused on infant oral feeding at discharge, Ross and Browne noted two main themes across the literature: preterm infants were frequently discharged with remaining feeding difficulties (e.g., coordination difficulties, not fully orally feeding); and 2.) the preterm infants with shorter gestation periods achieve full oral feeding later than longer gestation periods. While this certainly has an impact on the nutrition and growth of the infant, this may have an impact on the general health of the infant as well. One study noted that preterm infants 23-32 weeks had frequent unwell pediatric visits that resulted in a high number of prescriptions (Wade et al., 2008). While this study did not compare the infants to typically developing peers, the data presented expressed the high frequency for visits and prescriptions.

Cognitive Development. Due to most brain growth, development, and networking occurring during the last 6 weeks of gestation, cognitive impairment is the most common and severe disability in preterm infants (Adams-Chapman, 2006; Bhutta, Cleves, Casey,

Cradock, & Anand, 2002). In fact, prevalence of cognitive delay is significantly higher than that of other post-discharge outcomes discussed throughout this section (Delobel-Ayoub et al., 2009; Latal, 2009). While the survival rate in this population is increasing, so is the rate of adverse neurodevelopmental outcomes (Arpino et al., 2010). Early intervention services have been known to improve the child's cognitive development and decrease the impact of this prevalent delay (Achenbach, Howell, Aoki, & Rauh, 1993; Nordhov et al., 2010; McCormick et al., 2006). Recent studies demonstrate that the level of care and management of symptoms in the NICU also have a direct impact on cognitive outcomes (Hintz et al., 2005; Ehrenkranz et al., 2006).

Though the gestational age of the infant is likely what causes the cognitive delays later in life, it has been evidenced that NICU care can impact the extent of these delays. In 2006, Ehrenkranz et al. completed a research study that examined the effects of growth in the NICU on cognitive outcomes post-discharge When toddlers were examined between 18- and 22-months adjusted age, it was discovered that children who had higher in-hospital growth velocity performed better on neurodevelopmental measures (Ehrenkranz et al., 2006). A separate study observed cognitive development in preterm infants with Necrotizing Entercolitis (NEC), a complication which places the infant at even higher risk of cognitive delay (Hintz, et al., 2005). In this study, it was found that infants who had surgically managed NEC had a less severe cognitive impact later in life than those who had medically managed NEC while in the NICU (Hintz, et al., 2005). In general, better management of preterm complications in the NICU predicts the likelihood and severity of delays in cognitive development.

Hearing. Infants who have stayed in the NICU greater than 5 days are at a high risk for hearing loss (JCIH, 2019). Infants who have received care in the NICU represent approximately 10% of the newborn population; this population has been evidenced to have a higher prevalence of hearing loss compared to infants from well-baby nurseries (Robertson et al., 2009; Vohr et al., 2000). In a 2005 study, it was found that 24% of the infants' hearing tested in the NICU who failed ABR unilaterally or bilaterally passed OAE testing, indicating the necessity for using both measures to screen hearing abilities (Berg, Spitzer, Towers, Bartosiewicz & Diamond, 2005). As of 2019, the Joint Committee on Infant Hearing (JCIH) recommends use of two technologies in order to adequately screen for infant hearing loss in the NICU-AABR and OAE. However, screening for the infants' hearing abilities in the NICU alone is not enough. The need for continued, post-discharge care for infants' hearing was indicated in a study that retested infants who passed their hearing screenings in the NICU (Yoon, Price, Gallagher, Fleisher, & Messner, 2003). Throughout this research, eighty-two children who had stayed in the NICU were retested during the first two years of their life. Although these children passed their initial screening in the NICU, the retesting revealed that 37% had unilateral abnormal tympanometry, 29% had bilateral abnormal tympanometry, indicating hearing impairments (Yoon, Price, Gallagher, Fleisher, & Messner, 2003). Also worth noting is that children who have stayed in NICUs are more likely to have otitis media, which can affect speech and language because it impairs the ability to hear and process speech sounds (Berman, Balkany, & Simmons, 1978).

Speech and Language. Beyond the impactful cognitive effects that can occur, a NICU stay can also affect a child's speech and language development. Language-based

learning disabilities occur in at approximately 50% of premature survivors (Aylward, 2002; Grunau et al., 2002; Hille et al., 1994). It has been evidenced by multiple studies that prematurity alone (independent of gender, SES, and IQ) increases the likelihood for delayed receptive and expressive language skills and reading skills when the infant matures to school age (Lee, Yeatman, Luna, & Feldman, 2011; Smith, DeThorne, Logan, Channell, & Petrill, 2014). Research has also supported that the degree of prematurity (factors including how premature and the weight of the infant) positively correlates with the degree of the language and reading deficits, and thus poorer performance in school (Lee, et al., 2011; Chyi, Lee, Hintz, Gould, & Sutcliffe, 2008). However, these language delays are evident before school-age, even at infancy. In their 2012 study, Key, Lambert, Aschner, and Maitre (2012) found that brain maturity at birth impacts speech sound perception in infants in the first four months of life. In this study, the researchers recorded auditory event-related potentials in response to syllables in premature infants before they were discharged from the NICU, which revealed that a greater gestational age and postnatal age resulted in better speech sound processing and sound discrimination. These early skills are key for language development later in life. Research has also analyzed abilities for grammatical and phonological working memories after preterm birth. It has been supported that preterm birth affected these abilities until 3.5 years of age (Sansavini, et al., 2007). The same study further investigated the role of this working memory on grammatical development in preterm children, which found that there is a strong relationship between phonological working memory and grammar unless there was a compensatory effect by maternal level of education (Sansavini, et al., 2007).

Impact of NICU Environment. While the outcomes infants face due to their NICU stay are likely to have an impact on their lives, there are certain factors that can influence these outcomes. Namely, one of these factors is the NICU environment in which they stayed. While every NICU seeks to support and enhance the infants' health, there are four different levels of NICUs that provide scaffolded levels of support, as well as a multitude of designs that the NICU can select to use.

NICU Level. The different levels of NICUs provide more support in ascending order. In the United States, the AAP has outlined a policy statement that defines the levels as follows: Level I (well newborn nursery), Level II (special care nursery), Level III (neonatal intensive-care unit), Level IV (regional NICU; Committee on Fetus and Newborn, 2012).

Level I units are able to resuscitate at delivery, provide postnatal care to healthy infants, provide care for infants born between 35- and 37-weeks' gestation, and care for unstable infants or infants who were born before 35-weeks' gestation until transportation can be provided (Committee on Fetus and Newborn, 2012). While infants in this level of unit can still be considered unstable, they are in less critical condition than infants in higher-level NICUs.

Level II units hold the same responsibilities as Level I with additional abilities to provide care for moderately ill infants born before 32 weeks' gestation, provide mechanical ventilation for less than 24 hours, and stabilize infants born before 32 weeks' gestation until transportation can be provided to an appropriate facility (Committee on Fetus and Newborn, 2012). Similarly to Level I NICUs, these infants are not yet

considered to be in “critical condition”; however, they are more medically unstable than infants who are in level 1 units.

Including all responsibilities from Levels I and II, Level III NICUs are required to have pediatric surgeons, provide sustained life support, provide care for infants born before 32 weeks’ gestation, provide care for all infants with critical infants, provide care from subspecialists such as pediatric surgery, pediatric anesthesiology, and pediatric ophthalmology, provide respiratory support, and provide imaging and interpretation services (Committee on Fetus and Newborn, 2012). While Level III NICUs are able to care for any infant in critical condition, one more level does exist.

Level IV NICUs can also located in an institution that can perform surgeries for congenital conditions on-site and facilitate transport to and provide outreach education for NICUs (Committee on Fetus and Newborn, 2012). Being the highest level of NICU, Level IV NICUs provide care to the most critical infants. These NICUs are typically in large hospitals with easy access to surgical teams, which are commonly consulted for the infants in Level IV care.

Setting. While the level of the NICU is an important factor in the infants’ stay, the environment in which they are kept for an extended period of time after their birth is also greatly impactful on their outcomes. The most notable settings include single room and open-bay designs.

The single room design is the most intimate layout; mothers are in a single hospital room in with the crib with their infant. While this seems like the ideal design for the infant, these rooms actually lead to more stress for mothers and isolate the infant from other noises, leading to decreased language exposure for the infant (Rand & Lahav,

2014). However, this environment does improve the infants' hearing health as the noise level caused by ambient noises such machines and constant rotations of nurses and healthcare services is drastically decreased (Rand & Lahav, 2014).

When one thinks of a NICU, open-bay designs are often the layout that comes to mind. In this design, infants are placed in a crib in one large room filled with a number of beds (dependent on the NICU, there may be as little as 10 beds or up to over 100 beds). There are no walls or panels separating the infants. While this more open design allows for more exposure to language (healthcare teams speaking, parents speaking to other infants, etc.), it also allows for more ambient noise (as noted previously) that leads to greater distress for the infants and can potentially harm the infants' hearing (Rand & Lahav, 2014).

There is no research at present available regarding the impact of the environment on some of the other outcomes beyond communication and hearing noted in *2.2.1* (such as cognition and feeding), which may be explored in future studies. However, it is clear that no design is perfect; ultimately, each design has some negative outcome on the infants who stay in them, especially regarding communication and hearing.

Caregiver Outcomes

NICU stays are associated with high levels of psychological and emotional distress. Previous research has evidenced that both acute stress disorder and posttraumatic stress disorder are present in parents whose infants have spent time in a NICU (Shaw, et al., 2006; Holditch-Davis, Bartlett, Blickman, & Miles, 2003). Parents of children who have endured a NICU stay are also more likely to develop maternal or paternal Postpartum Depression (Lefkowitz, Baxt, & Evans, 2010). A number of factors,

including length of NICU stay, NICU environment, education in the NICU, and interaction with the infant can influence the occurrence and severity of these negative outcomes (Thomas & Martin, 2000; Pineda et al., 2012; Holditch-Davis, Bartlett, Blickman, & Miles, 2003; Dudek-Shriber, 2004).

Stress. In 2006, Shaw and colleagues asked forty parents of infants who have been in the NICU to complete a survey to self-report factors of acute stress disorder. It was evidenced that the prevalence of acute stress disorder in this population was 28%, which is the same prevalence rate as development of acute stress disorder after a traumatic event. There are also reports that all mothers of infants who stayed in the NICU in their study experienced posttraumatic stress symptoms (even if just one symptom), and severity of the child's illness was directly related to severity and number of posttraumatic stress symptoms (Dudek-Shriber, 2004; Holditch-Davis, Bartlett, Blickman, & Miles, 2003). In 2010, Lefkowitz, Baxt, and Evans reported that 35% of mothers and 28% of fathers of infants in the NICU met criteria for a diagnosis of acute stress disorder 3-5 days after their infant's admission into the NICU. Thirty days later, 15% of mothers and 8% of fathers met criteria for a posttraumatic stress disorder diagnosis (Lefkowitz, Baxt, & Evans, 2010). Worth noting is a study that detailed the way the parents handle stress that is experienced during a NICU stay. In this study, mothers of premature infants were given a questionnaire to assess acute stress disorder and posttraumatic stress disorder coping, which revealed that improper coping mechanisms played a large role in the development of acute stress disorder and posttraumatic stress disorder in mothers (Shaw, Bernard, Storfer-Isser, Rhine, & Horwitz, 2013). Further research has evidenced that a number of environmental factors negatively impacted parental stress while in the NICU,

including high sound levels in the NICU and NICU rooming type (Thomas & Martin, 2000; Pineda et al., 2012).

However, another study compared environmental factors to parent role alteration factors. This study evidenced that while the environmental factors were impactful, the aspects that have the largest negative influence on parental stress in the NICU related to the parents' inability to care for their child, both due to education and medical needs (Chourasia, Surianarayanan, Adhisivam, & Bhat, 2013). Examples of parental role alteration factors that parents reported increased stress include "Being separated from my baby", "Not feeding my baby myself", "Not being able to care for my baby myself", "Feeling helpless about how to help my baby during this time" and "Feeling that staff is closer to my baby than I am" (Chourasia, Surianarayanan, Adhisivam, & Bhat, 2012). For each of these examples, the parents do not feel as though they are the agent for their children's health, which is most often the case in typical births. Further research has supported that parents felt guilty for being unable to make decisions for their infant with minimal support, which adds another layer of stress (Petteys & Adoumie, 2018). Moreover, this stress has a direct impact on family functioning, increasing debt, financial worry, and social isolation while decreasing safety of the home environment and likelihood of maintaining relationship with a partner (Lakshmanan et al., 2017).

Depression. While stress poses a larger risk to parents in the NICU, many parents with infants in the NICU also endure depression. In 2010, Lefkowitz, Baxt, and Evans found that 39% of parents (both mothers and fathers) of infants who had an extended NICU stay met criteria for a positive screening for postpartum depression (PPD). Beyond this, 16.9% of the remaining mothers showed enough symptoms for

subsyndromal PPD (Lefkowitz, Baxt, & Evans, 2010). While PPD can occur to any parent following a NICU stay, it is more likely to occur in the mother (Doering, Moser, & Dracup, 1999). Furthermore, certain elements increased the risk of PPD, including ethnicity, employment status, and education (Doering, Moser, & Dracup, 2000). Another study noted that PPD was most common among mothers of VLBW infants (Nagata, Nagai, Sobajima, Ando, & Honjo, 2003). In sum, occurrence of PPD is linked to increased levels of stress factors outside of the NICU.

While past research has focused on incidence and prevalence of PPD in parents of infants who have stayed in the NICU, current literature is working toward a solution. In an attempt to lessen the occurrence of PPD for parents in the NICU, a number of programs have been developed that can be administered by a plethora of healthcare workers to the parents during their children's NICU stays. These programs are formatted to help parents cope with the stress of their infant being in NICU, as well as other outside stressors. One study noted that simply journaling throughout the NICU experience was an effective and inexpensive method to decrease PPD and stress (Rabiepoor, Vatankhah-Alamdary, & Khalkhali, 2019). However, more complex programs focus on educating and working with the parents to reduce feelings of anxiety, which lead to depression. One such program, which has resulted in decreased postpartum depression in caregivers, is the Close Collaboration with Parents (CCP) intervention (Ahlqvist-Björkroth, Axelin, Korja & Lehtonen, 2019; Ahlqvist-Björkroth, S., Boukydis, Z., Axelin, A. M. & Lehtonen, L. 2017). Specifically, CCP aims to support parents in the NICU by educating NICU staff to 1) give specific feedback about the individual needs of the infant to the parent, 2) actively listen to parents about their perception of their infant

and work with the parent on the plan of care, 3) understand that each family is individual and thus decision-making may look different for each, and 4) incorporate parents into the daily care of their infant from admission through discharge and plan discharge in conjunction with them (Ahlqvist-Björkroth, Axelin, Korja & Lehtonen, 2019).

The Role of the SLP in the NICU

The goal of the NICU team is to improve and prevent as many of these potential negative outcomes-in both parents and infants-as possible. This is done through intervention in which the SLP can play a critical and multifaceted role, as outlined by ASHA (2004). Roles and responsibilities of the NICU-based SLP include identification and management of feeding and swallowing problems, as well as counseling to caregivers to promote current and future communication and cognition skills. It is important to note, however, that PT and OT services are much more widely used in the NICU than SLP services (Ross, Heiny, Conner, Spener, & Pineda, 2017). In fact, the American Academy of Pediatrics (AAP) guidelines state that all Level III and IV NICUs are required to have a PT or OT on staff. A recent study evidenced that in a Level IV NICU, all (100%) of infants in the NICU received PT and OT services, while only 51% received SLP services (Ross, Heiny, Conner, Spener, & Pineda, 2017). According to this study, while automatic orders were generated for PT and OT, SLPs received referrals on a case-by-case basis related to difficulty with feeding or swallowing (Ross, Heiny, Conner, Spener, & Pineda, 2017).

Feeding and Swallowing

While in the NICU, SLPs provide feeding and swallowing services to the infant, oftentimes along with a team of other specialized neonate healthcare providers. In order

to function on this team, the SLP must be able to identify infants that are at-risk for feeding and swallowing disorders, conduct and interpret informal/clinical and formal/instrumental assessments to determine if these disorders are present, provide intervention if they are present, and educate staff and parents about the implications and management of feeding and swallowing disorders in infants (ASHA, 2004). SLPs require specialized knowledge in etiologies that may alert them to potential feeding and swallowing disorders in the pediatric population, such as preterm birth, cerebral palsy, craniofacial or airway malformations, brain injury, etc. (ASHA, 2004; Dodrill & Gosa, 2015).

While the SLP plays an important role in the assessment, diagnosis, and parental education of these disorders, an even more notable role is intervention. In the NICU, SLPs provide feedings to infants in order to intervene. In recent years, SLPs have advocated for the focus of the feeding to shift from volume-driven to infant-driven (or cue-driven) feeding (Shaker, 2010; Shaker, 2012). In previous years (and even in some NICUs today), the culture of feedings is to bottle feed the infants a certain amount in order to increase their weight. However, as SLPs have slowly taken on larger roles in this setting, the shift to feedings that focus on the quality of the infants' eating from start to finish (and only feeding the infant when they cue/are hungry) has taken place. This supports not only the role SLPs play in intervention, but advocacy for changes as well. SLPs are required to have knowledge of the anatomy and proper functioning of structures required for feeding, and they are able to provide intervention during feedings that help infants better coordinate their feeding patterns (suck-swallow-breathe) and support a safer swallow (ASHA, 2004).

Communication

In addition to feeding and swallowing services, SLPs also play and important role in communication development for infants in the NICU. While this population does not yet intentionally communicate, the SLPs role is to identify and monitor behaviors that help determine whether communication deficits may be a risk for this infant. Behaviors SLPs can monitor include preverbal audition, recognition and attention to environmental noise, gestures, and vocal behaviors (ASHA, 2004). While intervention with the infant is likely not appropriate at this age and with the other, higher-order risks, being able to identify signs of communication disorders allows the SLP to educate and inform the parent of these potential risks and help the parents develop a type of "bedside therapy" as a way to provide speech stimulation to their infant in this speech-deprived environment.

Education and Counseling

Of the many roles of the SLP, the role of counseling and education is likely the most understated. The NICU is one of the most stressful environments for parents, and one of the best ways to reduce this stress is to provide education services regarding care for their infant and future implications. While it is the role of the entire healthcare team to provide education and counseling to the parents, it is the role of the SLP to educate both parents and staff on intervention and potential implications within the realm of speech therapy (ASHA, 2004). This includes the aforementioned topics (feeding, swallowing, and communication). Education for the parents includes informing them of: a.) current and future implications of the disorder that caused the infant's NICU stay, b.) ways they can interact with their infant to ameliorate the potential disorders or delays, c.) the

therapeutic interaction the SLP is having with their infant, and d.) the signs that their infant is ready and able to benefit from such interaction (ASHA, 2004). Counseling for the parents includes talking to them about concerns, working with them to decide a course of action for therapy, advocating for the infants and families, and providing resources for counseling outside the scope of practice of the SLP. It is the SLP's job to both educate and counsel in an ethical, family-centered manner that considers and adapts to the numerous potential cultures and family dynamics. Education for the staff from the SLP should result in the staff's understanding of the role of the SLP on the NICU team and implication of findings from assessments, which the SLP should communicate in a clear, professional manner (ASHA, 2004).

Family Centered Care

Family Centered Care has been extensively researched in the past few decades; however, in recent years, the approach has gained much attention due to research supporting that family-centered services across all healthcare professions and settings are beneficial in a number of ways for young clients (Clark et al., 1998; Clark et al., 2000; Denboba et al., 2006; Farmer, Sherman, & Selva, 2005; Jessop & Stein, 1994; Kuhlthau, et al., 2018; Mangione-Smith, 2005; Ngui & Flores, 2006; Wissow et al., 1998; Wolraich et al., 2005). The goal of family-centered care is to empower the caregivers to care and advocate for their infant by considering the needs of the infant in the context of their families (Burns, Dunn, Brady, Starr, & Blosser, 2012). Hence, the caregivers/family unit will be involved and considered during all portions of assessment and treatment in all healthcare professions who employ this strategy. This requires a constant open line of communication between the healthcare provider and the family.

Family-Centered Care in the NICU

Family-centered care was first proposed for use in the NICU environment in 1992 as a means to improve parental inclusion in decision-making and care for the infant admitted into the NICU (Harrison, 1993). This proposal was not specific to one healthcare field within the NICU; rather, it was suggested that all healthcare providers practice this strategy to address a number of parental concerns (Harrison, 1993). Since then, many (but not all) NICUs have made efforts to enact family-centered practice due to guidelines published by the Institute of Medicine in 2001 (Celenza, Zayack, Buus-Frank, & Horbar, 2017). Recent studies have shown that NICUs whose healthcare providers use family-centered care have reduced maternal anxiety, reduced length of NICU stays, reduced readmissions to the hospital, increased weight gain for LBW or VLBW infants, and improved maternal interactions with the infant (Pineda, et al., 2018; Gonya, Martin, McClead, Nelin, & Shepherd, 2014; Hane, et al., 2015, Neu, et al., 2020). A major aspect of family-centered care, however, is the communication between the caregiver and the professionals caring for the child. Thus, this is an important feature of family-centered care in the NICU as well.

Caregiver-Staff Communication. Communication between the healthcare provider and the caregiver is a key aspect of family-centered care and is therefore an important factor to consider in the NICU environment. Recent research has not only uncovered importance and benefits of good communication between doctors or nurses and the caregivers in the NICU, but also revealed the strengths and shortcomings in these conversations (Wigert, Dellenmark, & Bry, 2013). Oftentimes, caregivers believe that communication in the NICU falls short of their expectations (Mok & Leung, 2006).

In Wigert, Dellenmark, & Bry's 2013 research, "Strengths and weaknesses of parent–staff communication in the NICU: a survey assessment", (which the present study is modeled after), the authors administered a sixteen-question survey with questions regarding satisfaction, strengths, and weaknesses of communication between parents of infants in the NICU and their nurses and doctors. This survey was administered to 270 parents over the course of a year in a Level III NICU in Sweden, who rated their overall communication with their doctors and nurses in the NICU highly, but still offered critiques regarding areas that were lacking (Wigert, Dellenmark, & Bry, 2013). While emotional understanding and clarity of communication were a strength for the staff, over 20% of parents reported that "something was lacking" with nurses' and doctors' communication (Wigert, Dellenmark, & Bry, 2013). Participants were allowed to report strengths and weaknesses of this communication via a free-response question, which the authors reported based upon emotional support, information giving, professionalism, and organization (Wigert, Dellenmark, & Bry, 2013). There were strengths and weaknesses reported in each of these areas.

While "good communication" is certainly a subjective term depending on the needs of the caregivers, recent studies show that caregivers most often want emotional support, information about the status of their child's health, and to feel comfortable asking questions regarding care for their infant (Mok & Leung, 2006; De Rouck & Leys, 2009). While research is growing in this area, the majority of these studies are focused on NICU nurses and neonatal care doctors; thus, there is limited research available regarding the same relationships in communication between the SLP in the NICU and the caregiver. However, research is available regarding SLP communication with caregivers in

populations other than the NICU. One study examined caregiver perceptions of Caregiver-SLP communication regarding their child's language disorder via a semi-structured interview (Porter, 2015). This study evidenced that caregivers value diagnostic information about their infant that is "clear, concrete, and timely" using language without excessive jargon (Porter, 2015, p. 9). While this study did not examine overall caregiver satisfaction with Caregiver-SLP communication, many of the participants noted areas that they felt were weaknesses regarding the SLPs' communication, such as purpose and role of the SLP, establishing a shared meaning of the diagnosis, and in-depth education of their child's diagnosis (Porter, 2015). Furthermore, another study examined Caregiver-SLP communication in the School-Based setting by reviewing weekly communication logs (Tambyraja, Schmitt, & Justice, 2017). The findings indicated that some caregivers were never contacted/communicated with and that most communication was not via direct contact (but rather, homework). Additionally, SES level impacted frequency of SLP communication with higher SES resulting in increased communication frequency. Tambryraja and colleagues work (2017) also highlighted the importance of communication between the caregivers and their child's SLP as increased communication with the child's caregivers resulted in increased grammar gains throughout the school year. While these populations and the ways in which an SLP will communicate differ vastly from the NICU, the current literature shows that Caregiver-SLP communication is critical for improved speech and language outcomes and that there are also areas of SLP-Caregiver communication that can be improved. The importance of communication, as well as need for improvement in this area is also evident in the literature on Caregiver-Staff (nurses and doctors) communication in the NICU. While both areas of inquiry have

added greatly to the literature base, there are currently no studies on the topic of caregiver communication with SLPs specific to their child's NICU stay.

Justification

As evidenced in previous sections, the SLP is an important member of the NICU team. As such, they play an important role in communicating pertinent information about the infants' statuses to their caregivers. Beyond this, SLPs provide resources and education to these caregivers regarding how to best support their children's cognitive, linguistic, and feeding development post-discharge from the NICU. While this information can be overwhelming, providing it in a clear, concise manner can allow parents to leave the NICU with confidence in how to care for their child, which may reduce the stress that greatly impacts caregivers post-discharge from the NICU. However, since previous research has reported that SLPs in other populations and healthcare workers (nurses and doctors) in the NICU population have areas in which they may improve communication with caregivers, it is important to understand how well SLPs are communication with caregivers in the NICU and what caregivers feel could be improved.

The purpose of the present study is to describe strengths and weaknesses in caregiver/SLP communication in order to improve our understanding of caregivers' needs and to inform and improve SLPs practice patterns when communicating with caregivers in the NICU setting.

Specifically, the research aims to answer the following questions:

1. Do caregivers of infants receiving speech pathology services in the NICU report that provided services are family centered?

- Hypothesis: The majority of participants will report that services from the NICU SLP are family-centered since this is the standard of care; however, there will still be some SLPs who engage in child-centered care (Celenza, Zayack, Buus-Frank, & Horbar, 2017).

2. Are caregivers satisfied with SLP communication in the NICU?
    - Hypothesis: The majority of caregivers will be generally satisfied with SLP communication in the NICU. However, caregivers will still report areas for improvement in the strengths and weaknesses portion of the survey, indicating that not all aspects of SLP communication are ideal (Wigert, Dellenmark, & Bry, 2013)
3. Is there a relationship between caregiver satisfaction with SLP communication in the NICU and degree of family-centered care?
    - Hypothesis: There will be a positive relationship between caregiver satisfaction and degree of family-centered care. Caregivers who report stronger agreement with family-centered care statements will report higher satisfaction with SLP communication.
4. What specific areas of communication with the SLP do caregivers report as strengths and weaknesses
    - Hypothesis: Emotional support, information giving, and encouragement to participate in the care of their infants will be rated highly for SLPs who engage in family-centered care (Wigert, Dellenmark, & Bry, 2013). Weaknesses will include frequency of communication, descriptions of the role of the SLP in their child's care, and in-depth education about the

diagnosis (as opposed to the care for the diagnosis; Tambyraja, Schmitt, & Justice, 2017; Porter, 2015).

5. Does communication with SLP decrease caregiver's stress levels while in the NICU?
    - Hypothesis: The majority of caregivers will report that communication with their SLP decreased their stress levels during their NICU stay.

Chapter 3: Methodology

Participants

In order to participate in the study, the following inclusion criteria were required: primary caregivers of a child admitted to the NICU whose child received services from a speech-language pathologist during their stay. Exclusion criteria included: being under 18 years of age, a lack of fluency in English, a NICU stay in a country other than the United States, and a lack of presence during the child's NICU stay (e.g., participants would be excluded if they are an adopted parent who was not in the hospital at the time of birth.). If the participant had more than one infant in the NICU at separate times (i.e., not due to multiple births; months/years apart), he/she was asked to answer the questions based upon the most recent experience. Individuals who did not meet inclusion criteria or met exclusion criteria were taken to the end of the survey and thanked for their time.

Materials

To answer the research questions presented in Chapter 3, the researchers created a web-based, 48-item survey via Qualtrics software (See Appendix 1). Survey questions were developed based on a review of the literature pertaining to FCC and caregiver communication in the NICU (Wigert, Dellenmark, & Bry, 2013; Tambyraja, Schmitt, & Justice, 2017; Spinhoven et al., 1997; Trout, Tarazi, & Rodriguez, 2018). Specific survey questions addressed the following areas:

- Inclusion and Exclusion Criteria: These questions were used to qualify participants for the survey by indicating agreement with statements based on the aforementioned criteria.

- Demographic Information: These questions were used to determine background information about the participants, their children, and their time in the NICU. These explore general information such as sex, race, geographic location, etc. as well as information specific to the child's medical status and NICU stay, such as gestational age at birth, diagnosis, length of NICU stay, etc.
- Family Centered Care: These questions queried the SLPs' collaboration with caregivers to determine whether the care provided by the SLP in the NICU was family-centered or child-centered.
- Caregiver-SLP Communication Scale; These questions were used to assess the quality of communication between the SLP and the participants in the NICU using an adaptation of the Caregiver-Staff Communication Scale (Wigert, Dellenmark, & Bry, 2013). The scale was created by the original authors in accordance with research that outlined "good communication" with staff in the NICU from caregivers' perspectives (DeRouck & Leys, 2009; Bialoskurski, Cox, & Wiggins, 2002; Orzalesi & Aite, 2011). It was initially created to gather caregiver perspectives on communication with doctors and nurses in the NICU. The scale has been adapted with permission from the original authors to be appropriate for Caregiver-SLP communication in the NICU.
- Impact on Stress; This question was used to determine if interaction with the SLP impacted the caregiver's stress levels during the NICU stay using a self-report Likert-scale.

- Strengths and Weakness in Communication: These questions were free response and allowed the participants to voice opinion on strengths and weaknesses of the NICU SLP's communication.

Survey Conduction and Distribution

While technological advances have allowed for electronic surveys as well as larger-scale distribution and recruitment measures, they have also increased the probability that participants may ignore or fail to notice recruitment efforts (Dillman, Smyth, & Christian, 2014). In order to decrease these effects and improve the probability of obtaining responses, a number of cautions were observed during distribution.

Social Exchange Theory

According to social exchange theory, "people are more likely to comply with a request from someone else if they believe and trust that the rewards for complying with that request will eventually exceed the costs of complying" (Dillman, et al., 2014, p. 24). Thus, researchers must distribute electronic surveys in such a way that there are minimized barriers and maximized reward for respondents' completion. In order to implement this theory, the below procedures were followed in an attempt to improve the rate by which participants completed the survey.

Specific measures. The survey was distributed via social media support groups and email recruitment. In order to implement social exchange theory, a number of procedures were followed during dissemination. First, the associated message posted with the survey was relatively short and stated the purpose of the survey as well as appreciation for completion of the survey in order to establish trust (Dillman et al., 2014).

Another aspect of survey construction is dependent upon the reputability request for participation. According to social exchange theory, it is essential that participants trust all involved in conducting the research and do not believe that there are significant associated risks (Dillman et al., 2014). In order to build this rapport with the participants, once the survey was opened, a longer introduction message was provided with:

- a short introduction of the researchers,
- a more in-depth purpose of the survey,
- an assurance that the respondents' answers are confidential
- an assurance that the respondents may close the survey at any time,
- a time-estimate (provided by Qualtrics software) for survey completion, and
- a point of contact for respondents' questions or concerns.

Procedures

Prior to distribution, the survey was piloted with two SLPs employed in NICUs. Feedback was provided in order to improve the content, structure, and validity of the survey. Following approval from the Auburn University Institutional Review Board, participants were recruited by three methods. Initially, invitations were posted in five Facebook groups specifically for caregivers of children who had either stayed in the NICU or had medical diagnoses associated with NICU stays (e.g., Prematurity, CHARGE syndrome, Low/Very Low Birth Weight). Once a potential participant indicated interest by clicking on the provided link, they were taken to the survey. The information letter and indication of consent were provided as the first question.

In addition, a nation-wide search of public email addresses of Early Intervention Coordinators, Coordinators of NICU-specific online support groups, and hospitals with Level III and level IV NICUs was completed. Five hundred and eighty-two emails were sent to Early Intervention Coordinators, twenty-six emails were sent to coordinators of identified online support groups, and seventy-eight emails were sent to NICU administrators at hospitals with Level III and Level IV NICUs. EI coordinators, support group coordinators, and NICU administrators were asked to forward the email to potentially interested caregivers. Interested participants could then read the attached information letter and were taken to the survey upon indicating agreement with the statement "Click here to take the survey."

The survey was administered using the online survey tool Qualtrics, a secure Internet-based software program used for online survey development. All data was collected anonymously. Participants were informed that all responses are confidential, and that no personal identifying information was included in the computer-generated dataset other than the date and time they completed the online study.

Data Analysis

Survey responses were exported to an excel spreadsheet and SPSS Version 25 for analysis. To determine a mean response for each item, the responses for all individuals who answered a question were averaged. In cases where some participants chose not to respond to a question, the averages were calculated using the number of participants who responded to that item, as opposed to the number of participants who completed the survey. With regard to the relationship between caregiver satisfaction and communication, a Spearman rank-order correlation coefficient was used to investigate the

linear association between variables. This nonparametric measure was selected due to the small number of participants. With regard to qualitative data, *n*'s and percentages are provided for participant responses. Additionally, thematic analysis of written responses was utilized in order to identify common themes among participants.

Chapter 4: Results

Participants

A total of nineteen individuals indicated the survey. Of the participants who consented, eight participants completed the survey and met the inclusion criteria. Of the 11 participants who wer not eligible, the most commonly selected reason not being the primary caregiver of a child who had been in the NICU within the last 12 months (26.32%; *n* =5). Four participants (21.05%) indicated their child's NICU stay was outside the United States. Three participants (15.79%) reported their child did not work with an SLP while in the NICU. Three participants (15.79%) responded they did not visit their child in the NICU during their stay. It should be noted that the total number of these responses exceeds 11 because some caregivers were excluded for multiple reasons. Table 1 outlines responses to each inclusion/exclusion criteria item.

Table 1
Inclusion Criteria Responses

Criteria	**Yes** ***n* (%)**	**No** ***n* (%)**
You are 18 years of age or older	19 (100%)	0 (0%)
You are a primary caregiver of a child who has been admitted to the NICU within the last 12 months.	14 (73.68%)	5 (26.32%)
Your child's NICU stay was in the United States	15 (78.95%)	4 (21.05%)
You are fluent in English	19 (100%)	0 (0%)
During your child's stay in a NICU, they worked with a speech therapist	16 (84.21%)	3 (15.79%)
You visited your child in the NICU during their stay	16 (84.21%)	3 (15.79%)

Demographics of caregivers

With regard to the respondents' relationship as the primary caregiver to the NICU infant, the majority of participants (75%; *n* = 6) responded "mother;" while two participants (25%) reported "foster parent". The majority of participants' NICU stays occurred in the southern region of the United States (87.5%, *n*=7), while one participant's NICU stay occurred in the West (12.5%). The majority of respondents (87.5%; *n* = 7) indicated they were White. One respondent indicated they were Black or African American (12.5%). No caregivers indicated they were of Hispanic, Latino, or Spanish Origin. Participants were then asked how often they visited their infant in the NICU. Of the participants who responded to this question, all reported that they visited their infant in the NICU daily (100%, *n* = 8). Table 2 outlines caregiver demographics.

Table 2
Participant Demographics

Category	*n* (%)
Relationship	
Mother	6 (75%)
Father	0 (0%)
Grandmother	0 (0%)
Grandfather	0 (0%)
Aunt	0 (0%)
Uncle	0 (0%)
Cousin	0 (0%)
Non biologically related custodial caregiver	0 (0%)
Foster Parent	2 (25%)
Other	0%
Race	
White (only)	7 (87.5%)
Black or African American (only)	1 (12.5%)
Native American or Other Pacific Islander (only)	0 (0%)
Asian (only)	0 (0%)
American Indian or Alaska Native (only)	0 (0%)
Other or Mixed Race	0 (0%)
State of NICU Stay	
South	**7 (87.5%)**
Alabama	3 (37.5%)

Louisiana	1 (12.5%)
Tennessee	2 (25%)
Texas	1 (12.5%)
West	**1 (12.5%)**
Washington	1 (12.5%)
Frequency of Visit	
Less than once per week	0 (0%)
1-2 times per week	0 (0%)
3-4 times per week	0 (0%)
5-6 times per week	0 (0%)
Daily	8 (100%)

Note. N = 8; *n* = number of respondents; % = percentage of respondent

Demographics of infants

Participants were also asked demographic questions about their infant who stayed in the NICU. The majority were female (62.5%; n=5), while three were male (37.5%). Next, participants were asked to "select all that apply" with regard to the medical reason for their infant's NICU stay. The majority of respondents selected more than one medical diagnosis requiring their child's NICU stay (62.5%; *n*=5). With regard to primary reason for NICU admission, the majority indicated Prematurity (87.5%; n=7) and Low or Very Low Birth Weight (50%; *n*=4), while 25% (n = 2) indicated respiratory distress and Bradycardia, and 12.5% indicated "Other."

Parents were also asked to report their infant's gestational age at birth. The greatest number reported 28+0 - 33 weeks gestational age (62.5%; *n*=5), while two participants (25%) indicated less than 28 weeks, and 1 participant (12.5%) indicated greater than 37 weeks' gestation. Following this, parents were asked to indicate their child's weight at birth. The majority of respondents reported their child to be between 1000-2499 grams (2.2-5.5 lbs). Specifically, slightly over one-third of participants (37.5%; *n* = 3) reported their child to be 1000-1499 grams (2.3-3.3 lbs) and 1500-2499

grams (3.4-5.5 lbs) at birth. Additionally, one participant (12.5%) indicated their infant was less than 1,000 (2.2. pounds) grams and one additional participant indicated their child was greater than 2,499 grams (5.6 pounds)

Next, participants were asked the length of their infant's NICU stay. The majority (*n*=4; 50%) reported their stay was greater than 30 days, while over one-third of participants (37.5% *n* = 3) reported their stay was 15-30 days and 12.5% (*n* = 1) reported as stay of 3-7 days. Parents were also asked to report the time that has passed since discharge from the NICU. The largest number of participants (37.5%; *n* = 3) reported that it has been 1-3 months since discharge, while smaller numbers reported 4-6 months (25%; *n* = 2), 10-12 months (25%; *n* = 2) and 7-9 months (12.5%, *n* = 1). With regard to discharge care, the majority of parents reported their child was discharged home without neonatal care (75%; *n*=6). Additionally, one infant (12.5%) was sent home without neonatal care and one infant (12.5%) was discharged to the PICU. Table 3 displays infant demographics.

Table 3
Infant Demographics

Category	*n* (%)
Sex	
Male	3 (37.5%)
Female	5 (62.5%)
Reason for Admission to NICU	
Prematurity	7 (87.5%)
Low/Very Low Birth Weight	4 (50%)
Respiratory Distress Syndrome	2 (25%)
Bradycardia	2 (25%)
Sepsis/Infection	0 (0%)
Other (birth defect)	1 (12.5%)
Gestational Age at Birth	
Less than 28 weeks	2 (25%)
28+0 – 33 weeks	5 (62.5%)
33+1 – 37 weeks	0 (0%)
Greater than 37 weeks	1 (12.5%)

Weight at Birth	
Less than 1000 grams (2.2 lbs)	1 (12.5%)
1000-1499 grams (2.3-3.3 lbs)	3 (37.5%)
1500-2499 grams (3.4-5.5 lbs)	3 (37.5%)
Greater than 2499 grams (5.6 lbs)	1 (12.5%)
Length of NICU Stay	
1-2 days	0 (0%)
3-7 days	1 (12.5%)
8-14 days	0 (0%)
15-30 days	3 (37.5%)
Greater than 30 days	4 (50%)
Time Passed since Discharge	
Not yet discharged	0 (0%)
Less than one month	0 (0%)
1-3 months	3 (37.5%)
4-6 months	2 (25%)
7-9 months	1 (12.5%)
10-12 months	2 (25%)
Discharge Plan	
Home without neonatal home care	6 (75%)
Home with less than 24/7 neonatal home care	1 (12.5%)
Newborn nursery	0 (0%)
Different NICU level at other hospitals	0 (0%)
Pediatric ICU (PICU)	1 (12.5%)
Home with neonatal home care	0 (0%)
Other	0 (0%)

Note. N = 8; *n* = number of respondents; % = percentage of respondents

Family-Centered Care in the NICU

Using a five-point Likert scale, caregivers were asked to rate their agreement with statements querying their SLP's use of FCC practices during their child's NICU stay. To do so, numbers were assigned to each point on the scale (1-5; 1=strongly disagree, 5=strongly agree; see Appendix 1, question 13). Of the eight participants, all eight responded to statements 1, 2, 3, and 5. However, it should be noted that only seven participants responded to statement 4. The majority of participants agreed or strongly agreed with each statement; however, three participants (37.5%) did not agree that their child's SLP sought out their input for their child's care. Additionally, two participants

(28.5%) reported that they neither agreed nor disagreed that their child's SLP took their family dynamic (including culture, language, ethnicity, and structure) into account when planning treatment. Table 4 illustrates average ratings by question.

Table 4
FCC by Item

FCC Item	Strongly agree *n* (%)	Somewhat agree *n* (%)	Neither agree nor disagree *n* (%)	Somewhat disagree *n* (%)	Strongly disagree *n* (%)
1. I worked with the speech therapist while creating goals for my child's speech	5 (62.5%)	2 (25%)	0 (0%)	0 (0%)	1 (12.5%)
2. The speech therapist asked for my ideas and input for my child's care	3 (37.5%)	2 (25%)	1 (12.5%)	1 (12.5%)	1 (12.5)
3. I took part in my child's speech therapy sessions (rather than watched).	4 (50%)	4 (50%)	0 (0%)	0 (0%)	0 (0%)
4. My family dynamic (including culture, language, ethnicity, and structure) was considered by the speech therapist during therapy	2 (28.6%)	3 (42.8%)	2 (28.6%)	0 (0%)	0 (0%)
5. The speech therapist listened to my concerns when working with my child	3 (37.5%)	5 (62.5%)	0 (0%)	0 (0%)	0 (0%)

In order to assess the overall level of FCC for each respondent, scores were averaged across the five questions for each participant, with higher numbers indicating higher overall FCC. FCC would be considered high with an average score of 4 or above as this indicates agreement or strong agreement. FCC would be considered moderate if

the average score was a 3 as this indicates neither agreement nor disagreement. FCC would be considered low with average scores of 2 or below as that indicates disagreement or strong disagreement. All participants reported some level of FCC during their infant's stay in the NICU; however, the degree varied between participants. The majority of participants (87.5%, *n*=7) averaged a score greater than or equal to 4, indicating a high degree of FCC; one participant (12.5%) averaged a score of 3, indicating a moderate degree of FCC. See Table 5 for results.

Table 5
FCC by Participant

Participant	Mean FCC Score
Participant 1	3
Participant 2	4.75
Participant 3	4
Participant 4	4
Participant 5	4.6
Participant 6	4
Participant 7	4.8
Participant 8	4.2

Caregiver Satisfaction with Communication in the NICU

Similarly, to the determining degree of FCC, in order to determine degree of caregiver satisfaction with SLP communication in the NICU, caregivers were asked to rate their experiences with SLP communication across eight questions, which were adapted from the Parent-Staff Communication Survey (Wigert, 2013). Results from this section were quantified by assigning a number to each point on the scale (1-5; 1 indicating lowest level satisfaction or most difficulty with communication, 5 indicating highest level satisfaction rating or easiest communication; See Appendix 1, questions 14-21). The majority of respondents indicated satisfaction with each item related to

communication with their child's SLP. It should be noted, however, that 3 participants (37.5%) were neutral with regard to their satisfaction with their conversations with their child's SLP. Additionally, one participant (12.5%) reported dissatisfaction with each of the following areas: being given answers from the SLP that were easy to understand, being given instructions that were easy to understand, understanding of the caregiver's emotional situation, and encouragement to participate in their child's care. See Table 6 for results.

Table 6
Communication Satisfaction by Item

Item	**Score 5** ***n*** **(%)**	**Score 4** ***n*** **(%)**	**Score 3** ***n*** **(%)**	**Score 2** ***n*** **(%)**	**Score 1** ***n*** **(%)**
	"Very well"	*"Fairly well"*	*"Neither well nor poor"*	*"Fairly poor"*	*"Very poor"*
How well do you feel the speech therapist gave you ways to help your child outside of therapy?	4 (57.1%)	3 (42.9%)	0 (0%)	0 (0%)	0 (0%)
How well do you feel that the speech therapist you talked to understood your emotional situation?	4 (50%)	3 (37.5%)	0 (0%)	1 (12.5%)	0 (0%)
How well did you feel the speech therapist encouraged you to participate in caring for your child?	5 (62.5%)	2 (25%)	0 (0%)	1 (12.5%)	0 (0%)
	"Yes, always easy"	*"Yes, usually easy"*	*"Neither easy nor difficult"*	*No, usually difficult*	*No, always difficult*
Were the answers you received from the speech therapist easy to understand?	5 (62.5%)	1 (12.5%)	1 (12.5%)	1 (12.5%)	0 (0%)
Were the instructions/information given by the speech therapist about the care of your child easy to understand?	4 (50%)	3 (37.5%)	0 (0%)	1 (12.5%)	0 (0%)

	"Very easy"	*"Fairly easy"*	*"Neither easy nor difficult"*	*"Fairly difficult"*	*"Very difficult"*
How easily did you and the speech therapist communicate?	4 (50%)	3 (37.5%)	1 (12.5%)	0 (0%)	0 (0%)
	"Yes, always"	*"Yes, usually"*	*"Yes, sometimes"*	*"No, not usually"*	*"No, never"*
Did the speech therapist answer your questions?	3 (37.5%)	3 (37.5%)	1 (12.5%)	1 (12.5%)	0 (0%)
	"Very satisfied"	*"Fairly satisfied"*	*"Neither satisfied nor dissatisfied"*	*"Fairly dissatisfied"*	*"Very dissatisfied"*
How satisfied are you with the conversations you have had with your speech therapist?	3 (37.5%)	2 (25%)	3 (37.5%)	0 (0%)	0 (0%)

Furthermore, in order to assess the level of communication satisfaction overall for each respondent, scores were averaged across the eight questions for each participant, with higher numbers indicating higher overall satisfaction. Satisfaction would be considered high with an average score of 4 or above as this indicates agreement or strong agreement. Satisfaction would be considered moderate if the average score was a 3 as this indicates neutrality. Satisfaction would be considered low with average scores of 2 or below as that indicates disagreement or strong disagreement. Degree of satisfaction varied between participants. The majority of participants (n=5; 62.5%) averaged a score greater than or equal to 4, indicating a high degree of satisfaction. The remaining three participants (37.5%) averaged a score of 3-3.5, indicating a moderate degree of satisfaction. See Table 7 for results.

Table 7
Caregiver Satisfaction by Participant

Participant	Mean Satisfaction Score
Participant 1	3.5
Participant 2	5
Participant 3	4
Participant 4	3.5
Participant 5	5
Participant 6	4.5
Participant 7	5
Participant 8	3

Following these questions, caregivers were asked if they felt something was missing from SLP communication in the NICU. Caregivers could select from "yes" or "no". The majority of participants (*n*=5; 62.5%) responded "no". The three (37.5%) participants who selected "yes" were asked a follow-up, free response question. They were asked "What did you feel was missing in communication with your speech therapist?". The caregivers who responded to this query noted a need for education with regard to feeding, a lack of availability, and a desire for more personalized care. See Table 8 for individual responses.

Table 8
What was missing in SLP Communication?

Participant	Response
Participant 1	"Education on the safety and equivalent types of bottles/nipples that were similar to the ones I already had at home, and how to use those when I got home."
Participant 4	"She was never available when my husband visited."
Participant 8	"My oldest was a preemie so they took advantage of that knowing I knew a lot but every child is different so I wish I couldn't been more personal than it was."

Relationship between FCC and Caregiver Satisfaction

A Spearman's rank-order correlation was used to determine the relationship between degree of FCC and degree of caregiver satisfaction with SLP communication in the NICU. For each participant, the mean FCC score was compared to the mean satisfaction score (see Table 9). There was a strong, positive correlation between FCC and caregiver satisfaction with SLP communication, which was statistically significant ($r_s(8) = .669$, $p = .032$). This indicates that higher degree of FCC correlates with higher degree of caregiver satisfaction with SLP communication in the NICU.

Table 9
FCC and Caregiver Satisfaction with SLP Communication

Participant	Mean FCC Score	Mean Satisfaction Score
Participant 1	3	3.5
Participant 2	4.75	5
Participant 3	4	4
Participant 4	4	3.5
Participant 5	4.6	5
Participant 6	4	4.5
Participant 7	4.8	5
Participant 8	4.2	3
Mean of all Participants:	4.2	4.2

Strengths and Weaknesses of SLP Communication

Caregivers were asked to express their perception of strengths and weaknesses of SLP communication in the NICU via two open-ended, free-response questions. Caregivers were first asked “Please describe strengths of communication with the speech therapist in the NICU.” Four participants answered this question. While a common theme was not identified among participants’ responses specific to communication three out of

the four participants who responded indicated a positive experience interacting with their infant's SLP during feeding.

Caregivers were then asked, "Please describe weaknesses of communication with the speech therapist in the NICU." Five participants chose to respond to weaknesses of SLP communication. Two participants reported "none" for weaknesses. A common theme, lack of availability, emerged from three participants responses. See Table 10 below for individual participants' responses.

Table 10
Strengths and Weaknesses

Participant	Strengths	Weaknesses
Participant 1	"[SLP] was always very nice and allowed me to feed my baby after she was done with her assessment."	"[SLP] was hardly ever there when I was visiting (at night)"
Participant 2	No response	No response
Participant 3	No response	No response
Participant 4	No response	"[SLP] was not available at all times."
Participant 5	"Tried my home bottles."	"None"
Participant 6	"[SLP was] available for meetings about my child when I was visiting, easy to get in contact with."	"[SLP was] not available on the weekends, only part time."
Participant 7	"[SLP] showed me best way to feed my baby"	"NA"
Participant 8	No response	No response

SLP Communication and Caregiver Stress

Finally, caregivers were asked to report the impact that SLP communication had on their stress during their child's NICU stay. The majority of participants reported a decrease in stress (62.5%; n=5). Of those who reported a decrease in stress, four reported a slight decrease (50%), while one participant noted a great decrease in stress (12.5%; n=1). Only one participant selected that communication with the SLP in the NICU greatly

increased stress (12.5%), while two respondents noted no impact on stress (25%; See Table 11).

Table 11
SLP Communication Impact on Caregiver Stress

Participant	Impact on Stress
Participant 1	Greatly increased stress
Participant 2	Slightly decreased stress
Participant 3	Slightly decreased stress
Participant 4	Slightly decreased stress
Participant 5	Greatly decreased stress
Participant 6	Slightly decreased stress
Participant 7	No impact on stress
Participant 8	No impact on stress

Chapter 5: Discussion

The main purpose of this study was to determine caregiver satisfaction with Speech-Language Pathologist's (SLP) communication in the Neonatal Intensive Care Unit (NICU). Caregiver's perceptions of strengths and weaknesses of SLP communication were also examined to determine how SLPs can better serve their clients and their clients' families. It was hypothesized that caregivers whose SLPs engaged in FCC would be more satisfied with communication with their SLP than those who did not. Furthermore, it was hypothesized that strengths of SLP communication would include emotional support, information giving, and encouragement to participate in the care of their infants (Wigert, Dellenmark, & Bry, 2013). Weaknesses were suspected to include frequency of communication, descriptions of the role of the SLP in their child's care, and in-depth education about the diagnosis (Tambyraja, Schmitt, & Justice, 2017; Porter, 2015). Caregivers indicated that they are more satisfied with SLP's communication when SLPs engage in FCC. Caregivers also noted SLP communication strengths to include positive experiences with feeding which involved encouragement to participate in care of infants. Finally, caregivers indicated that SLP weaknesses include their limited availability which aligns with both frequency of communication and description of the role of SLP in the child's care.

Family Centered Care in the NICU

The first study hypothesis was evidence supported. The majority of caregivers reported receiving FCC from their SLPs while their child was in the NICU; however, some participants still reported care to be child-centered. As noted in the results, the majority of participants (87.5%, n=7) averaged a score greater than or equal to 4, which

indicated agreement that their SLPs engaged in FCC practices. This aligns with previous research as well as literature that reports that FCC is now the standard of care in healthcare, both in hospitals- especially in the NICU (Celenza, Zayack, Buus-Frank, & Horbar, 2017; Crawford et al., 2002; Griffen, 2006), as well as other settings such as private practices, school systems, and home health early intervention that service a variety of populations (Christson & Meyers, 2018; Mandak and Light, 2018; Carpenter, 2018).

While this is a positive finding it should be noted that three participants did not agree that their child's SLP sought out their input for their child's care. Additionally, two participants reported that they neither agreed nor disagreed that their child's SLP took their family dynamic into account when planning treatment. These findings indicate that while FCC is being implemented, there are still areas of improvement necessary in the NICU. Also, while FCC is the standard of care, there are still SLPs who do not fully participate in FCC. This evidences the need for a more standardized approach to engaging in FCC in the NICU as well as self-assessment on the part of the SLP. One example of a potential self-assessment tool is the Measure of Processes of Care for Service Providers (MPOC SP; Woodside, Rosenbaum, King, & King, 1998). The MPOC SP is designed for pediatric service providers to determine the degree to which the services they provide are family centered. Self-reflection is critical to professional growth and best practice. Use of a validated instrument such that the MPOC SLP, will allow SLPs to examine their use of strategies of FCC within their service delivery and draw their attention to areas which would benefit from increased attention.

Caregiver Satisfaction with Communication

The second hypothesis is evidence supported. All caregivers reported satisfaction with the SLPs communication in the NICU. However, as noted in the results section of this paper, there were participants who were either neutral or dissatisfied with specific items on the satisfaction portion of the survey. Three participants were neutral with regard to their satisfaction with their conversations with their child's SLP. Participants also noted dissatisfaction regarding being given answers from the SLP that were easy to understand, being given instructions that were easy to understand, understanding of the caregiver's emotional situation, and encouragement to participate in their child's care. This aligns with previous research that studied caregiver communication both from SLPs in other healthcare settings (Tambyraja, Schmitt, & Justice, 2017; Porter, 2015) and nurses and physicians in NICUs (Wigert, Dellenmark, & Bry, 2013). This evidences that while generally caregivers report satisfaction, there are areas of communication SLPs in the NICU can improve. SLPs should take special care with the delivery of information to caregivers so that it conveyed in a caregiver friendly manner. As SLPs are specialists in communication, SLPs are in a unique position to both treat their clients and also make certain the communication with clients and their families is clear and understood. NICU SLPs are in an increasingly unique position in that they are typically conveying large amounts of medical information regarding the infants' health status and well-being. This can be daunting for caregivers who are already experiencing a high level of stress Therefore it is critical that SLPs should make every effort to look for signs of whether the information was understood and clarify as needed. Furthermore, while SLPs are likely repeating this information daily, the caregiver is potentially hearing this information for

the first time. Providing printed handouts of this information as references for the caregiver to consult when the SLP is unavailable may increase effectiveness of communication. Caregivers may use these handouts to support verbal instructions, thus enhancing communication.

Relationship between FCC and Caregiver Satisfaction

The third hypothesis of this study was evidence supported. There was a significant positive correlation between caregiver satisfaction with SLP communication and the degree of FCC implemented. As open communication with caregivers is an integral part of FCC this finding is not unexpected. The relationship between communication and FCC aligns with previous research and literature that has noted that FCC results in better healthcare service overall for children with special healthcare needs (Kuhlthau, et al., 2018), especially regarding communication (Clark et al., 1998; Clark et al., 2000; Jessop & Stein, 1994; Wissow et al., 1998; Wolraich et al., 2005) and satisfaction with services (Denboba et al., 2006; Farmer, Sherman, & Selva, 2005; Mangione-Smith, 2005; Ngui & Flores, 2006)..

This result highlights the importance of implementing FCC practices across healthcare settings-especially in the NICU. SLPs should engage the family in conversations about their child and shape therapy to the whole family's needs rather than just the child's needs. This includes engaging in conversations regarding culture, expectations, and family dynamic. Deeper conversations with family members will result in improved engagement from the family in therapy and better rapport between the family and the SLP, which are important factors in therapy outcomes.

Strengths and Weaknesses of SLP Communication

The fourth hypothesis for this study was supported by the evidence. The comments made by participants with regard to feeding management indicated that they were being given information effectively (e.g., what bottle to use), emotional support (e.g., being "nice"), and encouragement to participate in their child's care (e.g., allowing caregiver to feed their child after therapy). This finding aligns with previous research, as it has been noted that these aspects of communication are all strengths in caregiver-staff communication in the NICU (Wigert, Dellenmark, & Bry, 2013).

With regard to weaknesses in communication, the majority of respondents indicated that SLPs were not available to caregivers. A lack of availability will impact the hypothesized weaknesses: frequency of communication, descriptions of the role of the SLP, and in-depth education about the diagnosis. If an SLP is not regularly interacting with caregivers they will likely not be communicating as frequently as caregiver's desire, nor describing their role as SLP, which can be easily misunderstood. Additionally, an in-depth education on their child's diagnosis related to communication and or swallowing will not occur when the SLP is not present. Based on these premises, the weakness of availability does align with the previous literature (Tambyraja, Schmitt, & Justice, 2017; Porter, 2015).

It is therefore necessary for SLPs to align their sessions to align with the caregivers visits to the degree they are able. Communicating directly with the caregiver will allow for necessary caregiver education, as well increase the caregiver's understanding of the role of the SLP. It also indicates the necessity for SLPs to have collaborative relationships with the NICU staff. While SLPs are often not available for

night shifts, for example, NICU nurses are trained in feeding infants and can often answer questions parents have. If they are unable to answer these questions, or these questions fall outside the nurses' scope of practice, they can communicate to the caregivers when an SLP will return for therapy or be available for questions.

Another solution to this issue is to expand hours of care provided by SLPs in the NICU. While SLPs advocate to be considered vital team members for these infants' care, it can be difficult to support this claim when unavailable for around-the-clock care. Current standards in the field are that full-time SLPs work weekdays during typical business hours, while PRN SLPs (who are often not the main SLP on a child's case) are available on weekends and holidays. However, it may be useful for full-time SLPs to be available in the evenings to provide this standard of care and meet caregiver communication needs.

SLP Communication and Caregiver Stress

The final hypothesis of the study is evidence supported. The majority of participants reported that communication with their SLP decreased their stress; however, one participant noted that the SLPs communication increased their stress. NICU stays are a stressful time for caregivers, especially because they are often unable to physically be with their child and because they are unsure of the many specialists the child is seeing and the child's prognosis. While previous studies have indicated strategies to reduce caregiver stress in the NICU (Chourasia, Surianarayanan, Adhisivam, & Bhat, 2012; Petteys & Adoumie, 2018; Turan, Babakkal, & Ozbek, 2008), this study is the first to examine how SLPs' communication impacts stress in the NICU. SLPs can be a large factor in ameliorating these stress levels, as evidenced by this study; however, they can

also be associated with increased stress as one participant noted. It is therefore critical that SLPs stay up to date on the literature related to stress management in caregivers so that they are applying evidence-based strategies in their interactions with caregivers, such as using easily understood language, communicating in a timely manner, reassuring caregivers, and providing updates on their child's progress and prognosis (Chourasia, Surianarayanan, Adhisivam, & Bhat, 2012; Day, 2019; Petteys & Adoumie, 2018; Turan, Babakkal, & Ozbek, 2008).

Strengths, Limitations, and Future Directions

While previous studies have examined caregiver satisfaction with physician/nurse communication in the NICU, caregiver feedback for school-based SLPs' communication, and caregiver-SLP communication strategies, this is the first study examining caregiver satisfaction with SLP communication in the NICU. Additionally, the Caregiver-Staff Communication Scale (Wigert, Dellenmark, & Bry, 2013), a peer-reviewed, published survey instrument was used to assess caregiver satisfaction with SLP communication thereby increasing the validity of the current findings. This research provides the first glimpse into ways that SLPs can improve their communication with caregivers in the NICU.

A primary limitation of the current investigation is the sample size. While inclusion criteria responses provide some insight as to the reduced response rate despite extensive efforts to obtain participants, there are outside factors that may have contributed. Previous research has evidenced that SLPs are not routinely included in NICU care (CITE), and a low percentage of SLPs work in NICUs (CITE). While three eliminated participants reported they did not work with an SLP in the NICU, it is likely

that a much wider population preemptively chose to not participate in the study, as the recruitment statements noted that the infant must have worked with an SLP while in the NICU. Additionally, the majority of participants were White, which is not representative of the racial/ethnic population found in neonatal intensive care. It is worth acknowledging that inclusion criteria for participation in the survey (e.g., speaking English, NICU stay within the United States) may have resulted in bias toward White, monolingual respondents. Both of these factors limit the generalizability of the findings. Furthermore, a survey effect is always possible when conducting survey research. Those who responded to the survey may have had specific interest in this topic due to notable experiences with SLPs (whether good or bad). Results may therefore be either over or under representative of caregiver perspectives on communication with their child's SLP.

Future research should explore caregiver satisfaction with SLP communication in the NICU through recruitment of a much larger, more representative population. Furthermore, while the survey format is beneficial as a first step to better understand SLP communication in the NICU, qualitative interviews with parents may reveal would be helpful to examine the lived experience with regard to caregivers' perspectives of SLPs in the NICU.

Conclusions and Clinical Implications

The findings of this study can be used to inform future clinical practice for SLPs in the NICU. Regarding FCC, SLPs should ensure that they regularly communicating with caregivers and incorporating the families' wants, needs, and dynamics into therapy. SLPs should use the responses from these conversations to create family-centered goals that improve healthcare for the child both within the hospital and when the child is

discharged home. Engaging in FCC in this way also allows for open lines of communication between the SLP and the caregiver.

With regard to availability, SLPs should make every effort to schedule sessions when the caregiver is visiting, but this may not be logistically possible. Unlike many hospital staff (e.g., nurses, physicians), SLPs are not available 24/7. Often SLPs are only available on the weekdays. However, this is a choice within the field. Providing more flexible hours (working weekends, evenings, etc.) will likely provide caregivers with improved communication and improve care for the infant. Because these changes may be difficult to implement quickly, ensuring the caregiver has the SLPs direct contact information so that they can reach out to them with questions will be very important. Furthermore, when the SLP is not able to be on the NICU floor when the caregiver is, the SLP should offer (but not push) an alternative meeting format, such as a Zoom meeting or telephone call. Also of importance is building a collaborative relationship with the NICU staff as they will most likely see parents more than SLPs and will need to be kept abreast of the infant's current status so that they can answer questions the caregiver may have and also communicate caregiver questions/concerns to the SLP.

Finally, the SLP should consider how their communication can impact caregiver stress in the NICU. While this study did not collect specific data regarding *why* SLPs' communication increased or decreased caregiver stress levels, it is still important to note that SLPs may play a role in increasing or decreasing caregiver stress. SLPs should acknowledge their contribution to caregiver stress in the NICU and remain informed of evidence-based practices that can ameliorate stress. By acknowledging the SLPs role in stress, it becomes apparent that SLPs should communicate in an empathetic manner with

caregivers. Acknowledging stress, discussing the cause of the stress, and communicating in a clear and timely manner can ease caregivers who are handling an emotionally and physically taxing experience. If the caregivers' stress is secondary to being anxious/concerned about their child's development (especially speech and language) or feeding their child, it is well within the scope of practice for the SLP to counsel caregivers. By providing this education, caregivers may better understand their child's prognosis, and thus some stress may be reduced. In order to follow through with these approaches, it is important that SLPs read literature that discusses stress management strategies. While it's most applicable to read and implement a resource regarding how SLPs should manage caregiver stress in the NICU, these resources are currently limited. In order to have a better understanding of the current research and how to manage these situations, SLPs should seek out information regarding how SLPs can help manage caregiver stress (in general, not just in the NICU), how healthcare providers (in general, not just SLPs) can decrease caregiver stress in the NICU, and general stress management strategies between healthcare providers and clients.

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Appendix 1: Survey Instrument

Inclusion Criteria

1. Please indicate your agreement with the following statements.

	Yes	No
I am 18 years old or older.	o	o
You are a primary caregiver of a child who has been admitted to the NICU within the last 12 months.	o	o
Your child's NICU stay was in the United States.	o	o
You are fluent in English.	o	o
During your child's stay in the NICU, they worked with a speech therapist (aka Speech-Language Pathologist, SLP).	o	o
You visited your child in the NICU during their stay.	o	o

Demographic Information

2. On average, how often did you visit your child in the NICU?
   - o less than once per week
   - o 1-2 times per week
   - o 3-4 times per week
   - o 5-6 times per week
   - o Daily

3. Which of the following best describes your roll as primary caregiver?
   - o Mother
   - o Father
   - o Grandmother
   - o Grandfather
   - o Aunt
   - o Uncle
   - o Cousin
   - o Non biologically related custodial caregiver
   - o Foster parent
   - o Other: _____

4. In what state was your child's NICU stay?

▼ Alabama (1) ... Wyoming (50)

5. Are you of hispanic, Latino, or Spanish origin?

- Yes
- No

6. What is your race? (Select all that apply)

- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Other

7. Why was your child admitted to the NICU? (Select all that apply)

- Prematurity
- Low or Very Low Birthweight
- Respiratory Distress Syndrome (RDS)
- Bradycardia
- Sepsis/Infection
- Other: _____

8. What was your child's gestational age at birth?

- less than 28 Weeks
- 28+0 - 33 Weeks
- 33+1 - 37 Weeks
- greater than 37 Weeks

9. About how much time has passed since your child's discharge from the NICU?

- 10-12 months
- 7-9 months
- 4-6 months
- 1-3 months
- less than 1 month
- Not yet discharged

10. Please estimate the length of your child's NICU stay.
    - 1-2 days
    - 3-7 days
    - 8-14 days
    - 15-30 days
    - greater than 30 days
    - Not yet discharged (please state the number of days your child has been in the NICU at present):_____

11. If your child has been discharged from the NICU, where was he/she discharged to?
    - Home without neonatal home care
    - Home with 24/7 neonatal home care
    - Home with less than 24/7 neonatal home care (Please state number of hours per week)
    - Newborn Nursery
    - Different NICU level at other hospitals
    - Pediatric Intensive Care Unit (PICU)
    - Other:_____

12. What was your child's weight at birth?
    - less than 1000 grams (2.2 lbs)
    - 1000-1499 grams (2.2-3.3 lbs)
    - 1500-2499 grams (3.4-5.5 lbs)
    - greater than 2499 grams (5.6 lbs)

Family-Centered vs/ Child-Centered Care

13. Please rate your agreement with the following statements with regard to your interaction with your child's SLP during their NICU stay.

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
I worked with the speech therapist while creating goals for my child's speech therapy	o	o	o	o	o
The speech therapist asked for my ideas and input for my child's care.	o	o	o	o	o
I took part in my child's speech therapy sessions (rather than watched).	o	o	o	o	o
My family dynamic (including culture, language, ethnicity, and structure) was considered by the speech therapist during therapy.	o	o	o	o	o
The speech therapist listened to my concerns when working with my child.	o	o	o	o	o

Communication

The following 9 questions were adapted from the Parent-Staff Communication Survey to assess satisfaction with SLP communication in the NICU. Adapted and reprinted by permission of the original author, Helena Wigert. Research © 2013.

14. How well do you feel the speech therapist gave you ways to help your child outside of therapy?

- Very well
- Fairly well
- Neither well nor poor
- Fairly poor
- Very poor

15. How satisfied are you with the conversations you have had with your speech therapist?

- Very Satisfied
- Fairly Satisfied
- Neither satisfied nor dissatisfied
- Fairly dissatisfied
- Very dissatisfied

16. How easily did you and the speech therapist communicate?

- Very easy
- Fairly easy
- Neither easy nor difficult
- Fairly difficult
- Very difficult

17. Did the speech therapist answer your questions?

- Yes, always
- Yes, usually
- Yes, sometimes
- No, not usually
- No, never

18. Were the answers you received from the speech therapist easy to understand?

- Yes, always easy
- Yes, usually easy
- Neither easy nor difficult
- No, usually difficult
- No, always difficult

19. Were the instructions/information given by the speech therapist about the care of your child easy to understand?

- Yes, always easy
- Yes, usually easy
- Neither easy nor difficult
- No, usually difficult
- No, always difficult

20. How well do you feel that the speech therapist you talked to understood your emotional situation?

- Very well
- Fairly Well
- Neither well nor poor
- Fairly poor
- Very poor

21. How well did you feel the speech therapist encouraged you to participate in caring for your child?

- Very well
- Fairly well
- Neither well nor poor
- Fairly poor
- Very poor

22. Was something missing in communication with the speech therapist?

- Yes
- No

23. What did you feel was missing from your communication with the speech therapist?

Stress

24. What impact did communication with your child's speech therapist have on your stress during your child's NICU stay?

- Greatly decreased stress
- Slightly decreased stress
- No impact on stress
- Slightly increased stress
- Greatly increased stress

Strengths and Weaknesses of SLP Communication in NICU

25. Please describe strengths of communication with the speech therapist in the NICU.

26. Please describe weaknesses of communication with the speech therapist in the NICU

27. How was the speech therapist helpful to you?

Appendix 2: Information Letter
Auburn University
Department of Speech, Language, and Hearing Sciences

(NOTE: DO NOT AGREE TO PARTICIPATE UNLESS IRB APPROVAL INFORMATION WITH CURRENT DATES HAS BEEN ADDED TO THIS DOCUMENT.)
INFORMATION LETTER
for a Research Study entitled
"Caregiver/Speech-Language Pathologist Communication in the Neonatal Intensive Care Unit"

You are invited to participate in a research study to determine the strengths and weaknesses of communication between speech-language pathologists and caregivers in the NICU setting. The study is being conducted by Rachel Jenkins, a graduate student in the Auburn University Department of Speech, Language, and Hearing Sciences, under the direction of Dr. Allison M. Plumb, Associate Professor in the Auburn University Department of Speech, Language, and Hearing Sciences. You are invited to participate because you are a caregiver of a child who was admitted to the NICU and are age 18 or older.

What will be involved if you participate? Your participation is completely voluntary. If you decide to participate in this research study, you will be asked to complete a 39-item survey via Qualtrics software that will assess your personal experience with the SLP in the NICU. Your total time commitment will be approximately 10 minutes.

Are there any risks or discomforts? The risk associated with participating in this study is the possibility that the answers to the survey may be intercepted between the participant's computer and Qualtrics.com. To minimize these risks, we will collect all data anonymously and all answers to survey questions are de-identifiable.

Are there any benefits to yourself or others? If you participate in this study, you can expect to help speech-language pathologists who work in the NICU better understand how they can improve their communicate with caregivers. We cannot promise you that you will receive any or all of the benefits described. Benefits to others may include better information made available to speech-language pathologists who work in the NICU.

Will you receive compensation for participating? There is no compensation for completing this survey.

Are there any costs? There are no costs associated with this survey with the exception of approximately 10 minutes of your time to complete the survey.

If you change your mind about participating, you can withdraw at any time by closing your browser window. Once you've submitted anonymous data, it cannot be withdrawn since it will be unidentifiable. Your decision about whether or not to participate or to stop participating will not jeopardize your future relations with Auburn University or the Department of Speech, Language, and Hearing Sciences.

Any data obtained in connection with this study will remain anonymous. We will protect your privacy and the data you provide by NOT asking for any identifiable information. Information collected through your participation may be used to fulfill an educational requirement, be published in a professional journal, or and/or presented at state or national conferences.

If you have questions about this study, please contact Rachel Jenkins at rmj0017@auburn.edu or Dr. Allison Plumb at amp0016@auburn.edu.

If you have questions about your rights as a research participant, you may contact the Auburn University Office of Research Compliance or the Institutional Review Board by phone (334) 844-5966 or e-mail at IRBadmin@auburn.edu or IRBChair@auburn.edu.

HAVING READ THE INFORMATION ABOVE, YOU MUST DECIDE IF YOU WANT TO PARTICIPATE IN THIS RESEARCH PROJECT. IF YOU DECIDE TO PARTICIPATE, PLEASE SELECT "YES, I WISH TO PARTICIPATE IN THE STUDY". YOU MAY PRINT A COPY OF THIS LETTER TO KEEP.

Thank you for your time,

Rachel Jenkins, Graduate student in Speech, Language, and Hearing Sciences

Allison M. Plumb Ph.D., CCC-SLP

The Auburn University Institutional Review Board has approved this document for use from September 16, 2020 to ---------. Protocol # 20-444 EX 2009, Jenkins