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Neonatal Intensive Care Unit Speech-Language Pathologists' Perceptions of Infants with
Neonatal Abstinence Syndrome

A thesis

presented to

the faculty of the Department of Audiology and Speech-Language Pathology
East Tennessee State University

In partial fulfillment of
the requirements for the degree

Master of Science in Speech-Language Pathology

by

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August 2019

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Keywords: neonatal abstinence syndrome, infants, feeding and swallowing, neonatal intensive
care unit, speech-language pathologist

ABSTRACT

Neonatal Intensive Care Unit Speech-Language Pathologists' Perceptions of Infants with Neonatal Abstinence Syndrome

by

Lauren E. Fabrize

Objective: The purpose of this study was to determine the characteristics, assessment, and treatment of infants with Neonatal Abstinence Syndrome (NAS) as perceived by Speech-Language Pathologists (SLP) and whether it differed from those of other Neonatal Intensive Care Unit populations.

Methods: A secure web-based questionnaire with 62 questions collected information on NAS, caseloads, treatment environment, and demographics. Twenty-six respondents initiated the survey; 42% completed most or all questions. Response analyses included descriptive and nonparametric inferential statistics.

Results: Infants with NAS were on the caseloads of 73% of respondents. The majority (79%) only saw infants with NAS and feeding problems. Primary problems included incomplete or increased time to complete feeds, increased/excessive/irregular sucking rates, and reflux.

Working on teams, respondents provided assessment, treatment, and education of infant feeding and state.

Conclusion: Growing demand for SLP intervention with infants with NAS is likely to persist if opioid use continues to increase as projected.

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Romans 12:12 - Philippians 4:13 - Psalm 40

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CHAPTER 1

INTRODUCTION

Every 15 minutes, an infant experiencing opioid withdrawal is born as a consequence of the current opioid epidemic in the United States of America (Honein, Boyle, & Redfield, 2019). As the number of women who use drugs while pregnant has risen, so has the incidence of neonatal abstinence syndrome (NAS) in their infants. “Neonatal abstinence syndrome (NAS) is a postnatal drug withdrawal syndrome that occurs primarily among opioid-exposed infants shortly after birth” (Ko et al., 2016, p. 799). This study aims to determine the characteristics, assessment, and treatment of infants with NAS as perceived by speech-language pathologists (SLPs) and whether it differs from their perceptions of other NICU populations. The anticipated result of this study is to identify how SLPs can best serve infants with NAS in the neonatal intensive care unit (NICU) and whether intervention differs from that of other NICU populations.

Statement of the Problem

The incidence of NAS in the United States of America increased 383% from 2000 to 2012 (Ko et al., 2016) with a prevalence of 7.3 per 1,000 births totaling 27,315 cases in 2013 (Brown, Doshi, Pauly, & Talbert, 2016). This increase in the number of infants born with NAS led to the inclusion of a new population on the caseloads of SLPs who work in NICUs. SLPs’ knowledge base and skill set of early intervention and feeding enable them to play a key role in the treatment of infants with NAS in the NICU.

There is a dearth of research regarding the role of the SLP in both the assessment and treatment of infants with NAS. There is also a lack of evidence regarding the specific nature of the feeding problems and characteristics of infants with NAS (LaGasse et al., 2003; Maguire, Rowe, Spring, & Elliott, 2015). There is, however, some evidence about the feeding

characteristics of infants diagnosed with NAS that indicates they are hard to feed, tend to overeat, and demonstrate excessive sucking (LaGasse et al., 2003). There is limited research evidence at the level of detail needed to provide SLPs with specifics about these infant's feeding characteristics as it pertains to clinical practice. As a result, there is no widely-accepted evidence on the feeding characteristics of infants with NAS nor how to assess or treat their specific feeding difficulties. Current practices derived from the treatment methods for feeding premature infants may not necessarily inform best practice for infants with NAS, but it is a starting point. Research is required to determine what current SLP practice is with infants with NAS and whether it differs from that of other infant NICU populations. This exploratory, descriptive survey research aims to determine the characteristics, assessment, and treatment of infants with NAS as perceived by SLPs and whether it differs from their perceptions of other NICU populations.

CHAPTER 2

REVIEW OF THE LITERATURE

Neonatal Abstinence Syndrome

NAS may occur following birth when infants are no longer receiving the opioids, such as morphine, codeine, heroin, fentanyl, buprenorphine, methadone, or oxycodone, upon which they became dependent in utero. This sudden discontinuation can lead to symptoms of withdrawal in the infant in the days and weeks following birth (Hudak & Tan, 2012; Jansson, Velez, & Harrow, 2009; Kocherlakota, 2014).

Characteristics of NAS

Nervous system disruptions to both the central and autonomic systems, as well as gastrointestinal, respiratory, metabolic, and vasomotor system disruptions, are characteristic of NAS (Logan, Brown, & Hayes, 2013). In particular, disruptions that impact respiration regulation, latching, sucking, swallowing, and digestion affect feeding. Other characteristics include behaviors such as inconsolable and excessive high-pitched crying, increased irritability and agitation, reduced quality and length of sleep following a feeding, excessive sweating, and frequent sneezing (Kocherlakota, 2014). Feeding can be impacted in infants with NAS due to characteristics such as frantic rooting, ineffective latching, uncoordinated and excessive sucking, longer sucking bursts, uncoordinated breathing, apneic and uncoordinated swallow, nasal regurgitation during and post feeding, reflux, and projectile vomiting (Gewolb, Fishman, Qureshi, & Vice, 2004; Goetz & Rolloff, 2012; LaGasse et al., 2003).

Etiology

Due to the water-soluble, lipophilic nature, and low molecular weight, opiates are able to cross the lipid membrane and enter the placenta (Greig, Ash, & Douiri, 2012; Kocherlakota,

2014). However, placental transfer rates are affected by the nature of the opioid (Reynolds, 1987). Studies show semisynthetic drugs (e.g., oxycodone, heroin, hydrocodone, buprenorphine) have more difficulty permeating the placental membrane than synthetic drugs (e.g., methadone, fentanyl) (Kocherlakota, 2014; Szeto, 1993). Polarization properties of opioids also influence placental transfer; therefore, a highly polar opioid like morphine, crosses at a slower rate than other opioids (Reynolds, 1987). Furthermore, gestational age and transmission are positively correlated; that is, transmission increases with the increase in gestational age (Kocherlakota, 2014). When there is a combination of opioids, like heroin and methadone, it increases the permeability of the methadone across not only the placenta but the blood-brain barrier as well (Lind et al., 2017; Malek, Obrist, Wenzinger, & von Mandach, 2009).

The pathophysiology in neonatal withdrawal more complex due to the infant's early stage of neurologic development. Once the opioid permeates the blood-brain barrier, its prolonged half-life can exacerbate the withdrawal process of infants (Kocherlakota, 2014; Malek et al., 2009). In utero, these infants' neuroreceptors were chronically stimulated by the opioids their mothers used. The withdrawal of opioids following birth that these infants experience results in altered production of neurotransmitters. Depending on the specific opioid or polysubstance exposure, decreases can occur in serotonin and dopamine, and increases can occur in the production of acetylcholine, corticotrophin, also in serotonin, and, most influentially in infants with NAS, norepinephrine/noradrenaline (Kocherlakota, 2014). The different symptoms that the infants with NAS experience stem from these neurotransmitters and neuroreceptor changes. For example, lower serotonin levels can lead to the sleep disruptions many infants with NAS experience (Kocherlakota, 2014). Current speculation is that the feeding difficulties noted in infants with NAS more likely results from neurological dysregulation rather than from the

immaturity more commonly seen in premature infants (K. Shaker, personal communication, August 15, 2018).

Substance Exposure and Detection

Infants with NAS may display different symptoms based on factors such as their exposure to specific substances, the length of exposure, when they were last exposed, their metabolic rates, birth weight, and gestational ages. Symptoms may begin within the first seventy-two hours after birth but can take up to five days to appear (Hudak & Tan, 2012).

Infants are at risk for and may experience NAS if they are prenatally exposed to natural, synthetic, semi-synthetic opioids, or polysubstance exposure (LaGasse et al., 2003).

Polysubstance exposure occurs when the mother uses two or more substances at the same time (one of which is typically an opioid) or sequentially while the infant is in utero (United Nations Office on Drugs and Crime, 2014). Infant development of NAS is unpredictable, and estimates vary widely across studies. Kocherlakota (2015) reports that 22–67% of infants present with NAS when there is a history of maternal buprenorphine use, 40-80% when there is a history of heroin use, and 13-94% when there is a history of methadone use. No relationship has been found between NAS and the mother's opioid dose (Kocherlakota, 2015). Studies have reported no relationship between maternal buprenorphine or methadone dose and the severity of the infant's NAS (Jones et al., 2012; Kraft, Stover, & Davis, 2016; Shah et al., 2016).

When there is suspected opioid substance use, misuse, or abuse by the mother, a number of toxicology screenings can be performed on mothers and infants. These tests can confirm if the infant has been exposed to any substances, especially opioids, in utero. Once exposure is confirmed, it is necessary to determine if the infant is demonstrating symptoms of withdrawal, as

not all infants who have been exposed in the womb are diagnosed with NAS (Hudak & Tan, 2012).

Behavioral Assessment of NAS

Most commonly, the full *Finnegan Neonatal Abstinence Score Tool* (FNAST) (Finnegan & Kaltenbaach, 1992) or the modified *Finnegan Scale* (Jansson et al., 2009), standardized scoring systems, determine the severity of an infant's withdrawal process by dynamically scoring disturbances of the central nervous system, vasomotor, respiratory, metabolic, and gastrointestinal systems. This assessment is given every three to four hours in a twenty-four-hour period, typically within an hour of a feeding. If an infant scores an eight or higher, consecutively across three administrations, or greater than 12 across two consecutive administrations, pharmacological treatment may be considered for the infant (Gomez-Pomar et al., 2017; Logan et al., 2013). Both of the Finnegan assessment tools are objective and validated with strong inter-user reliability (Gomez-Pomar et al., 2017). These are the most widely used assessments across the United States of America for NAS. However, without a standard protocol recommended across medical associations, the tool used for evaluating these infants varies somewhat from hospital to hospital.

There are also other physiological and behavioral assessments available and in use. The *Lipsitz Neonatal Drug-Withdrawal Scoring System* (Lipsitz, 1975), like the FNAST, also determines the severity but conversely, it does so in a subjective manner but, is recommended by the American Academy of Pediatrics (Jansson et al., 2009). The *Neonatal Narcotic Withdrawal Index* (NNWI) (Green & Suffet, 1981) also scores the symptoms of the infant in order to determine the need for pharmacological treatment. Another assessment, the *Neonatal Withdrawal Inventory* (NWI) (Zahorodny et al., 1998) looks at not only symptoms of NAS but

behaviors as well. These assessments are invaluable guides to selecting the best treatment for the infant with NAS.

Intervention Approaches

Two primary intervention approaches are followed in the treatment of infants with NAS: non-pharmacological and pharmacological. Most infants with NAS begin on a non-pharmacological treatment plan and then, if necessary, receive additional pharmacological treatment (Jansson et al., 2009).

Non-pharmacological. A non-pharmacological approach is chosen to begin with because not only does it cost less, but it is easy to implement and less controversial. Non-pharmacological treatment promotes withdrawal symptom management without the use of opioids. It is comprised of environmental arrangements to decrease stimuli, includes rapid-response to infant's needs, proper care, consistent comforting, precise swaddling, specific soothing approaches, frequent hypercaloric feedings, correct posture of the infant, and even acupuncture therapy (Boucher, 2017; Hudak & Tan, 2012; Jansson & Velez, 2012; Kocherlakota, 2014).

Pharmacological. Symptoms of NAS can sometimes take three to five days to emerge or present as severe enough to require pharmacological treatment (Hudak & Tan, 2012). For example, NAS as a result of heroin exposure may present within the first 24 to 48 hours, where NAS as a result of methadone exposure can take 48 to 72 hours (Kocherlakota, 2014).

Pharmacological treatment consists of using prescribed opioids, such as morphine, methadone, buprenorphine, or phenobarbital to wean the infant slowly and diminish the infant's withdrawal symptoms (Hudak & Tan, 2012; Merhar et al., 2018; O'Grady, Hopewell, & White, 2009; Sarkar & Donn, 2006). The prescribed opioid is chosen for each infant on a case-by-case basis after

careful consideration of multiple factors, such as alcohol content, length of half-life, dosage schedule, sedation, and of course side effects such as constipation and hypotension. Morphine and methadone are the most commonly prescribed for opioid NAS, where phenobarbital is more common for NAS resulting from non-opioids (Kocherlakota, 2014; Merhar et al., 2018). There is a 60-80% possibility that an infant exposed to opioids in utero will develop NAS that requires pharmacological treatment (Kraft et al., 2016). Although there is no standard protocol for pharmacological treatment of NAS to date, infants who score on higher of the Finnegan Scale are the strongest candidates for pharmacological treatment using opioids like morphine (Kocherlakota, 2014). An infant with NAS treated using this multi-modal approach may reduce their length of hospitalization (Boucher, 2017; Hudak & Tan, 2012; Kocherlakota, 2014).

Impact of NAS on NICU Stay

Nationally in the United States, the length of stay for an infant with NAS on average is over three times as long (16.57 days) and costs three times as much (an estimated \$16,893 USD) as that of an infant without NAS (Corr & Hollenbeak, 2017). Patrick, Davis, Lehman, and Cooper (2015) found that infants with NAS requiring pharmacologic treatment had a mean length of stay of 23 days and hypothesized the infants who are treated using the non-pharmacological approach or show minimal signs of withdrawal positively skew the overall mean length of stay of 16 days.

The length of stay and cost also vary by geographic area and state. In 2011 it was reported that in Tennessee, the mean length of inpatient hospitalization stay for an infant with NAS on average was 17.5 days and the mean costs four times as much (an estimated \$30,800 USD) as that of an infant without NAS (Bauer & Li, 2013). With the increased length of stay and incidence of NAS, specific units are being established within some hospitals to accommodate

these infants and their families. The designated NAS units provide individualized support for not only for the infant but also the infant's primary caregivers in an environment that is free from stigma (Kraft et al., 2016). NAS units that reside within a pre-existing NICU often provide a sensory haven for the infants with NAS and their families. Often, the practice of a caregiver rooming-in is a part of the environmental arrangements made to benefit infants with NAS. Rooming-in allows infants to remain in the same room as their mother within the medical setting and has reduced the mean length of hospital stay from 24 days to 5 days, as well as the total morphine exposure for infants with NAS (Boucher, 2017). This is an example of the crucial role caregivers can play in the treatment process and why they should be involved in their infant's care whenever possible (Kraft et al., 2016).

Maternal Involvement

Maternal involvement is a key component in the recovery of infants with NAS, especially when included as a member of the non-pharmacological treatment team. Maternal involvement includes components of the non-pharmacological treatment approach, such as breastfeeding, rooming-in, and bonding (Kocherlakota, 2014).

Breastfeeding of infants with NAS is encouraged for infants exposed to opioids when mother's opioid uses is known and closely monitored. The infant continues to receive low doses of the opioid through the breastmilk while also receiving the desired physical contact, specifically skin-to-skin. This improves bonding and decreases the severity of the withdrawal process (Kraft et al., 2016; Proctor-Williams, 2018). Mothers who receive medication-assisted treatment (MAT) are supervised by a physician to monitor the levels of methadone or buprenorphine found in breastmilk, which alone is not enough to treat NAS but assists in the weaning process (Proctor-Williams, 2018). The American Academy of Pediatrics lifted the

restrictions on breastfeeding for mothers on any dosage of methadone in 2001 (Kocherlakota, 2014). Caution should be taken when breastfeeding with the presence of other opioids, such as hydrocodone and oxycodone; however, as both can cause adverse effects (Kocherlakota, 2014). Breastfeeding has also been shown to reduce stress and the severity of NAS while increasing maternal confidence. This family-centered approach benefits the infant while improving the bond between mother and child. It also benefits the mother as research has shown that mothers who receive MAT and participate in breastfeeding their infant are more likely to comply and less likely to resort to the use of illicit drugs (Proctor-Williams, 2018; Reddy, Davis, Ren, & Greene, 2017). As treatment is shifting to include more maternal involvement, the importance of maternal involvement and the different roles the mother could play in the treatment of NAS is being investigated (Vogel, 2018).

The mothers of infants with NAS often share some characteristics in common. Most of these mothers have experienced multiple adverse childhood events, have lower education levels, and have low socioeconomic status. Risk factors such as a poverty, recent history of domestic violence, homelessness, history of child abuse and/or neglect, experiences with child protective services, incarceration, partner/spousal substance abuse, and/or maternal history of substance abuse treatment have been noted in mothers of infants with NAS (Greig et al., 2012; Minnesota Hospital Association (MHA) Perinatal Committee, n.d.). Based on these risk factors, mothers of infants with NAS also require specific considerations when it comes to involvement in the intervention process.

To encourage maternal involvement, a nonjudgmental and supportive environment must be upheld. Mothers report being fearful of identification as substance-users by authority figures, including health care professionals (HCP) (Stone, 2015). Mothers receiving methadone, while

pregnant and postpartum, require specialized assessment and treatment, which will consider psychiatric problems and include mental health counseling with individual and group therapy. They also need intensive social support, including, but not limited to, financial, legal, housing, child welfare, and domestic violence services (Velez & Jansson, 2008). Further research is needed to define how maternal involvement and family-centered approaches can be the best practices for infants with NAS while in the NICU (McGuire et al., 2015). To prepare and set parents up to succeed in parenting an infant with NAS, a variety of healthcare professionals are needed to provide counseling and education to mothers of infants with NAS.

Interprofessional Team Approach to Treatment

Although there is a paucity of research on an interprofessional approach to the treatment of infants with NAS and their caregivers, a wide range of healthcare professionals (HCPs) are involved in the process. Nurses, physicians, therapists, and specialists alike all play vital roles in the treatment of infants with NAS, and in some settings work together as an interprofessional team. Such teams provide the required support and treatment for the infant with NAS as well as their caregivers during their time in the NICU and beyond (Greig et al., 2012). The HCPs on a NAS treatment team rely on their specific areas of expertise to provide the best possible care collectively. These infants need multi-modal services, and the best way to achieve this is through interprofessional collaboration (Kraft et al., 2016). In the NAS population, both mothers and their infants with NAS require complex care. The SLP plays a crucial role in the interprofessional team serving infants with NAS and their families as they address the feeding and communication needs of these infants.

Speech-Language Pathologists as An Interprofessional NAS Team Member

SLPs working within the NICU provide services and education for feeding, swallowing, communication, and cognition problems to infants at risk for or who are identified as having a disorder and their families (ASHA, 2004). There is scant literature defining the role of the SLP in the assessment and treatment of infants with NAS within the NICU specifically. The American Speech-Language Hearing Association (ASHA) developed guidelines for the roles and responsibilities of SLPs providing services in the NICU; which, however, do not explicitly mention the NAS population as a result of its new presence on SLP caseloads. These guidelines may serve as a starting point for SLPs serving these infants with NAS in the NICU. SLPs serving infants with NAS in the NICU and other settings may apply these guidelines when deemed appropriate and in the absence of guidelines specific to infants with NAS. Generally, SLPs contribute to the assessment and treatment of feeding and swallowing in infants with NAS, educate caregivers on communication and feeding, and facilitate bonding between the mother/families and the infant.

Assessment. Consistent with the role SLPs typically play in assessing infants within the NICU, they complete oral mechanism exams, evaluate swallowing, and evaluate the feeding characteristics of infants with NAS (ASHA, 2004). Additional assessments that SLPs may complete with this population include: *Clinical Bedside Swallow Evaluation* (CBSE), *Videofluoroscopic Swallowing Study* (VFSS), *Fiberoptic Endoscopic Evaluation of Swallowing* (FEES), and *The Early Feeding Skills Assessment* (EFS) (Reynolds, Carroll, & Sturdivant, 2016; Thoyre, Shaker, & Pridham, 2005). SLPs also collaborate with other interprofessional team members in the NICU and may contribute in part towards other assessments such as the FNAST, which is not typically completed solely by an SLP.

Feeding Intervention. SLPs' support of infants learning to feed within the NICU impacts their short-term and long-term success. For example, an SLP may utilize cue-based feeding where the focus is on the infant's cues rather than the volume-driven approach which focuses on feeding a specific volume, improving the feeding experience and promoting the development of feeding characteristics (Shaker, 2013). Since there is no true evidence base to support how infants with NAS should be fed, SLPs may draw on their knowledge, experience, and practices for feeding premature infants and other NICU populations. For example, despite the dearth of procedural evidence for feeding, as discussed earlier, there is evidence that the mother's breastmilk has been shown to decrease the severity of an infant's NAS (Logan et al., 2013). Therefore, priority should be placed on either breastfeeding or bottle feeding using the mother's breastmilk. The SLP would encourage infant-guided feeding and emphasize the importance of cue-based feeding through education provided within feeding intervention.

Counseling and Education. SLPs also provide counseling, education, and support to the mothers, families, and caregivers of the infants with NAS. SLPs educate their colleagues as well in order to inform the holistic treatment of infants with NAS further. SLPs provide information on the infant's cues, communication, feeding, and breastfeeding, as well as maternal-infant bonding (Proctor-Williams, 2018). If an infant with NAS presents with any signs of discoordination or aspiration, SLPs can teach mothers and other caregivers to recognize distress signals during a feeding and to respond quickly, therefore, providing positive feeding experiences (Shaker, 2013). The information provided by SLPs ensures a well-rounded understanding of the impact NAS can have on development not only short-term but long-term as well. SLPs can play an essential role and have a positive impact on the treatment of infants with NAS through the resources and encouragement they provide to others during intervention.

In summary, based on the literature review, it is evident that the role of the SLP in this new population of infants with NAS has not been researched in any depth to date, and many questions remain regarding evidence-based treatments for this vulnerable population. As the opioid crisis continues to grow and spread across the nation, it is imperative to increase research to improve the treatment of the infants with NAS that result from this growing epidemic.

Research Questions and Predictions

This exploratory, descriptive survey research aims to determine the characteristics, assessment, and treatment of infants with NAS as perceived by SLPs and whether it differs from their perceptions of other NICU populations. Identifying how SLPs can best serve infants with NAS in the NICU is essential to their immediate well-being as well as to the development of these infants. The study will address the following research questions and predictions were made based on an in-depth review of current literature:

1. Are infants with NAS on hospital-based SLPs caseloads?

The results are predicted to confirm the presence of infants with NAS on SLPs caseloads based on increasing incidence and prevalence as found by Brown et al. (2016) and Ko et al. (2016).

2. What are SLPs' perceptions of how NAS affects the infants' feeding skills?

It is predicted that the study will gather descriptions of how NAS affects the infants' feeding skills aligning with the findings of Gewolb et al., 2004, Goetz and Rolloff, 2012, and LaGasse et al., 2003.

3. How do SLPs in the NICU describe their role in intervention for infants with NAS?

As far as could be determined, there is currently not any literature addressing this topic. No prediction for this question can be formulated.

4. Have SLPs encountered infants with NAS who also present with Craniofacial Anomalies (e.g., Cleft Lip/Cleft Palate (CL/CP), Pierre-Robin Sequence, high arched palate)?

It is predicted that SLPs will provide evidence of infants with NAS who also present with Craniofacial Anomalies on SLPs caseloads based on the study of Mullens, McCulloch, Hardy, Mathews, and Mason, 2019.

5. Have SLPs received education on NAS?

It is predicted that SLPs will indicate that they have received limited to no education on NAS based on the findings of Ratliff, 2017.

6. Who is on the care/treatment team for infants with NAS?

As far as could be determined, there is currently not any literature addressing this topic. No prediction for this question can be formulated.

7. What are the hospital/NICU environments where these SLPs practice like?

As far as could be determined, there is currently not any literature addressing this topic. No prediction for this question can be formulated.

CHAPTER 3

METHODS

Research Ethics

The ethical principles of beneficence, justice, and respect for persons were considered while planning the study (Orlikoff, Schiavetti, & Metz, 2014). For example, respect for persons was addressed in the personal identity protection measures taken. Identifying information such as respondents' names, emails, and IP addresses were not collected in order to ensure anonymity. Respondents were sent information regarding the purpose of the survey employing email or online posting. A copy of these letters can be found in Appendices H and J. They were made aware that their participation was entirely voluntary and that by completing the survey, they provided their informed consent. There were no risks to participants, only the inconvenience of spending approximately 20-25 minutes of their time completing the survey. On December 20th, 2018, exempt approval for the study was granted by the chair of East Tennessee State University Institutional Review Board (IRB) in accordance with 45 CFR 46. 101(b)(2). Therefore, this study was "conducted in full accordance with all applicable sections of the IRB Policies."

Research Design

An exploratory, descriptive design was selected for this study with planned quantitative and qualitative data analysis. Survey research was deemed appropriate for this study in order to reach a specific set of respondents who were widely distributed across the United States of America, a large geographical area. Survey research provides insight on conditions, practices, attitudes and opinions of respondents while revealing trends (Blessing & Forister, 2013; Orlikoff et al., 2014) and is popular within Speech-Language Pathology to gain insight into professional issues, conditions, caseloads, client/clinician feedback, and other clinical issues (Orlikoff et al.,

2014). An electronic survey was developed based on an in-depth review of the literature on the topic and on compiling surveys.

Materials

Survey Tool

Based on an in-depth literature review, a questionnaire, “The Perceptions of Neonatal Intensive Care Unit Speech-Language Pathologists” was developed to collect information on NAS, caseloads, treatment environment, and respondent demographics. For the secure web-based questionnaire, SurveyMonkey™ provided the online survey platform. The question and response format consisted of: one open-ended question, 30 multiple choice questions, 19 matrix-style questions, 14 dichotomous questions, three numerical response questions, and 18 dropdown choice questions. Only one open-ended question was included to respect the time constraints of the participants.

The survey consisted of three sections: NAS, Environmental Description, and Respondent Demographics. Within the NAS section, questions 1-18 provided information on NAS prevalence on SLPs caseload, feeding/swallowing characteristics of infants with NAS, and behavioral characteristics of infants with NAS. A portion of question 9 was based on the Neonatal Behavior Assessment Scale (Brazelton, 1973) as it matched well with the purpose of this question. Then, the NAS section was then further divided into three subsections: NAS Assessment, NAS Treatment, NAS Education. The first NAS subsection, NAS Assessment, consisted of six possible questions gaining insight on SLP roles in the assessment of infants with NAS. The second NAS subsection, NAS Treatment, consisted of 12 possible questions looking at the treatment of infants with NAS. The third NAS subsection, NAS Education, consisted of 14 possible questions regarding education with high-risk infant populations, SLP roles in

intervention, and members of a NAS treatment team. The Environmental Description section, questions 54-62, asked respondents to provide a description of specific environments in which infants with NAS receive treatment. The Respondent Demographics section of the questionnaire, questions 63-69, inquired about the respondents' demographic information, including the highest level of education, gender, and years of experience. It also provided a space for participants to share any additional comments and experiences related to infants with NAS and their feeding characteristics. The survey was designed to allow respondents to complete the survey even if they skipped questions.

Pilot Study

The questionnaire was piloted to enhance its validity and reliability (Orlikoff et al., 2014). On October 26th, 2018, the chair of East Tennessee State University Institutional Review Board (IRB) deemed that the pilot study met neither the US Food and Drug Administration (FDA) nor the Department of Health and Human Services (DHHS) definition of research involving human subjects and therefore did not require ETSU IRB approval to be completed.

Respondents. Respondents were three practicing speech-language pathologists who held a certificate of clinical competency and are members of ASHA. One respondent was a practicing clinician in a local hospital, one was a field expert in feeding, and another was an expert in feeding currently in private practice. These participants agreed that they would not participate in the final survey, so as not to impact the internal validity of the study. There were no risks to participants, only the inconvenience of spending approximately 20 minutes of their time completing the survey.

Materials. The participants were invited to participate in the pilot study by email which can be found in Appendix B and were reminded by email as well, which can be found in

Appendix C. The pilot study participants consented to the consent letter. The participants provided feedback about the content and questions of the questionnaire. They used a feedback form that listed the survey questions alongside space for feedback regarding the specific questions; it can be found in Appendix E. The pilot survey is contained in Appendix A.

Pilot Study Data. The pilot study yielded feedback for the survey from all three of the participants. As a result of their feedback, multiple questions were revised. Pilot study respondents reported that the survey took 20-25 minutes to complete; therefore, this information will be included in the letter to the participants. Their feedback supported the use of a secure web-based questionnaire on the online survey platform SurveyMonkey™. The final version of the questionnaire is based on feedback from these participants and is included in Appendix G.

Respondents

Purposive sampling was used to target hospital-based SLPs practicing in the United States of America (Fade, 2003). The purpose of this study is to determine the characteristics, assessment, and treatment of infants with NAS as perceived by SLPs and whether it differs from their perceptions of other NICU populations. Therefore, the population studied exclusively included adult members of the American Speech-Language-Hearing Association (ASHA) in hospital settings who hold their Certificate of Clinical Competence. Speech-language pathologists are required to have an ASHA Certificate of Clinical Competence to practice; which was deemed to be an appropriate inclusion criterium. A response rate could not be determined as membership numbers for distribution groups were unavailable.

At survey closure, 26 respondents completed portions of the survey, and the survey itself had a 44% completion rate. Only 11 respondents answered the demographic information questions.

Respondent Demographics

Education. A master's degree was the highest level of education for 100% ($n=11$) of respondents, which is consistent with the degree requirements to work as an SLP within the United States of America.

Gender. Respondents ($n=11$) predominantly identified as female (90.90%), which aligns with the membership demographics reported for ASHA (2018) gender distribution of 96.3% female.

Additional demographic information for the 11 respondents is displayed in Figures 1-3 below.

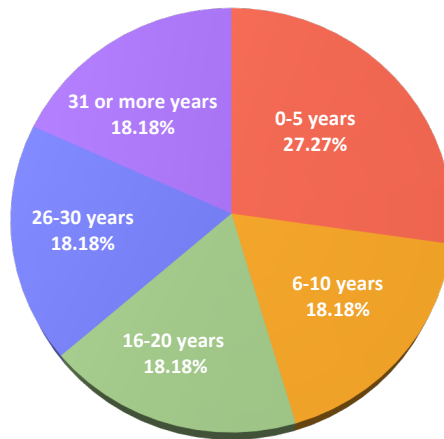


Figure 1: Respondents' Years of Experience as an SLP ($n=11$)

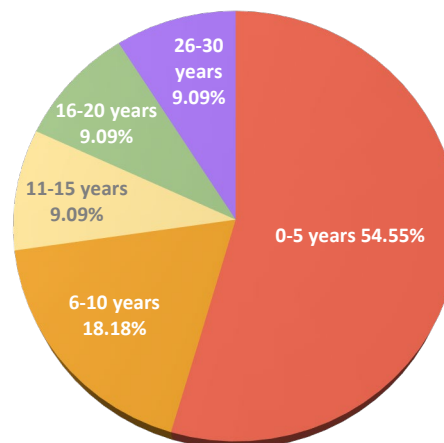


Figure 2: Respondents' Years of Experience with Infants in a Hospital ($n=11$)

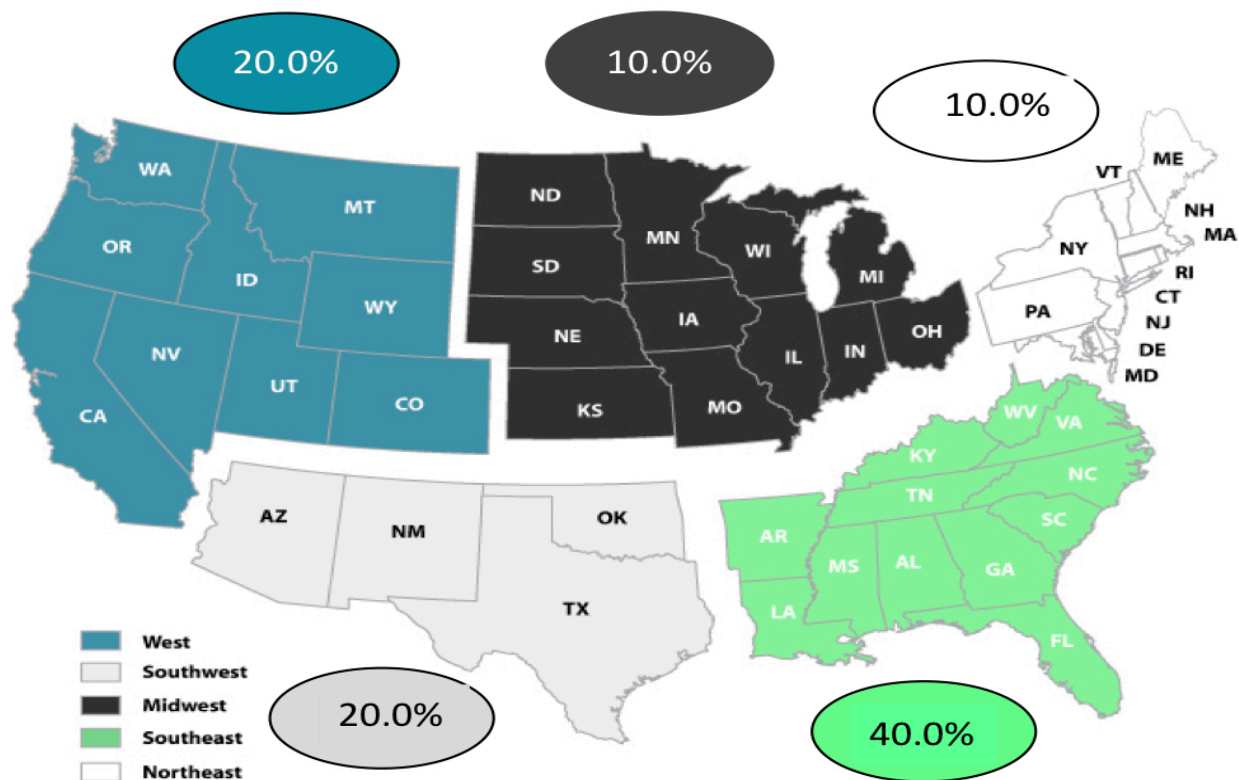


Figure 3: Geographic Representation of Respondents (n=10)

Geographical Data. Only 38.46% ($n=10$) of respondents provided an answer for geographical location. A respondent representing at least one state from each of the five geographic regions responded to the questionnaire. However, only seven different states were represented in the sample by 38.46% ($n=10$) of the respondents. Alaska and Hawaii, which would have been included in the West region, are not pictured as participants in this study did not represent them. Respondents indicated their population densities are as follows ($n=11$): rural (36.36%), urban (72.73%), or suburban (9.09%).

Data Collection Procedure

The SurveyMonkey™ link was distributed through email and online postings by State Associations and Special Interest Group (SIG) coordinators from ASHA SIGs 5 and 13, Craniofacial and Velopharyngeal Disorders and Swallowing and Swallowing Disorders

(Dysphagia) respectively. The SIG coordinators reviewed the request before approval and posting. The recruitment email contained a description of the study and a hyperlink to the questionnaire. Once respondents accessed the link, the consent for participation was completed as part of the SurveyMonkey™ questionnaire. To obtain the desired sample size of 50 snowball sampling was encouraged. Respondents were able to forward the survey link to others who agreed that they met the criteria within the consent form before participating in the survey. Participants were not compensated in any way to complete the survey.

Data Extraction

SurveyMonkey™'s data analysis features were used to analyze some of the responses, and the results were also extracted for the aims of the study. Respondent responses were manually entered individually into Statistica™ for the survey questions. The data was also extracted in both PDF and Excel file form and downloaded onto an encrypted flash drive designated for the study.

Data Analysis

Descriptive statistics, inferential statistics, and an item-by-item analysis were performed on the survey response data. As well, quantitative data analysis was performed for comparisons between NAS subgroups. Descriptive statistics, using measures of frequency, were used to describe responses and represent data. Although one open question was included in the survey, only two responses were obtained, which was not sufficient enough to warrant a qualitative data analysis. The one open response that applied to the study was incorporated into result data that informed research question six. The secure online platform, SurveyMonkey™, allows for analysis of the data using descriptive statistics. Data was also entered in the statistical program, Statistica™, to allow inferential analysis.

Nonparametric inferential statistics were used to determine relationships between qualitative findings (Ali & Bhaskar, 2016). Because the data for survey questions number nine (and its 24 subparts) and 42 to 52 were categorical (e.g., different comorbidities of NAS) and nominal (identified as either true/present or false/absent by binary code), the nonparametric Fisher's Exact Test, two-tailed analysis was applied. This test provides the probability of differences between two groups based on observed frequencies. Two strategies were employed to reduce the likelihood of finding a difference by chance, given the high number of possible comparisons. First, only the questions that at least seven respondents answered were analyzed, because of concerns about power and error. Second, for each question with an adequate number of responses, statistical analyses began with the greatest difference in frequency of observation across categories, as it would be the most likely to reveal a significant difference. If a significant difference was found, the next smaller difference in frequency was analyzed. This process continued until a significant difference was not found, at which point analysis was suspended. In all, 14 Fisher's Exact Tests were conducted.

CHAPTER 4

RESULTS

The purpose of this study is to determine the characteristics, assessment, and treatment of infants with NAS as perceived by SLPs and whether it differs from their perceptions of other NICU populations. This section contains the results of both descriptive and inferential statistics. The results will be presented in sections that correspond to the research questions of the study.

Presence of NAS on Caseloads of Respondents

Research Question 1: *Are infants with NAS on hospital-based SLPs caseloads?* Survey questions 2-8 were analyzed to answer this research question. Results indicated a presence of infants with NAS on the caseloads of the hospital-based SLPs who responded to the survey, with 73.08% ($N=26$) respondents reporting having infants with NAS on their caseloads. The majority of the respondents reported they see only infants with NAS and feeding problems (78.95%, $n=19$); however, 15.79% ($n=19$) reported they see all infants with NAS regardless of the presence of feeding or swallowing problems. None of the respondents reported seeing only infants with NAS and suspected swallowing problems. Respondents provided estimates for the percent of infants with NAS with comorbidities on their caseloads as depicted in Figure 4.

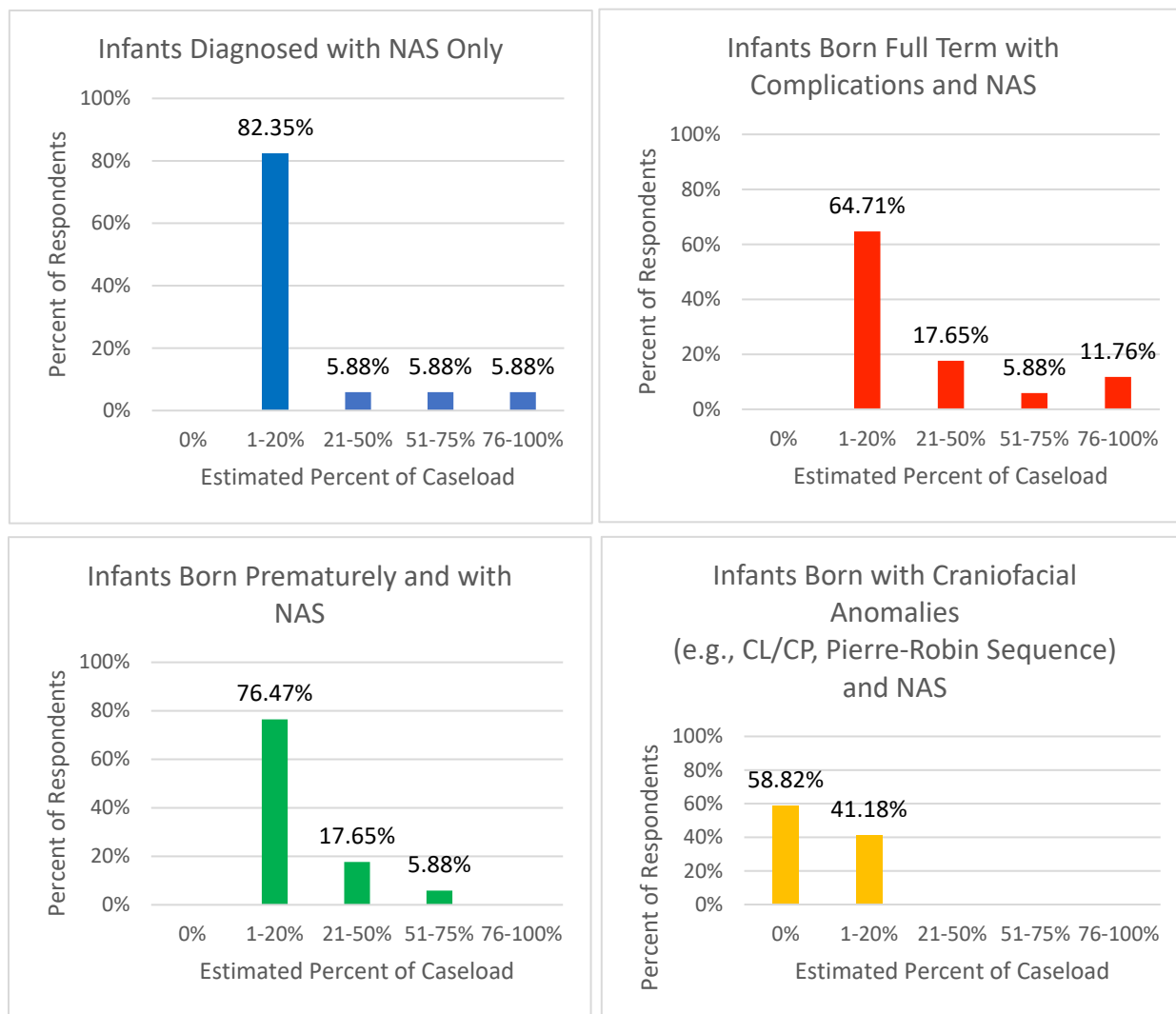


Figure 4: Respondents' Estimates of the Percent of Infants with NAS and Comorbidities on Their Caseloads as a Percentage of Respondents (n=17)

Feeding Characteristics

Research Question 2: *What are SLPs' perceptions of how NAS affects the infants' feeding skills?* Survey questions 9-19 were analyzed to answer this research question.

NAS Effects on Infants' Feeding Characteristics

Respondents indicated the presence or absence of feeding/swallowing characteristics commonly observed in infants with NAS on their caseloads. For each question the *n* differed,

ranging from 2-8 respondents. A two-tailed Fisher's Exact Test was used to examine the differences between infant NAS categories for the following variables. The percentage of respondents who reported a normal swallow was significantly greater for infants with NAS only than for premature infants with NAS, ($p=0.0291$; $n=7$). The percentage of respondents who reported difficulties with respiration regulation and presented with signs of cardio-respiratory instability was significantly greater for premature infants with NAS than for infants with NAS only ($p=0.0406$; $n=8$). The percentage of respondents who reported difficulties achieving intraoral pressure was significantly greater for infants with NAS and Craniofacial Anomalies than for infants with NAS only ($p=0.0101$; $n=8$). The percentage of respondents who reported shorter sucking bursts was significantly greater in infants with NAS and Craniofacial Anomalies than for infants with NAS only ($p=0.0406$; $n=8$). The percentage of respondents who reported shorter sucking bursts was significantly greater in premature infants with NAS than for infants with NAS only ($p=0.0406$; $n=8$).

Two to eight respondents (the n differed for each question) reported the presence of feeding characteristics for infants with NAS only, full term infants with NAS and complications, premature infants with NAS, and infants with NAS and Craniofacial Anomalies. There were no other significant differences found using a Fisher's Exact Test. This included the following feeding characteristics: respiration regulation for integration of breathing within the sucking burst; adequate and inadequate latching; spillage during latching; refusal to latch; normal/adequate intraoral pressure; sucking rate/frequency (normal, increased/excessive, decreased/slow); sucking burst that were normal or longer; auditory signals of poor coordination (e.g. gulping, gurgle, yelp, cough, gag, choke) during a swallow; aspiration; an oral mechanism with normal, low, high, or transient tone; nasal regurgitation; reflux/spit-up; and arching away.

The data for the descriptions of the feeding characteristics of infants with NAS are illustrated in Table 1.

Table 1:

Feeding/Swallowing Characteristics Observed in Infants with NAS: Percentage of Respondents

Feeding Characteristic	Infants with NAS Only	Full Term Infants with NAS and Complications	Premature Infants with NAS	Infants with NAS and Craniofacial Anomalies	<i>n</i>
Respiration Regulation	25.0%	62.5%	62.5%	50.0%	8
Adequate Latching	66.7%	66.7%	66.7%	33.3%	3
Inadequate Latching	57.1%	85.7%	71.4%	100.0%	7
Spillage During Latching	62.5%	75.0%	87.5%	100.0%	8
Refusal to Latch	57.1%	85.7%	71.4%	71.4%	7
Normal/Adequate Intraoral Pressure	71.4%	57.1%	71.4%	28.6%	7
Normal Sucking Rate	50.0%	100.0%	75.0%	75.0%	4
Increased/Excessive Sucking Rate	85.7%	71.4%	42.9%	57.1%	7
Decreased/Slow Sucking Rate	0.0%	20.0%	80.0%	80.0%	5
Normal Sucking Burst	50.0%	50.0%	50.0%	50.0%	2
Longer Sucking Burst	71.4%	57.1%	28.6%	28.6%	7
Auditory Signals of Poor Coordination During a Swallow	50.0%	75.0%	87.5%	100.0%	8
Aspiration	0.0%	60.0%	80.0%	100.0%	5
Oral Mechanism: Normal Tone	66.7%	83.3%	83.3%	16.7%	6
Oral Mechanism: Low Tone	0.0%	20.0%	60.0%	60.0%	5
Oral Mechanism: High Tone	66.7%	83.3%	33.3%	83.3%	6
Oral Mechanism: Transient Tone	57.1%	71.4%	71.4%	71.4%	7
Nasal Regurgitation	20.0%	40.0%	20.0%	100.0%	5
Reflux/Spit-Up	75.0%	87.5%	87.5%	87.5%	8
Arching Away	75.0%	75.0%	62.5%	75.0%	8

As shown in Table 1, the most problematic feeding characteristics for infants with NAS

with and without comorbidities was reflux/spit up (75.0-87.5%, *n*=8) followed by spilling during

latching (62.5-100%, $n=8$) and arching away (62.5-75%, $n=8$). The least problematic feeding characteristics for infants with NAS with and without comorbidities, was low tone for the oral mechanism (0-60%, $n=5$) followed by respiration regulation (25-62.5%, $n=8$). Across all infants with NAS, with and without comorbidities, normal sucking burst was reported by 50% ($n=2$) of respondents. For infants with NAS only, the most problematic feeding characteristic was increased/excessive sucking rate as reported by 85.71% ($n=8$) of respondents. The least problematic feeding characteristics as a result of 0% ($n=5$) of respondents selecting infants with NAS only for these characteristics were: decreased/slow sucking rate; aspiration; and low tone for the oral mechanism. Nasal regurgitation was the least problematic feeding characteristic reported for infants with NAS only by 20% ($n=5$) of respondents.

For full term infants with NAS and complications, the most problematic feeding characteristic was reflux/spit up as reported by 87.5% ($n=8$) of respondents. The least problematic feeding characteristic reported for full term infants with NAS and complications was normal sucking rate by 100% ($n=4$) of respondents.

For premature infants with NAS, the most problematic feeding characteristics as reported by 87.5% ($n=8$) respondents were spillage during latching; auditory signals of poor coordination during a swallow; and reflux/spit up. The least problematic feeding characteristic reported for premature infants with NAS was normal tone for the oral mechanism by 83.33% ($n=6$) of respondents.

For infants with NAS and craniofacial anomalies, the most problematic feeding characteristics as reported by respondents were: inadequate latching (100%, $n=7$); spillage during latching (100%, $n=8$); auditory signals of poor coordination during a swallow (100%, $n=8$); aspiration (100%, $n=5$); nasal regurgitation (100%, $n=5$); normal/adequate intraoral pressure

(28.57%, $n=7$); and normal tone for the oral mechanism (16.67, $n=6$). The least problematic feeding characteristic reported for infants with NAS and craniofacial anomalies was respiration regulation: integrates breathing within the sucking burst by 50% ($n=8$) of respondents.

Behavioral States Associated with the Feeding Characteristics of Infants with NAS

The behavioral states most commonly noted in the infants with NAS on respondents' caseloads were that their general sleep state is light (100%, $n=8$) and that post-feeding, they present with reduced sleep quality (100%, $n=7$) and reduced length of sleep (85.71%, $n=7$). Additional behavioral states and behaviors most commonly noted in the infants with NAS on respondent caseloads included their awake states and respiratory behaviors. The percentage of respondents' observations of each of the states and behaviors are illustrated in Figures 5 and 6, respectively.

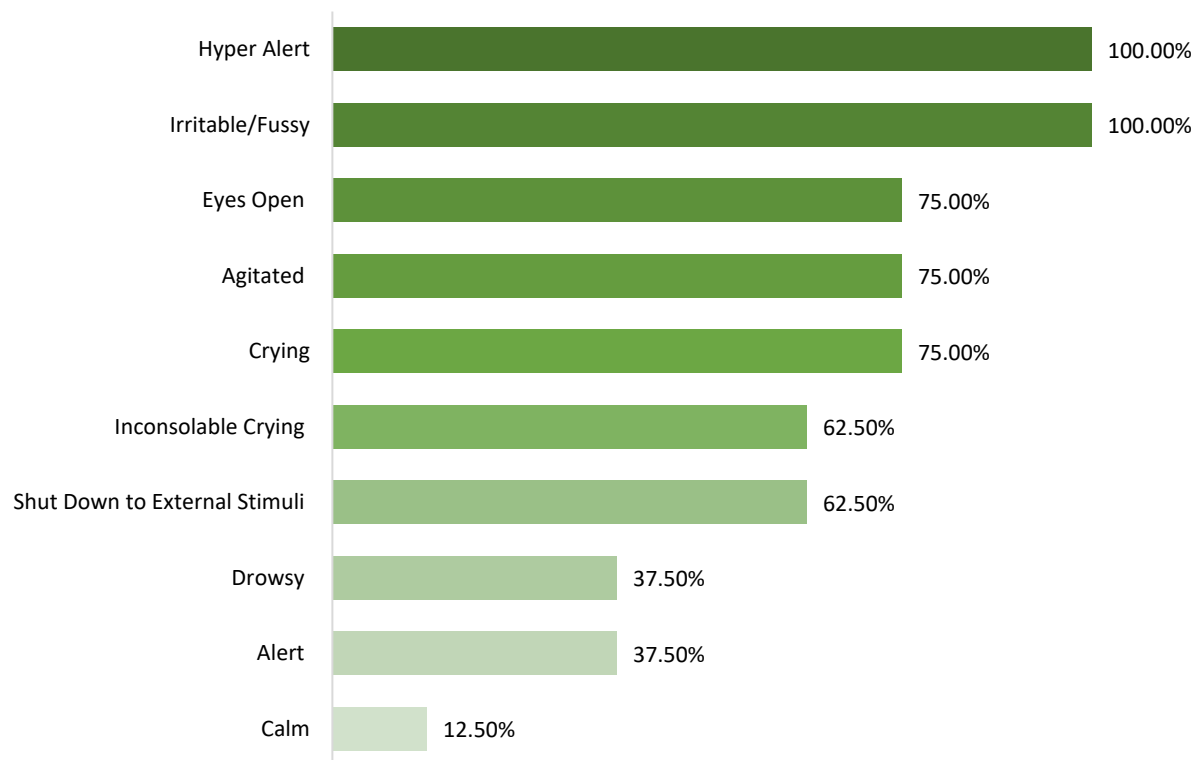


Figure 5: Respondents' Descriptions of the Awake States of Feeding Infants with NAS as a Percentage of Respondents ($n=8$)

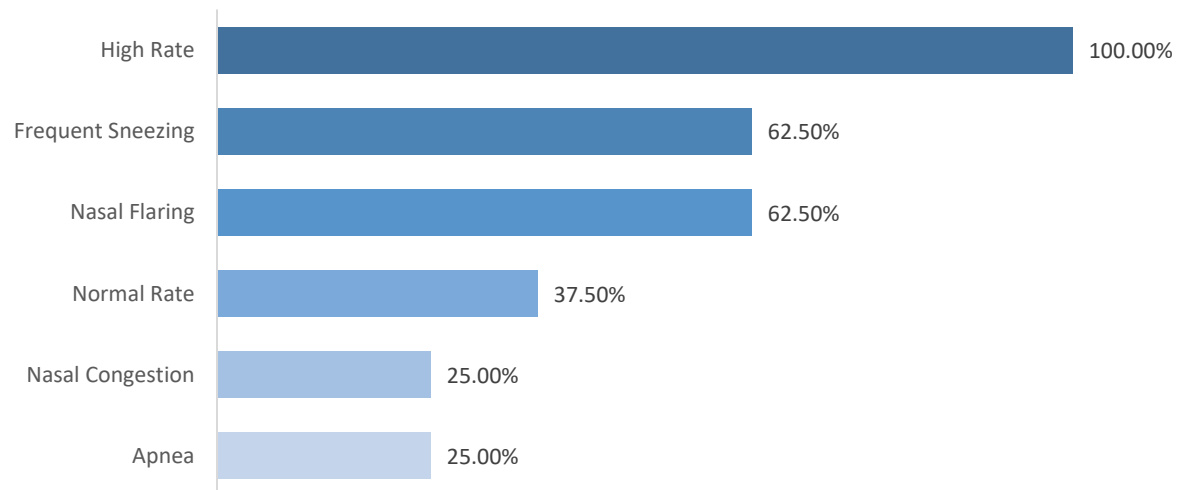


Figure 6: Respondents' Descriptions of the Respiratory Behaviors of Infants with NAS as a Percentage of Respondents (n=8)

For infants with NAS, time to complete a feed was described as: increased in 42.86% of the infants, decreased in 28.57% of the infants, and not completed in 28.57% of the infants according to 7 respondents. Out of a total feeding session, the infants with NAS were reported to spend less than 75% of the time feeding according to 71.42% (n=7) of the respondents.

The respondents provided the following information on feeding methods of infants with NAS in the NICU. On average, greater than 50% are exclusively orally fed as indicated by 71.42% (n=7) of respondents, less than 50% are briefly fed via nasogastric tube (NG-tube) as indicated by 71.42% (n=7) of respondents, 1-20% of infants with NAS are fed for an extended period of time via nasogastric tube (NG-tube) as indicated by 71.43% (n=7) of respondents, and only a small number (20% or less) are transitioned to a gastronomy tube (G-tube). Of infants with NAS, 1-20% are transitioned to a gastronomy tube (G-tube) according to 50% of respondents, and none are transitioned to a gastronomy tube (G-tube) according to the other 50% of respondents (n=6).

SLPs' Roles in the NICU

Research Question 3: *How do SLPs in the NICU describe their role in intervention for infants with NAS?* Survey questions 20-53 were analyzed to answer this research question.

SLPs' Role in Assessment of Infants with NAS in the NICU

Six respondents reported they all gather relevant medical history and current status, assess mother/infant interaction, and identify potential risks of aspiration and physiologic compromise. Some of the respondents ($n=6$) report that they conduct procedures such as Modified Barium Swallow Study (66.67%), Videofluoroscopic Instrumental Swallow Studies (66.67%), and Endoscopic Assessments of Swallowing Function (33.33%). However, some respondents ($n=5$) indicate that they make referrals to other health professionals for additional procedures: Gastric Emptying Assessment (80%) Pulmonary Testing (60%), Bronchoscopy (60%), ENT Assessment (60%), pH Probe for Reflux (40%), Endoscopic Assessments of Swallowing Function (20%), and Milk Scan (20%). While 50% of the six respondents do not contribute to the diagnosis of NAS, those who do, contribute to the diagnosis of NAS using the *Finnegan Neonatal Abstinence Score* tool. Other assessments tools used to assess the feeding/swallowing characteristics of infants with NAS reported by respondents are presented in Figure 7.

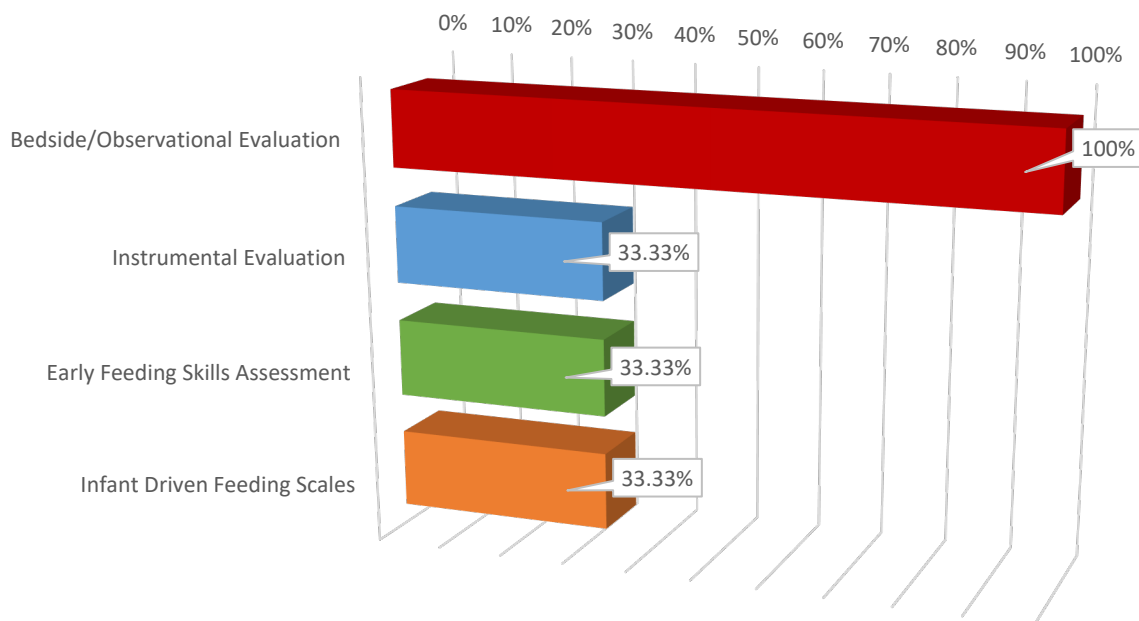


Figure 7: Assessments of the Feeding/Swallowing Characteristics of Infants with NAS as a Percentage of Respondents (n=6)

SLPs' Role in Treatment of Infants with NAS in the NICU

Six respondents reported that for infants with NAS they review daily medical notes; read, interpret, and respond to the behavioral cues; determine readiness for interaction and intervention; adjust interaction on the basis of variability in responses; identify and adjust feeding methods on the basis of variability in responses; recommend precautions to minimize risks of aspiration and physiologic compromise; provide cue-based feeding; support breastfeeding when appropriate. These respondents also reported providing family-centered care and developmentally appropriate environmental modulation, positioning and handling, as well as feeding interventions for infants with NAS. All six respondents indicated that they participate in non-pharmacological treatment; however, only 50% (n=6) reported that they contribute to pharmacological treatment decisions when appropriate.

SLPs' Role in Education on Infants with NAS and for Their Caregivers in the NICU

Six respondents reportedly provided education through coaching/counseling, communication of findings, and demonstrations. In addition, some of these respondents (16.67%, $n=6$) indicated they offer or lead support/informational groups. Five respondents conveyed that they offer education relating to infants with NAS on the general characteristics of NAS, the characteristics of feeding, swallowing, feeding methods, interpreting communication signals, interaction methods, and treatment. Only some of these respondents (60%, $n=5$) provided education on care following discharge. All six respondents reported providing education to biological mothers, biological fathers, caregivers (other family members - including foster and/or adoptive family members), and healthcare professionals. However, only 66.67% of these six respondents provided education to volunteers.

SLPs' Role in Intervention for Infants with NAS in Comparison to Infants without NAS

No significant differences (all $ps \geq 0.08$; $n=11$, $n=9$) were found for the roles of SLPs in intervention for infants with NAS and infants without NAS using a Fisher's Exact Test. This was considering the entire population of infants served in the hospital according to respondents. This included the following: playing a role in identifying patients at risk for feeding problems; participating in the assessment of the patient and family for feeding problems; conducting bedside/observational for feeding problems; providing support and intervention/treatment for feeding problems; providing education to families, other caregivers, and staff regarding preferred practices in the NICU to support current and future feeding skills; conducting instrumental evaluation of the patient for swallowing problems; referring for instrumental evaluation of the patient for swallowing problems; providing education to families, other caregivers, and staff regarding preferred practices in the NICU to support current and future swallowing skills;

providing support to families, other caregivers, and staff regarding preferred practices in the NICU to support current and future communication skills; providing discharge/transition planning and follow-up care; and collaborating with other team members to identify the need for additional assessment and consultation. The data for the SLPs' role in intervention is illustrated in Table 2.

Table 2:

Percentage of Respondents Playing Various Roles in Intervention

SLPs' Role in Intervention	Infants with NAS	Infants without NAS	Neither	<i>n</i>
Identifying patients at risk for feeding problems	63.6%	72.7%	27.3%	11
Assessment of the patient and family for feeding problems	63.6%	72.7%	27.3%	11
Conducting bedside/observational for feeding problems	63.6%	72.7%	27.3%	11
Providing support and intervention/treatment for feeding problems	63.6%	72.7%	27.3%	11
Educate families, other caregivers, and staff regarding preferred practices in the NICU to support current and future feeding skills	54.6%	63.6%	45.5%	11
Conducting instrumental evaluation of the patient for swallowing problems	54.6%	54.6%	45.5%	11
Refer for instrumental evaluation of the patient for swallowing problems	33.3%	44.4%	55.6%	9
Educate families, other caregivers, and staff regarding preferred practices in the NICU to support current and future swallowing skills	54.6%	54.6%	45.5%	11
Providing support to families, other caregivers, and staff regarding preferred practices in the NICU to support current and future communication skills	45.5%	45.5%	54.6%	11
Providing discharge/transition planning and follow-up care	45.5%	45.5%	54.6%	11
Collaborating with other team members to identify the need for additional assessment and consultation	63.6%	72.7%	27.3%	11

As seen in Table 2, 63.64% ($n=11$) of respondents reported that they play a role in identification of patients at risk for feeding problems; assessment of the patient and family for feeding problems; conducting bedside/observational for feeding problems; providing support and

intervention/treatment for feeding problems; and collaborating with other team members to identify the need for additional assessment and consultation for infants with NAS. In comparison, a majority, 72.73% ($n=11$), do so for infants without NAS and a minority of 27.27% ($n=11$) do not perform these roles for either population. Regarding playing a role in educating families, other caregivers, and staff on preferred practices in the NICU supporting current and future feeding skills, 54.55% ($n=11$) of respondents do so for infants with NAS compared to the 63.64% ($n=11$) who do so for infants without NAS and 45.45% ($n=11$) who do not perform this role for either population. Results indicate that 54.55% ($n=11$) of respondents play a role in conducting instrumental evaluation of infants with NAS for swallowing problems and educating families, other caregivers, and staff regarding preferred practices in the NICU to support current and future swallowing skills. About the same percentage (54.55%, $n=11$) do so for infants without NAS and 45.45% ($n=11$) do not perform this role for either population. Of the respondents, 45.45% ($n=11$) play a role in providing support to families, other caregivers, and staff regarding preferred practices in the NICU to support current and future communication skills and discharge/transition planning and follow-up care for infants with NAS. This matched the 45.45% ($n=11$) who do so for infants without NAS but 54.55% ($n=11$) do not perform these roles for either population. Of the respondents, 33.33% ($n=11$) play a role in referring infants with NAS for instrumental evaluation of the patient for swallowing problems whereas 44.44% ($n=11$) do so for infants without NAS, and 55.56% ($n=11$) do not perform these roles for either population.

NAS and Craniofacial Anomalies (e.g., CL/CP, Pierre-Robin Sequence)

Research Question 4: *Have SLPs encountered infants with NAS who also present with Craniofacial Anomalies (e.g., Cleft Lip/Cleft Palate (CL/CP), Pierre-Robin Sequence, high arched palate)?* Survey question 7 was analyzed to answer this research question.

A low presence (1-20%) of infants with NAS and craniofacial anomalies was indicated by 41.18% ($n=7$) of respondents when describing the populations on their caseload. The other 58.82% ($n=7$) of respondents reported no infants with NAS and craniofacial anomalies (0%) on their caseloads.

Education

Research Question 5: *Have SLPs received education on NAS?* Survey questions 65-66 were analyzed to answer this research question.

Eleven respondents provided information regarding the education they received. Some of the respondents (36.36%) reported having no formal education on NAS. Types of formal education reported by respondents included graduate clinic placement (9.09%, $n=11$) and continuing education units (CEU) (45.45%, $n=11$). In addition, 9% of the eleven respondents reported that they received education on NAS through “CFY and on the job,” and another 9% ($n=11$) reported that they educated themselves through “Self study.” In contrast, all eleven respondents received some form of formal pediatric feeding or swallowing education/training through graduate coursework (45.45%, $n=11$), graduate clinic placement (27.27%, $n=11$), post-graduate clinic placement (27.27%, $n=11$), and/or CEUs (100%, $n=11$).

Members of the Care/Treatment Team for Infants with NAS

Research Question 6: *Who is on the care/treatment team for infants with NAS?* Survey question 53 was analyzed to answer this research question.

Respondents ($n=7$) identified members of care/treatment teams for infants with NAS from a list of choices. One respondent picked the “Other, please describe” choice from the list and provided the response of “CPS.” The seven respondents identified a total of 25 different interprofessional team members. Figure 8 provides an overview of the presence of these interprofessional team members.



Figure 8: Members of Care/Treatment Teams for Infants with NAS ($n=7$)

Hospital/NICU Environments

Research Question 7: *What are the hospital/NICU environments where these SLPs practice like?* Survey questions 54-60 were analyzed to answer this research question. The number of beds in the ten respondents' hospitals ranged from 0 to 1157. The number of NICU beds in ten respondents' hospitals ranged from 0 to 120. The estimate the occupancy of 22.22% ($n=9$) respondents' NICUs over the last three months was 0%. The estimate the occupancy of 11.11% ($n=9$) respondents' NICUs over the last three months was 1-20%. The estimate the occupancy of 33.33% ($n=9$) respondents' NICUs over the last three months was 51-75%. The estimate the occupancy of 33.33% ($n=9$) respondents' NICUs over the last three months was 76-100%. The NICU Levels at the ten respondents' hospitals were: 10% Level II: Advanced Newborn Care; 30% Level III: Subspecialty Newborn Care; and 30% Level IV: Highest Level of Neonatal Care. There was no NICU at 30% of respondents' hospitals. Nine respondents reported that infants with NAS at their hospitals were cared for in the following settings: 55.56% are in the general NICU; 11.11% in a particular section of the NICU; 44.44% in a general nursery; 33.33% are "Rooming-In" with their caregiver; 10% answered *in (other, please describe:)* with "Continuing Care Nursery"; and 10% answered *in (other, please describe:)* with "Referred Out."

CHAPTER 5

DISCUSSION

The purpose of this study was to determine the characteristics, assessment, and treatment of infants with NAS as perceived by SLPs and whether it differs from their perceptions of other NICU populations. Interpretation of the results is discussed according to the research questions in the following sections.

Prevalence of Infants with NAS on Hospital-Based SLPs' Caseloads

This study asked whether infants with NAS are on hospital-based SLP caseloads. Some respondents from every geographic region of the country confirmed that infants with NAS appear on rural, urban, and suburban hospital-based SLPs caseloads. Of the respondents, 73%, reported that infants with NAS are on their caseloads. The respondents' answers are consistent with the spread of the opioid epidemic across the United States and the nature of the infants' symptomology.

The prevalence of infants with NAS on caseloads is a result of the current opioid epidemic in the United States, which is consistent with the literature (Brown et al., 2016; Ko et al., 2016). The incidence of NAS in the United States of America increased by 383% from 2000 to 2012, with a prevalence of 7.3 per 1,000 births totaling 27,315 cases in 2013 (Brown et al., 2016; Ko et al., 2016). If the incidence and prevalence of opioid use continue to increase as projected, the presence of infants with NAS on the caseloads of SLPs will as well, specifically those in the NICU. This increase necessitates a knowledge base on providing care and treatment for this population more essential for practice. As numbers of infants with NAS in the NICU increases, so does the need for a standardized assessment and treatment protocols for NAS, which could improve practices and outcomes nationwide.

Infants with NAS on SLP caseloads may present with comorbidities. Respondents estimated that the percent of infants with NAS only or combined with complications or prematurity each occupied an estimated 1-20% of their caseload according to 64.7-82.4% of the respondents. Their presence on SLP caseloads led to further investigation about the characteristics of infants with NAS only and those with comorbidities.

Feeding is the primary issue that SLPs play a role in managing for infants in the NICU (ASHA, 2004; Shaker, 2013). The majority of respondents (79%) report that the key factor for referrals they receive is that the infants with NAS present with feeding problems. This study further explored the feeding characteristics of infants with NAS.

SLPs' Perceptions of How NAS Affects Infants' Feeding Characteristics

The respondents' descriptions of the behavioral characteristics and how NAS affects the infants' feeding generally support the current evidence and add new information worthy of further study. The descriptions of the SLPs on how NAS affects the infants' feeding revealed difficulties across multiple skills and behaviors.

The Feeding Session Ability. Respondents indicated that the time it took to feed infants with NAS was different from that of typical babies in 71% of the cases, with increased time to complete a feed being most common. Furthermore, 29% of the infants with NAS did not complete a feed. Of the respondents, 71% reported the infants spent less than 75% of a total feeding session actually feeding. These outcomes are consistent with Maguire et al. (2015), who reported similar findings of increased feeding times due to disruptive behaviors. In their study, 25% of infants in their study did not complete a feed.

The disrupted feeds of infants with NAS may result in inadequate nutrition if not compensated for. One of the consequences that may result from inadequate nutrition is poor

weight gain. Poor weight gain can delay discharge, increasing the length of stay for these infants (Kocherlakota, 2014). In some cases, to compensate for inadequate nutrition as a result of feeding issues, an alternate method for feeding may be utilized such as NG tubes to supplement or aid in completion of a feed. Around 71% of respondents reported the use of an NG tube by infants with NAS on their caseloads. Feeding session abilities can also create issues for the care of infants with NAS where an increase in nursing staff, a change in their schedules and responsibilities, or the inclusion of other caregivers may be necessary to ensure the infants' needs are being met in the NICU.

Feeding Characteristics. When comparing the feeding characteristics of infants with NAS only, full term infants with NAS and complications, premature infants with NAS, and infants with NAS and Craniofacial Anomalies, there were few significant differences found. The most problematic feeding characteristics for infants with NAS with and without comorbidities were reflux/spit up, spilling during latching, and arching away. The least problematic feeding characteristics for infants with NAS with and without comorbidities were low tone of the oral mechanism and respiration regulation. Most feeding characteristics were reported across all comorbidities, with no significant differences between them. This suggests that they are symptomatic of the NAS diagnosis; however, they can be exacerbated by comorbidities.

For infants with NAS only, the most problematic feeding characteristic was increased/excessive sucking rate. As discussed by Logan et al. (2013), this may cause gastrointestinal issues. The respondents reported that for full term infants with NAS and complications, the most problematic feeding characteristic was reflux/spit up while the least common feeding characteristic was normal sucking rate. With irregular sucking rate and reflux, these infants will have difficulties feeding efficiently (Logan et al., 2013). For premature infants

with NAS, the most problematic feeding characteristics were spillage during latching; auditory signals of poor coordination during a swallow; and reflux/spit up. These difficulties may result in inadequate feeding while also presenting safety risks. Poor control of the swallow can lead to other complications for the infant, such as aspiration. For infants with NAS and craniofacial anomalies, the prevalent problematic feeding characteristics reported by respondents included: inadequate latching; spillage during latching; auditory signals of poor coordination during a swallow; aspiration; nasal regurgitation; and attaining normal/adequate intraoral pressure. These difficulties may result in insufficient feeding, present safety risks, and interfere with breastfeeding. This can cause distress for both the infant and the mother/caregiver during a feed and lead to negative feeding experiences for all parties.

Swallow. The percentage of respondents who reported a *normal* swallow was six times greater for infants with NAS only than for premature infants with NAS. The impacts of immature neurodevelopmental and physiological development on premature infants are described by Neu (2007). The findings of Neu (2007) support the respondents' reports of the premature infants with NAS presenting least often with a normal swallow in comparison to infants with NAS only. It may be that the swallowing problems are more associated with the complications of prematurity than NAS.

Because both premature infants and infants with NAS only are often difficult to feed, and little literature exists for the feeding behaviors of infants with NAS, researchers tend to draw from the literature of premature infants. However, the underlying causes and mechanisms are increasingly thought to be different (Shaker, 2013). For example, sometimes, feeding difficulties are physiological for premature infants with NAS due to immature development. As a result, premature infants take longer to feed while presenting with delays in motility and gastric

emptying (Neu, 2007). Intestinal dysmotility can present in infants with less than 34 weeks gestation, and low esophageal tone is common in infants with less than 30 weeks gestation. Intestinal motor function deficits have been shown to result in feeding intolerance (Neu, 2007). Therefore, for premature infants with NAS, many factors can contribute to their difficulties feeding from both prematurity and a diagnosis of NAS and the comorbidity.

Respiration. Irregular sucking bursts, cardiorespiratory instability, and suck-swallow-breathe discoordination can make respiration difficult and risky for a feeding infant. Respondents reported that difficulties associated with respiration were significantly greater for infants with NAS who were premature or full term with complications than for those with NAS only. Since full term with complications can include a wide variety of complications, it is possible that the respiratory symptoms resulted from the complications. Respiratory issues can take a toll on an infant in any situation, and feeding can add additional stress. In this study, shorter sucking bursts and signs of cardio-respiratory instability presented at a significantly greater rate for premature infants with NAS than for infants with NAS only. The findings of this study are also consistent with those of Neu (2007) with greater reported difficulties for respiration regulation and sucking bursts in premature infants. Suck-swallow-breathe coordination develops around 34 weeks gestation; therefore, premature infants may have difficulty with the aforementioned skills (Neu, 2007). Difficulties with these skills is a concern especially during feeding as it can create risks for the baby, can cause distress for the mother and lead to negative feeding experiences for both the mother and infant (Shaker, 2013). The comorbidity of NAS, in addition to prematurity or additional complications, could increase the likelihood of the aforementioned disruptions.

Infant States and Behaviors. Respondents provided information about sleep and awake states for infants with NAS as a single group. The states and behaviors most commonly noted in

the infants with NAS on respondents' caseloads were that their general sleep state is light, resulting in easily disrupted sleep. Post-feeding, infants with NAS present with reduced sleep quality and reduced length of sleep, which can lead to irritability. During their awake states, the infants with NAS on respondent caseloads were perceived as frequently hyperalert and irritable/fussy; often open-eyed, agitated, and crying, sometimes inconsolably. They reported that sometimes these infants shut down to external stimuli and seldom appear alert, drowsy, or calm. Furthermore, the symptoms associated with NAS are themselves uncomfortable, if not painful, which also impact both awake and sleep states. Without proper sleep, infants' awake states might be expected to include more behaviors and disruptions. Then, these infants would be difficult to soothe, and implementation of non-pharmacological approaches may require more effort and attention from caregivers.

Summary. The descriptions gathered from the respondents of how NAS affects the infants' feeding behaviors and characteristics, states are consistent with the findings of Gewolb et al. (2004), Goetz and Rolloff (2012), Jansson et al. (2009), Kocherlakota (2014), LaGasse et al. (2003), Logan et al. (2013), Maguire et al. (2015), and Velez and Jansson (2008). The differences among the findings exemplify how the effects of NAS vary from infant to infant. Infants with NAS experience a variety of effects of various drugs, the amount and timing of exposure, and additional congenital and health complications, disrupting typical function (Kocherlakota, 2014; Logan et al., 2013). NAS can negatively impact feeding in many ways, which can lead to further negative impacts on bonding and development. Therefore, it is essential for an SLP to be on the treatment team for an infant with NAS to assess feeding, provide intervention strategies, and monitor the process.

Many of the problematic feeding characteristics of infants with NAS may be addressed through cue-based feeding intervention. The SLP would need to encourage cue-based feeding, as suggested by Shaker (2013), while working together with other disciplines such as the occupational and respiratory therapist, as needed, to ensure the safety of the infant during a feed. Increasing the staff available to care for or assist in the care of the infants with NAS, redefining NICU team member schedules and responsibilities, and including other caregivers would help to ensure the infant's needs are being met in the NICU environment. For example, ensuring cue-based feeds can be provided frequently. Mothers and caregivers may need more assistance and guidance during feeding sessions to ensure positive experiences for both mother/caregiver and infant. Counseling might also be beneficial for some of the mothers/caregivers who may struggle with bonding resulting from the difficulty of feeding their infants or managing their needs (Gewolb et al., 2004; Kocherlakota, 2014; Maguire et al., 2015). SLPs can provide these services to the infants and their caretakers to improve the feeding experience and promote positive feeding sessions.

Craniofacial Anomalies in Infants with NAS

This study did not investigate prevalence or incidence of craniofacial anomalies on SLPs' caseloads but simply if there was any presence of infants with the comorbidity of NAS and craniofacial anomalies on the respondent's caseloads. As predicted, 41% of respondents indicated that 1-20% of their caseload included infants with NAS who also present with craniofacial anomalies. The findings of infants with NAS and craniofacial anomalies in this study are consistent with the findings described by Mullens et al. (2019). They reported that the prevalence of orofacial clefting in infants with NAS was over four times higher (6.79 compared to 1.63 in 1,000) than in the general live birth population. Isolated cleft palate (5.92 in 1,000) and

isolated cleft lip (3.79 in 1,000) were more prevalent in infants with NAS and associated with opioid exposure in utero. The current findings support those of Mullens et al. and identify the need for further research on this new and emerging population.

Ability to Achieve Intraoral Pressure. The percentage of respondents who reported difficulties achieving intraoral pressure and shorter sucking bursts was significantly greater for infants with NAS and craniofacial anomalies than for infants with NAS only. The significant difference pertains only to difficulties in achieving intraoral pressure and presenting with shorter sucking bursts. These findings validate research on the impact of craniofacial anomalies on feeding regardless of the presence of NAS. Miller (2011) explains how infants with craniofacial anomalies are more likely to have velopharyngeal insufficiency (VPI), which prevents the build-up of intraoral pressure and efficient sucking. This may lead to insufficient nutrition and negatively impact bonding between the parent and infant (Miller, 2011). Infants with NAS only do not appear to have VPI, which may explain why they have less difficulty in achieving intraoral pressure and tend not to have shorter sucking bursts as do infants with VPI. In this case, it appears that the comorbidity of craniofacial anomalies is what causes these issues for the infant with NAS. Therefore, it is important to identify craniofacial anomalies as early as possible.

The NICU SLPs' Role in Intervention for Infants with NAS

The SLP provides a unique perspective on intervention for infants with NAS and can improve both short- and long-term outcomes. SLPs serve infants with NAS by contributing to the assessment, treatment, and education (ASHA, 2004).

Assessment. The respondents' descriptions suggest that they participate in gathering relevant medical history and current status, assessing mother/infant interaction, and identifying potential risks of aspiration and physiologic compromise. Notably, half of the respondents

contribute to the diagnosis of NAS. Although diagnosis is not within the SLP scope of practice, the involvement of respondents contributing to the diagnosis of NAS could be due to procedures which vary by hospital. There is no standardized protocol for NAS, especially in the case where an interprofessional team approach may be utilized. SLPs may contribute to the diagnosis of NAS as a member of the team. In the approaches used in some settings, other disciplines may hold the responsibility of diagnosing without collaboration. It would be beneficial to promote better allocation of professional role responsibilities in both the NICU setting and within intervention teams to improve the care provided in team-based approaches by providing opportunities to contribute in all decisions within their respective scopes.

The respondents reported that they assess the feeding/swallowing characteristics of infants with NAS primarily using Bedside/Observational Evaluation but 33% report using the Instrumental Evaluation, Early Feeding Skills Assessment, and Infant Driven Feeding Scales sometimes. Some of the respondents (67%) report that they conduct procedures such as Modified Barium Swallow Study and Videofluoroscopic Instrumental Swallow Studies, with a small group (33%) conducting Endoscopic Assessments of Swallowing Function. The small group that conducts Endoscopic Assessments of Swallowing Function may reflect that some SLPs refer to other health professionals for this procedure. Respondents also indicated that they make referrals to other health professionals for additional procedures, primarily Gastric Emptying Assessment (80%), Pulmonary Testing (60%), Bronchoscopy (60%), and ENT Assessment (60%). Some refer for pH Probe for Reflux (40%), and few (20%) refer for Milk Scans or Endoscopic Assessments of Swallowing Function. Referrals can be attributed to many reasons, including local policies and regulations or availability of resources in their setting or local area. Referrals are important in ensuring well-rounded care by allowing different disciplines to complete

procedures falling within their respective scopes of practice and contributing to the assessment and treatment of the infant. Referrals also ensure necessary procedures are completed even when the technology and equipment are not available to the primary health care providers.

Treatment. Respondents reported that primarily for infants with NAS, they review daily medical notes; read, interpret, and respond to the behavioral cues; determine readiness for interaction and intervention; adjust interaction on the basis of variability in responses; identify and adjust feeding methods on the basis of variability in responses; recommend precautions to minimize risks of aspiration and physiologic compromise; provide cue-based feeding; support breastfeeding when appropriate. These respondents also reported providing family-centered care and developmentally appropriate environmental modulation, positioning, and handling, as well as feeding interventions for infants with NAS. This provides insight into the tasks that SLPs complete with NICU populations, including infants with NAS.

All six respondents indicated that they participate in non-pharmacological treatment; however, only 50% reported that they offer opinions about pharmacological treatment decisions when appropriate and invited. This disparity may also be a result of regulations, or in the case where an interprofessional team approach may be utilized, SLPs may contribute to treatment decisions as a member of the team. In other approaches, another discipline may hold the sole responsibility of making treatment decisions. Improved allocation of professional role responsibilities in both the NICU setting and within intervention teams to improve the care provided in team-based approaches may allow for more involvement in treatment decisions for SLPs while following the ASHA guidelines (ASHA, 2004).

These responses are consistent with the “Knowledge and Skills Needed by Speech-Language Pathologists Providing Services to Infants and Families in the NICU

Environment” roles as detailed by ASHA (2004). Since there is not a standard protocol for the assessment or treatment of infants with NAS procedures may vary from hospital to hospital or state to state, and in relation, the SLP may participate in different aspects of the assessment or treatment process based on the policies of their place of work. Some settings may even have restrictions on who can do which assessments so referrals may be more common in these cases. This is why it is important for SLPs to ensure that they are working within not only their scope of practice but also within the guidelines set forth by ASHA for their specific setting while advocating for inclusion in the treatment process when appropriate.

The NICU SLPs’ Role in Intervention for Infants with NAS: Education

Education was provided by respondents through coaching/counseling, communication of findings, and demonstrations on the general characteristics of NAS, the characteristics of feeding, swallowing, feeding methods, interpreting communication signals, interaction methods, and treatment. In addition, some of these respondents indicated they offer or lead support/informational groups. These education opportunities can be beneficial to anyone who cares for infants with NAS. The respondents reported providing education to a variety of caregivers from biological mothers and biological fathers to caregivers (other family members - including foster and/or adoptive family members) and healthcare professionals.

The SLPs’ responses align with the “Knowledge and Skills Needed by Speech-Language Pathologists Providing Services to Infants and Families in the NICU Environment” (ASHA, 2004) to provide education, counseling, and support to families, caregivers, and staff aiding in the identification of disruptions in infant communication, feeding, and swallowing functions.

Only 60% of respondents reported providing education on care following discharge. This is a crucial area where SLPs could be playing a more significant role. They are encouraged to do so in Role 9.0 as detailed in the “Knowledge and Skills Needed by Speech-Language Pathologists Providing Services to Infants and Families in the NICU Environment” (ASHA, 2004). SLPs provide education to biological mothers, biological fathers, and caregivers (other family members - including foster and/or adoptive family members) on follow-up care and transitioning to community-based services. It can be challenging for SLPs to provide education to biological fathers and other caregivers because, in some situations, only the biological mother is accessible during the hospital stay. In the case of mothers of infants with NAS, they too, may visit sporadically or not at all in some cases. The biological mothers may be in a recovery program themselves or removed from the picture in some situations where the infant’s safety and well-being are at risk. Education for caregivers such as foster and/or adoptive family members may not always be for the hospital-based SLP as contact with these individuals may be restricted. However, if it is possible, the SLP should try to provide education or at the least provide educational materials (Whincup & Johnson, 2012) to those who are involved in the care of the infant with NAS. An interprofessional approach to providing discharge education is standard practice for premature infants through bedside education, parent groups, electronic resources, and print resources (Jefferies, 2014). This results in a positive transition and effective care post-discharge. For infants with NAS, a similar approach may be utilized, but the information would differ in that it would be tailored to NAS. By doing so, the SLPs can provide the best care and guidance in terms of development once the infants with NAS are discharged. The SLPs can also educate families/caregivers on red flags to pay attention to in order to catch any additional

problems as early as possible. This allows for more successful intervention if future issues arise in feeding, swallowing, or communicating.

Also, while that healthcare professionals are receiving education from the SLPs on NAS as confirmed by the respondents, only 67% of respondents provided education to volunteers. Volunteers are becoming more common in the care of infants with NAS as a result of hospital programs such as baby cuddlers (Kraynek, Patterson, & Westbrook, 2012) and the accompanying media coverage advertising of these programs. This type of volunteer program is an integrated part of the care of infants with NAS, especially those receiving non-pharmacological treatment and has been shown to decrease the length of stay for these infants (Kraynek et al., 2012). As the volunteer force increases, SLPs should be educating these individuals as well since they assist in caring for these infants with NAS. Ensuring the volunteers have education on NAS would improve the quality of care they may provide to the infants with an improved understanding of the infants' needs.

Education on NAS for Hospital-Based SLPs

According to the responses of the respondents, receiving formal education about NAS is not standard for hospital-based SLPs, especially in comparison to the frequency of reported feeding/swallowing education. Of the eleven respondents, 36% reported having no formal education on NAS, whereas 100% reported receiving formal feeding/swallowing education.

Furthermore, all of the respondents had received some form of pediatric feeding or swallowing education/training in their graduate coursework, clinical placement, or through CEUs. The respondent response rates for pediatric feeding or swallowing education/training are supported by the ASHA required core courses in accredited graduate programs and the scope of practice for SLPs set forth by ASHA (ASHA, 2014; ASHA, n.d.). No respondents received

formal education on NAS in their graduate studies, which is consistent with the findings of Ratliff (2017) on the low rates of education on NAS. Ratliff (2017) found that only 4.8% of 228 school-based SLPs had formal NAS education, a clear indication that education is needed. The findings of Ratliff are confirmed by this study's results which support the need for formal education on NAS. The growing opioid crisis and increase in the NAS population necessitate the inclusion of this topic in graduate program education to ensure the education of future clinicians in NAS.

Respondents explored multiple avenues of education, and 54% of respondents reported that they educated themselves in NAS through CEUs and even independent study. The additional education opportunities sought by respondents suggests a growing interest and desire to acquire knowledge relating to this population, especially for currently practicing SLPs. This indicates that opportunities for education on NAS should continue to be offered to continue to inform the field as a whole, including those currently interacting with infants with NAS. Currently practicing SLPs would receive the most benefits from formal education on NAS through opportunities like CEUs as they are a part of not only SLPs certification maintenance requirements but also the code of ethics which SLPs abide by (ASHA, 2016).

Care/Treatment Team Members for Infants with NAS

Identifying who is on the care/treatment team for infants with NAS was an important component of this study because as far as can be determined, there is not any literature currently addressing this topic. This study produced a list of 25 different interprofessional team members based on responses of seven respondents in an effort to confirm the key members of the care/treatment team. In order of most prevalent among the respondent responses, interprofessional team members include SLPs, Family, Social Worker, Lactation Specialist,

Physical Therapist (PT), Neonatal Nurse Practitioner, Bedside Nurse, and Nurse. Sometimes the team will include Mother, Respiratory Therapist, Occupational Therapist (OT), Neonatologist, and Dietician. However, less than half include a Case Worker, Gastroenterologist, Pediatrician/Pediatric Specialist, Audiologist, Neurologist, Nurse Practitioner. Seldom do these teams include a Pharmacist, Child Life Specialist, Nutritionist, Pulmonologist, according to the respondents. Rarely, an Early Intervention Liaison and/or Radiologist may be included in the team.

The identification of team members by this study is unique because it has not been investigated before. However, this result validates recommendations of Kraft et al. (2016) as everyone in the NICU strives for best practice for infants with NAS. They encouraged a multidisciplinary approach, including obstetricians, pediatricians, nurses, social workers. Jefferies (2014) states that for a preterm infant, discharge planning begins when they are admitted to the NICU and requires an interprofessional, multidisciplinary approach. As a NICU population, infants with NAS should receive the same style approach. In the open-ended question on the survey, one respondent stated: “*NICU RNs need to refer to SLPs more,*” which could be addressed through an interprofessional team-based approach which would encourage communication between disciplines. Based on the results of the present study and literature findings (Jefferies, 2014; Kraft et al., 2016), treatment of infants with NAS by an interprofessional team is not universal. Vital to providing the best care, an interprofessional team-based approach in place is important for holistic treatment with communication between all of the infant’s HCPs.

Hospital/NICU Environments

Respondents identified that on average, only about 10% of the hospitals' beds were located in the NICU. The number of beds in the respondents' hospitals ranged between 0 and 1157, and the number of NICU beds ranged from 0 to 120. The respondent also identified that their NICU beds are more often full than empty. The estimated occupancy of their NICUs over the last three months for a third of respondents' NICUs was 51-75%; another third reported theirs were 76-100% occupied. The NICU Levels at the ten respondents' hospitals were mostly Level III: Subspecialty Newborn Care and Level IV: Highest Level of Neonatal Care which provides some of the highest levels of care to these vulnerable infants. This demographic information provides insight into the settings of the respondents and level of care their setting can provide.

Respondents reported that infants with NAS at their hospitals were cared for in the general NICU for the most part with some in a general nursery. A small set stayed in a particular section of the NICU; answered *in (other, please describe:)* with “*Continuing Care Nursery*”; or answered *in (other, please describe:)* with “*Referred Out.*” Of the ten respondents, 30% did not have a NICU at their hospital, and 10% refer out their infants with NAS, which calls into question the research study design. However, 33% have infants “Rooming-In” with their caregiver which is consistent with the literature on best practice for infants with NAS as discussed in Boucher (2017), Kocherlakota (2014), and Kraft et al. (2016). The practice of “Rooming-In” and keeping the mother and child together through their stay provides many benefits for the infant and mother but also is beneficial for hospitals that may not have a NICU or are unable to accommodate infants with NAS in the NICU as it can improve outcomes while reducing length of stay for infants with NAS.

Limitations

The primary limitation of this study was the inability to generalize the findings as perceptions of the field as a whole due to low response numbers. This resulted in the inability to identify how SLPs can best serve infants with NAS in the NICU, which was the original intent of the study. The limited number of respondents participating in the study can be ascribed to various factors. First, the survey itself may have been too long and complicated for busy hospital-based SLPs with productivity demands. A shorter survey with more straightforward questions may have resulted in a higher number of responses. Secondly, the researcher was limited to distribution through IRB approved channels. Despite public access to the names of every hospital containing a NICU through the Vermont Oxford Network, without publicly available direct email addresses, it proved difficult to reach the many SLPs across the country who serve NICUs. A paper-based survey mailed to the hospitals to the attention of their SLPs may have led to a higher response rate but would have come with additional cost and an extended distribution period given the time it would take for the mailed survey to reach their targeted audience and be returned.

In addition, all geographical regions of the United States were each represented, albeit by very limited numbers and few states, which resulted in an uneven representation of respondents. Only seven different states, Alabama, California, Montana, New Hampshire, North Carolina, South Dakota, and Texas, were represented in the sample by the respondents. Respondents indicated their population densities as primarily urban, some rural, and the minority suburban. Ultimately, this sample is not large enough to allow for generalization of the findings from this study. The low number of responses limited the findings of this study. The distribution approach did not allow for the calculation of a response or nonresponse rate, as membership numbers for

distribution groups were unavailable. The inability to establish the reach of the study may impact the validity of the results.

Time was also a barrier for this study. The number of responses may have been increased, had the time for data collection been extended. Extended duration of the survey period may have allowed for more responses. Additional time may have also increased distribution because many state associations did not respond in a timely manner to the email request or had a lengthy internal review/approval process. Some state associations also required a fee to distribute research, which was not an option for this study.

The survey design may have also contributed to the low number of responses. The survey was designed for hospital-based SLPs working in the NICU, but from responses received, it appeared that infants with NAS are not always treated within the NICU. Hospital-based SLPs who treat infants with NAS in other settings such as general nurseries or refer them out may not have participated as this study did not explicitly include them which may have affected the responses. It is recommended that in future all hospital-based SLPs be included in such a study without the restriction of a specific unit.

Finally, the low number of responses may also be due to professionals from other disciplines seeing infants for feeding. OT, PT, specialized Nurses, Lactation Specialists/Consultants, and/or SLPs may play a role for feeding an infant in the NICU depending on the setting and their policies (Crouse Hood, 2019). Cue-based feeding is often targeted not only by SLPs but also OTs as it is an activity of daily living (ADL). ADLs fall under the scope of occupational therapy, so feeding and parent education for feeding may be tasked to the OT serving the NICU (Caretto, Topolski, Linkous, Lowman, & Murphy, 2000). Therefore,

future studies may further investigate which discipline provides feeding intervention for infants with NAS.

Since the nature of this study was exploratory, the conclusions are limited to the research questions and, due to limitations, the study was not able to provide sufficient evidence to answer the research questions. The results gathered, however, provide a starting point for future research on this population.

Recommendations for Further Research

As a result of the exploratory nature of this study, future research and clinical implications were identified. This study indicates the need for the development of guidelines for education and clinical practice for NAS and the role of the SLP for this population. Further research should focus on establishing standard procedures for this population.

The findings of the current study have implications for the formal education of SLPs. Respondents indicated limited formal education in NAS. Education is vital because of the rapid growth in this population. The findings of the current study have identified that there is a disparity in formal education currently provided or, perhaps even available, to SLPs regarding infants with NAS which needs to be addressed.

The findings of this study serve to act as a stepping stone for further research within the field of speech-language pathology on infants with NAS to contribute to not only the understanding in the speech-language pathology field but also the interprofessional knowledge base. More research on NAS will result in a knowledge base of the characteristics and behaviors of infants with NAS, which will further inform strategies for assessment and treatment. These strategies can then be researched further to develop guidelines for evidence-based practice. However, SLPs must not rely solely on the research of other disciplines as the SLP perspective

has much to offer and would greatly inform practice for infants with NAS, especially for communication and feeding.

Recommendations for Future Collaboration

Clinician-researcher collaboration for future research will also provide greater insight into current practices and identification of possible areas of need for infants with NAS. Inclusion of practicing clinicians in the research process can advance the understanding of current practices while also acting as a way to educate on evidence-based best practice. Often there is a disconnect between current research and practices implemented within clinical settings, especially in the case of NAS where there is not a standard protocol. To continue strengthening the interprofessional knowledge base on infants with NAS, the opportunity for more research should not be divided by multiple disciplines but instead unified to represent better the many fields involved. Such research would contribute to not only improving the current understanding of infants with NAS but also improve the basis for evidence-based interprofessional practice for this population.. Working together, not only would it unite multiple disciplines, but it would also address the researcher-clinician gap (Orlikoff et al., 2014).

Conclusions

As the substance abuse epidemic continues to grow, the population of infants with NAS will be a growing population on the caseloads of SLPs. The role of the SLP with infants with NAS was explored in this study. It will be necessary for SLPs to utilize their clinical expertise as well as evidence-based knowledge of the population to ensure appropriate and effective identification and intervention. These infants need to receive assessment and intervention fitted to their particular needs to minimize or even prevent later communication disorders which can impact scholastic achievement. Additional research is needed to ensure the short- and long-term

development of these infants. The findings of this study are important since, as far as could be determined, it is presently the only study that emphasized the perspective of SLPs and their roles with this population specifically.

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APPENDICES

Appendix A

Pilot Survey Questionnaire with Logic Descriptions **The Perceptions of Neonatal Intensive Care Unit Speech-Language Pathologists**

Page 2: **Section 1: Neonatal Abstinence Syndrome (NAS)**

Neonatal abstinence syndrome (NAS) is the withdrawal experience that results from prenatal exposure to opioids. As the number of women who use drugs while pregnant has risen during the current opioid crisis, so has the incidence of NAS in their infants. The role of the SLP in the treatment of infants with NAS has not been researched in any depth to date and many questions remain regarding evidence-based treatments for this vulnerable population. As the opioid crisis continues to grow and spread across the nation, it is imperative to increase research for the treatment of the infants with NAS that result from this growing epidemic.

2. Do you have infants with NAS on your caseload? Y/N

If they have answered “No” above, respondent will be directed to Question 11.

All of the following questions will appear if they have answered “Yes” above.

Page 3: Neonatal abstinence syndrome (NAS) is the withdrawal experience that results from prenatal exposure to opioids. As the number of women who use drugs while pregnant has risen during the current opioid crisis, so has the incidence of NAS in their infants. The role of the SLP in the treatment of infants with NAS has not been researched in any depth to date and many questions remain regarding evidence-based treatments for this vulnerable population. As the opioid crisis continues to grow and spread across the nation, it is imperative to increase research for the treatment of the infants with NAS that result from this growing epidemic.

3. Please select the statement best describing your interaction with infants with NAS:
 - a. I see all infants with NAS.
 - b. I see only infants with NAS and feeding problems.
 - c. I see only infants with NAS with suspected swallowing problems.
 - d. Other, please describe: _____

Page 4: Please estimate the percentage of the infants with NAS on your caseload who:

4. Are diagnosed with NAS only?
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%
5. Are born full term with complications and NAS?
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%
6. Are born prematurely and with NAS?
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%
7. Are born with Craniofacial Anomalies (e.g. CL/CP, Pierre-Robin Sequence) and NAS?
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%

8. Other, please describe: _____
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%

Page 5:

9. Select the feeding/swallowing characteristics you most commonly observe in infants with NAS on your caseload, if applicable:

	Infants with NAS Only	Full Term Infants with NAS and Complications	Premature Infants with NAS	Infants with NAS and Craniofacial Anomalies (e.g. CL/CP, Pierre-Robin Sequence)
<u>Respiration Regulation:</u> Integrates breathing within the sucking burst				
Presents with signs of cardio-respiratory instability				
<u>Sucking: Intraoral Pressure</u> Normal/Adequate				
Difficulty in achieving negative intraoral pressure				
<u>Sucking: Sucking Rate/Frequency</u> Normal Sucking Rate				
Increased/Excessive Sucking Rate				
Decreased/Slow Sucking Rate				
<u>Sucking: Sucking Bursts</u> Normal bursts				
Longer bursts				
Shorter bursts				
<u>Swallow</u> Normal				
Auditory signals of poor coordination (e.g. gulping, gurgle, yelp, cough, choke)				
Aspiration				
<u>Oral Mechanism</u> Normal				
Low Tonicity				
High Tonicity				
Transient Tonicity				
<u>Other</u> Nasal Regurgitation				
Reflux				

Page 6: What behavioral characteristics do you most commonly note in infants with NAS on your caseload for each of the following categories?

- 10. General Sleep States. (Select one): Deep, Light
- 11. Sleeping Post Feeding. (Select all that apply): Normal, Reduced Quality, Reduced Length
- 12. Awake States During Feeding. (Select all that apply): Shut Down to External Stimuli, Drowsy, Alert, Eyes Open, Irritable/Fussy, Agitation, Crying, Inconsolable Crying
- 13. Respiratory Behaviors. (Select all that apply): Normal Rate, Low Rate, High Rate, Apnea, Nasal Flaring, Nasal Congestion, Frequent Sneezing
- 14. Time to Complete a Feed. (Select one): Appropriate, Decreased, Increased, Does not complete a feed

Page 7:

- 15. What percent of feeding time do the infants with NAS actually spend feeding, on average?

Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%

Page 8: On average, what percent of infants with NAS are:

- 16. Exclusively orally fed:

Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%

- 17. Briefly fed via nasogastric tube (NG-tube):

Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%

- 18. Fed for an extended period of time via nasogastric tube (NG-tube):

Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%

- 19. Transitioned to a gastrostomy tube (G-tube):

Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%

Page 9: **Section 1: Neonatal Abstinence Syndrome (NAS) – Assessment**

What activities do you use to assess infants with NAS?

- 20. I gather information of relevant medical history and current status. True/False
- 21. I contribute to the diagnosis of NAS using: (select all that apply) *Finnegan Neonatal Abstinence Score, Eat Sleep Console, None, Other, please specify:*

- 22. I assess the feeding/swallowing skills of infants with NAS using the following: (select all that apply) *Bedside/Observational Evaluation, Instrumental Evaluation, Early Feeding Skills Assessment, None, Other, please specify:*

- 23. I identify potential risks of aspiration and physiologic compromise. True/False

- 24. I conduct procedures such as: *Modified Barium Swallow Study, Videofluoroscopic Instrumental Swallow Studies, Endoscopic Assessments of Swallowing Function, Pulmonary Testing, pH Probe for Reflux, None, Other, please specify:*

- 25. I refer for additional procedures such as: *Modified Barium Swallow Study, Videofluoroscopic Instrumental Swallow Studies, Endoscopic Assessments of Swallowing Function, Pulmonary Testing, pH Probe for Reflux, None, Other, please specify:*

26. I assess mother/infant interaction. True/False

Page 10: **Section 1: Neonatal Abstinence Syndrome (NAS) – Treatment**

What activities do you use to treat infants with NAS?

27. I review daily medical notes. True/False

28. I provide developmentally appropriate: (select all that apply) Environmental Modulation, Positioning and Handling, Interventions, None, Other, please specify: _____

29. I read, interpret, and respond to the behavioral cues of the infant with NAS. True/False

30. I determine readiness for interaction and intervention. True/False

31. I adjust interaction on the basis of variability in responses. True/False

32. I identify and adjust feeding methods on the basis of variability in responses. True/False

33. I recommend precautions to minimize risks of aspiration and physiologic compromise. True/False

34. I provide cue-based feeding. True/False

35. I provide family-centered care including: (select all that apply) Environmental Modulation, Appropriate Positioning and Handling, Feeding Interventions, None, Other, please specify: _____

36. I support non-pharmacological treatment. True/False

37. I participate in non-pharmacological treatment. True/False

Page 11: **Section 1: Neonatal Abstinence Syndrome (NAS) – Education**

38. What educational activities do you provide about infants with NAS?

Coaching/Counseling, Support/Informational Groups, Communicate Findings, Demonstrations, None, Other, please specify: _____

39. I provide education on the following topics relating to infants with NAS: (select all that apply) General Characteristics, Characteristics of Feeding, Swallowing, Feeding Methods, Interpreting Communication Signals, Interaction Methods, Treatment, Care Following Discharge, None, Other, please specify: _____

40. I provide education to: (select all that apply) Biological Mothers, Biological Fathers, Caregivers (other family members - including foster and/or adoptive family members), Volunteers, Healthcare Professionals, None, Other, please specify: _____

Page 12: Considering the entire population of infants you serve in the hospital, what role(s) do you play in intervention for the following populations?

41. I play a role in identifying patients at risk for feeding problems. (Select all that apply) Infants with NAS, Infants without NAS, Neither

42. I participate in the assessment of the patient and family for feeding problems. (Select all that apply) Infants with NAS, Infants without NAS, Neither

43. I conduct bedside/observational for feeding problems. (Select all that apply)

44. I provide support and intervention/treatment for feeding problems. (Select all that apply) Infants with NAS, Infants without NAS, Neither

45. I provide education to families, other caregivers, and staff regarding preferred practices in the NICU to support current and future feeding skills. (Select all that apply) Infants with NAS, Infants without NAS, Neither
46. I conduct instrumental evaluation of the patient for swallowing problems. (Select all that apply) Infants with NAS, Infants without NAS, Neither
47. I refer for instrumental evaluation of the patient for swallowing problems. (Select all that apply) Infants with NAS, Infants without NAS, Neither
48. I provide education to families, other caregivers, and staff regarding preferred practices in the NICU to support current and future swallowing skills. (Select all that apply) Infants with NAS, Infants without NAS, Neither
49. I provide support to families, other caregivers, and staff regarding preferred practices in the NICU to support current and future communication skills. (Select all that apply) Infants with NAS, Infants without NAS, Neither
50. I provide discharge/transition planning and follow-up care. (Select all that apply)
51. I collaborate with other team members to identify the need for additional assessment and consultation. (Select all that apply) Infants with NAS, Infants without NAS, Neither, Prefer not to answer (continue survey)

If they have answered “Infants without NAS”, “Neither”, or “Prefer not to answer (continue survey)” above, respondent will be directed to Question 53.

If they have answered “Infants with NAS” above to “I collaborate...assessment and consultation” then the following question (53) will appear.

Page 13:

52. Identify the healthcare professionals who collaborate on your NAS treatment team: (Select All That Apply) Neonatologist, Nurse, Bedside Nurse, Nurse Practitioner, Neonatal Nurse Practitioner, Neurologist, Occupational Therapist, Physical Therapist, Speech-Language Pathologist, Audiologist, Respiratory Therapist, Pulmonologist, Radiologist, Gastroenterologist, Otolaryngologist (ENT), Pediatrician/Pediatric Specialist, Pharmacist, Obstetrician/Gynecologist (OB/GYN), Lactation Specialist, Nutritionist, Dietician, Case Worker, Social Worker, Drug Rehab Counselor, Early Intervention Liaison, Mother, Family, Other, please describe:
-

Page 14: **Section 2: Environmental Description**

53. What is the number of beds in your hospital: ____
54. What is the number of NICU beds in your hospital: ____
55. Estimate the occupancy of your NICU over the last 3 months:
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%
56. In which state is your hospital located:
USA State Drop Down
57. What best describes the population you serve at your hospital, please select all that apply:
Rural, Urban, Suburban
58. What is the NICU Level at your hospital: Drop Down
There is no NICU at my hospital

- Level I: Basic Newborn Care
- Level II: Advanced Newborn Care
- Level III: Subspecialty Newborn Care
- Level IV: Highest Level of Neonatal Care

59. Are infants with NAS in your hospital, select all that apply:

- In your general NICU
- In a particular section of NICU
- In a specialized unit for NAS
- In a general nursery
- In (other, please describe:) _____

If they have answered “In your general NICU”, “In a particular section of NICU”, “In a general nursery”, or “In (other, please describe:) _____” above, respondent will be directed to Question 62.

If they have answered “In a specialized unit for NAS” above to “Are infants with NAS in your hospital, select all that apply:” then the following questions (60 & 61) will appear.

- 60. What is the number of NAS beds in your specialized unit: _____
- 61. Estimate the occupancy of your NAS unit over the last 3 months:
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%

Page 15: **Section 3: Respondent Demographics**

- 62. What is your highest level of education?
Drop Down: Master's degree, Doctoral degree
- 63. Gender:
Drop Down: Male, Female, Non-binary/ third gender, Transgender, Prefer not to disclose
- 64. Indicate any types of NAS education/training you have received, please select all that apply: Graduate Coursework, Graduate Clinic Placement, Post-Graduate Clinic Placement, CEU, None, Other, please describe: _____
- 65. Indicate any types of Pediatric Feeding or Swallowing education/training you have received, please select all that apply:
Graduate Coursework, Graduate Clinic Placement, Post-Graduate Clinic Placement, CEU, None, Other, please describe: _____
- 66. How many years have you been employed as a speech-language pathologist? Please Select:
Drop Down: 0-5 years, 6-10 years, 11-15 years, 16-20 years, 21-25 years, 26-30 years, 31 or more years
- 67. How many years have you been working with infants in a hospital? Please Select:
Drop Down: 0-5 years, 6-10 years, 11-15 years, 16-20 years, 21-25 years, 26-30 years, 31 or more years
- 68. Please share any additional comments and experiences related to infants with NAS and their feeding skills:

Appendix B

Pilot Study Recruitment Letter

Subject Line: Pilot for ETSU Survey of the Perceptions of Neonatal Intensive Care Unit Speech-Language Pathologists

Body Text:

Dear [Pilot Participant],

I invite you to participate in the pilot study for my survey! My name is Lauren Fabrize and I am currently working on my master's degree in speech-language pathology at East Tennessee State University (ETSU). I am conducting a research study for my master's thesis.

About The Pilot Study: The purpose of this study is to gather information on your experience as a hospital-based speech-language pathologist (SLP), particularly as it pertains to infants diagnosed with Neonatal Abstinence Syndrome (NAS). Results from this survey will be disseminated and describe current SLPs' practices for infants with NAS and how intervention might differ from other NICU populations.

Your Role: Your participation in this pilot study is completely voluntary. You may skip any questions you do not wish to answer or simply exit the online survey at any time if you wish to remove yourself entirely. Declining to participate or opting to discontinue participation will not have any negative effects on you or your place of employment. All responses to the online survey are anonymous. Although your rights and privacy will be maintained, the ETSU IRB and our team members have access to the study records. Since this research is focused on your perspectives, there are no risks involved. On October 26th, 2018 ETSU IRB deemed that this pilot, as described on the Form 129, meets neither the US Food and Drug Administration (FDA) nor the Department of Health and Human Services (DHHS) definition of research involving human subjects and therefore does not require ETSU IRB approval to be completed.

I sincerely appreciate the time taken to provide your expert input into our pilot study.

Pilot Procedure: Please complete the pilot study survey online. To access the survey, please select this link: <https://www.surveymonkey.com/r/82R6M7X>

Attached is a form titled "Pilot Feedback Form November 2018" for you to provide your feedback during and after you have taken the survey. Attached you will also find a copy of my survey questions titled "Pilot Study Survey -- Survey of the Perceptions of Neonatal Intensive Care Unit Speech-Language Pathologists" for reference when you provide your feedback. Please complete the online survey as well as the form with your feedback and return it to us via email at your earliest convenience but if possible within a week. If this timeframe is problematic, please let me know.

If you have research-related questions or problems, you may contact Lauren Fabrize at fabrize@etsu.edu. You may also contact my research mentor, Dr. Kerry Proctor-Williams, at williamk@etsu.edu. Also, the chairperson of the Institutional Review Board at East Tennessee State University is available at (423) 439-6054 if you have questions regarding your rights as a

research subject. If you have questions or concerns about the research and want to talk to someone independent of the research team or you cannot reach the study staff, you may call an IRB Coordinator at (423) 439-6055 or (423) 439-6002.

I thank you for your time and appreciate your assistance in helping to improve my survey.

Sincerely,

Lauren Fabrize, B.S.
Primary Investigator - Graduate Student/Clinician
Department of Audiology and Speech-Language Pathology
College of Clinical and Rehabilitative Health Sciences
East Tennessee State University
fabrize@etsu.edu

Under the mentorship of Drs. Proctor-Williams & Louw
Department of Audiology and Speech-Language Pathology
College of Clinical and Rehabilitative Health Sciences
East Tennessee State University

Appendix C

Pilot Study Reminder Email

Subject Line: Re: Pilot for ETSU Survey of the Perceptions of Neonatal Intensive Care Unit Speech-Language Pathologists

Body Text:

Dear [Pilot Participant],

Once again, thank you for agreeing to participate in the pilot study for my survey! I sincerely appreciate the time taken to provide your expert input. Just a reminder, please complete the survey and send your feedback when you have a chance. I am excited to receive your response!

If you have any questions you may contact me at fabrize@etsu.edu. You may also contact my research mentor, Dr. Kerry Proctor-Williams, at williamk@etsu.edu.

I thank you again for your time and appreciate your assistance in helping to improve my survey.

Sincerely,

Lauren Fabrize

Lauren Fabrize, B.S.
Primary Investigator - Graduate Student/Clinician
Department of Audiology and Speech-Language Pathology
College of Clinical and Rehabilitative Health Sciences
East Tennessee State University

Under the mentorship of Drs. Proctor-Williams & Louw
Department of Audiology and Speech-Language Pathology
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East Tennessee State University

Appendix D

Pilot Study Feedback Form

	Comments:
1. Approximately how long did it take you to complete the questionnaire?	
2. Were the questions clear and easy to understand?	
3. Were the answer options suited to the questions posed?	
4. Was any aspect of the questionnaire unclear (ex. Terminology)?	
5. Did you ever feel forced to make a choice that did not fit your particular situation? Please indicate on which question.	
6. If you responded “Yes” to Question 5; why did you feel forced to make this choice on the question?	
7. Do you have any changes to suggest? Please indicate which question for any revisions.	
8. Do you have any suggestions for further questions to be included? Please indicate which section for any additions.	
9. In your opinion, were the questions appropriate to the topic being researched?	
10. Please share any suggestions of how this questionnaire could be improved.	

Appendix E

Survey Questionnaire with Logic Descriptions

The Perceptions of Neonatal Intensive Care Unit Speech-Language Pathologists

Page 2: Section 1: Neonatal Abstinence Syndrome (NAS)

Neonatal abstinence syndrome (NAS) is the withdrawal experience that results from prenatal exposure to opioids. As the number of women who use drugs while pregnant has risen during the current opioid crisis, so has the incidence of NAS in their infants. The role of the SLP in the treatment of infants with NAS has not been researched in any depth to date and many questions remain regarding evidence-based treatments for this vulnerable population. As the opioid crisis continues to grow and spread across the nation, it is imperative to increase research for the treatment of the infants with NAS that result from this growing epidemic.

2. Do you have infants with NAS on your caseload? Y/N

If they have answered “No” above, respondent will be directed to Page 12 beginning with Question 42.

All of the following questions will appear if they have answered “Yes” above.

Page 3: Neonatal abstinence syndrome (NAS) is the withdrawal experience that results from prenatal exposure to opioids. As the number of women who use drugs while pregnant has risen during the current opioid crisis, so has the incidence of NAS in their infants. The role of the SLP in the treatment of infants with NAS has not been researched in any depth to date and many questions remain regarding evidence-based treatments for this vulnerable population. As the opioid crisis continues to grow and spread across the nation, it is imperative to increase research for the treatment of the infants with NAS that result from this growing epidemic.

This survey will address the following 5 topics: NAS, Assessment, Treatment, Education, and Environmental Description.

3. Please select the statement best describing your interaction with infants with NAS:
1. I see all infants with NAS.
 2. I see only infants with NAS and feeding problems.
 3. I see only infants with NAS with suspected swallowing problems.
 4. Other, please describe: _____

Page 4: Please estimate the percentage of the infants with NAS on your caseload who:

4. Are diagnosed with NAS only?
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%
5. Are born full term with complications and NAS?
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%
6. Are born prematurely and with NAS?
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%

7. Are born with Craniofacial Anomalies (e.g. CL/CP, Pierre-Robin Sequence) and NAS?
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%
8. Other, please describe: _____
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%

Page 5:

9. Select the feeding/swallowing characteristics you most commonly observe in infants with NAS on your caseload, if applicable:

	Infants with NAS Only	Full Term Infants with NAS and Complications	Premature Infants with NAS	Infants with NAS and Craniofacial Anomalies (e.g. CL/CP, Pierre-Robin Sequence)
<u>Respiration Regulation:</u> Integrates breathing within the sucking burst				
Presents with signs of cardio-respiratory instability				
<u>Latching:</u> Adequate				
Inadequate				
Spillage				
Refusal				
<u>Sucking: Intraoral Pressure</u> Normal/Adequate				
Difficulty in achieving negative intraoral pressure				
<u>Sucking: Sucking Rate/Frequency</u> Normal Sucking Rate				
Increased/Excessive Sucking Rate				
Decreased/Slow Sucking Rate				
<u>Sucking: Sucking Bursts</u> Normal bursts				
Longer bursts				
Shorter bursts				
<u>Swallow</u> Normal				
Auditory signals of poor coordination (e.g. gulping, gurgle, yelp, cough, gag, choke)				
Aspiration				
<u>Oral Mechanism</u>				

Normal				
Low Tonicity				
High Tonicity				
Transient Tonicity				
<u>Other</u> Nasal Regurgitation				
Reflux/Spit-up				
Arching Away				

Page 6: What behavioral characteristics do you most commonly note in infants with NAS on your caseload for each of the following categories?

10. General Sleep States. (Select one): Deep, Light
11. Sleeping Post Feeding. (Select all that apply): Normal, Reduced Quality, Reduced Length
12. Awake States During Feeding. (Select all that apply): Shut Down to External Stimuli, Drowsy, Calm, Alert, Hyper Alert, Eyes Open, Irritable/Fussy, Agitation, Crying, Inconsolable Crying
13. Respiratory Behaviors. (Select all that apply): Normal Rate, Low Rate, High Rate, Apnea, Nasal Flaring, Nasal Congestion, Frequent Sneezing
14. Time to Complete a Feed. (Select one): Appropriate, Decreased, Increased, Does not complete a feed

Page 7:

15. About what percentage of a total feeding session do the infants with NAS actually spend feeding?
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%

Page 8: On average, what percent of infants with NAS are:

16. Exclusively orally fed:
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%
17. Briefly fed via nasogastric tube (NG-tube):
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%
18. Fed for an extended period of time via nasogastric tube (NG-tube):
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%
19. Transitioned to a gastrostomy tube (G-tube):
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%

Page 9: **Section 1: Neonatal Abstinence Syndrome (NAS) – Assessment**

What activities do you use to assess infants with NAS?

20. I gather information of relevant medical history and current status. True/False

21. I contribute to the diagnosis of NAS using: (select all that apply) *Finnegan Neonatal Abstinence Score, Eat Sleep Console*, None, Other, please specify: _____
22. I assess the feeding/swallowing skills of infants with NAS using the following: (select all that apply) *Bedside/Observational Evaluation, Instrumental Evaluation, Early Feeding Skills Assessment*, Infant Driven Feeding Scales, None, Other, please specify: _____
23. I identify potential risks of aspiration and physiologic compromise. True/False
24. I conduct procedures such as: Modified Barium Swallow Study, Videofluoroscopic Instrumental Swallow Studies, Endoscopic Assessments of Swallowing Function, Pulmonary Testing, pH Probe for Reflux, None, Other, please specify: _____
25. I refer for additional procedures such as: Modified Barium Swallow Study, Videofluoroscopic Instrumental Swallow Studies, Endoscopic Assessments of Swallowing Function, Pulmonary Testing, pH Probe for Reflux, Milk Scan, Gastric Emptying Assessment, Bronchoscopy, ENT Assessment, None, Other, please specify: _____
26. I assess mother/infant interaction. True/False

Page 10: **Section 1: Neonatal Abstinence Syndrome (NAS) – Treatment**

What activities do you use to treat infants with NAS?

27. I review daily medical notes. True/False
28. I provide developmentally appropriate: (select all that apply) *Environmental Modulation, Positioning and Handling, Feeding Interventions*, None, Other, please specify: _____
29. I read, interpret, and respond to the behavioral cues of the infant with NAS. True/False
30. I determine readiness for interaction and intervention. True/False
31. I adjust interaction on the basis of variability in responses. True/False
32. I identify and adjust feeding methods on the basis of variability in responses. True/False
33. I recommend precautions to minimize risks of aspiration and physiologic compromise. True/False
34. I provide cue-based feeding. True/False
35. I support breast feeding when appropriate. True/False
36. I provide family-centered care including: (select all that apply) *Environmental Modulation, Appropriate Positioning and Handling, Feeding Interventions*, None, Other, please specify: _____
37. I participate in non-pharmacological treatment. True/False
38. I contribute to pharmacological treatment decisions when appropriate. True/False

Page 11: **Section 1: Neonatal Abstinence Syndrome (NAS) – Education**

39. What educational activities do you provide about infants with NAS?
Coaching/Counseling, Support/Informational Groups, Communicate Findings, Demonstrations, None, Other, please specify: _____

40. I provide education on the following topics relating to infants with NAS: (select all that apply) General Characteristics, Characteristics of Feeding, Swallowing, Feeding Methods, Interpreting Communication Signals, Interaction Methods, Treatment, Care Following Discharge, None, Other, please specify: _____
41. I provide education to: (select all that apply) Biological Mothers, Biological Fathers, Caregivers (other family members - including foster and/or adoptive family members), Volunteers, Healthcare Professionals, None, Other, please specify:

Page 12: Considering the entire population of infants you serve in the hospital, what role(s) do you play in intervention for the following populations?

42. I play a role in identifying patients at risk for feeding problems. (Select all that apply)
Infants with NAS, Infants without NAS, Neither
43. I participate in the assessment of the patient and family for feeding problems. (Select all that apply) Infants with NAS, Infants without NAS, Neither
44. I conduct bedside/observational for feeding problems. (Select all that apply)
45. I provide support and intervention/treatment for feeding problems. (Select all that apply)
Infants with NAS, Infants without NAS, Neither
46. I provide education to families, other caregivers, and staff regarding preferred practices in the NICU to support current and future feeding skills. (Select all that apply) Infants with NAS, Infants without NAS, Neither
47. I conduct instrumental evaluation of the patient for swallowing problems. (Select all that apply) Infants with NAS, Infants without NAS, Neither
48. I refer for instrumental evaluation of the patient for swallowing problems. (Select all that apply) Infants with NAS, Infants without NAS, Neither
49. I provide education to families, other caregivers, and staff regarding preferred practices in the NICU to support current and future swallowing skills. (Select all that apply) Infants with NAS, Infants without NAS, Neither
50. I provide support to families, other caregivers, and staff regarding preferred practices in the NICU to support current and future communication skills. (Select all that apply)
Infants with NAS, Infants without NAS, Neither
51. I provide discharge/transition planning and follow-up care. (Select all that apply)
52. I collaborate with other team members to identify the need for additional assessment and consultation. (Select all that apply) Infants with NAS, Infants without NAS, Neither, Prefer not to answer (continue survey)

If they have answered “Infants without NAS”, “Neither”, or “Prefer not to answer (continue survey)” above, respondent will be directed to Question 54.

If they have answered “Infants with NAS” above to “I collaborate...assessment and consultation” then the following question (53) will appear.

Page 13:

53. Identify the healthcare professionals who collaborate on your NAS treatment team: (Select All That Apply) Neonatologist, Nurse, Bedside Nurse, Nurse Practitioner, Neonatal Nurse Practitioner, Neurologist, Occupational Therapist, Physical Therapist, Speech-Language Pathologist, Audiologist, Respiratory Therapist, Pulmonologist,

Radiologist, Gastroenterologist, Otolaryngologist (ENT), Pediatrician/Pediatric Specialist, Pharmacist, Obstetrician/Gynecologist (OB/GYN), Lactation Specialist, Nutritionist, Dietician, Case Worker, Social Worker, Drug Rehab Counselor, Early Intervention Liaison, Child Life Specialist, Mother, Family, Other, please describe:

Page 14: **Section 2: Environmental Description**

54. What is the number of beds in your hospital: ____
55. What is the number of NICU beds in your hospital: ____
56. Estimate the occupancy of your NICU over the last 3 months:
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%
57. In which state is your hospital located:
USA State Drop Down
58. What best describes the population you serve at your hospital, please select all that apply:
Rural, Urban, Suburban
59. What is the NICU Level at your hospital: Drop Down
There is no NICU at my hospital
Level I: Basic Newborn Care
Level II: Advanced Newborn Care
Level III: Subspecialty Newborn Care
Level IV: Highest Level of Neonatal Care
60. Are infants with NAS in your hospital, select all that apply:
In your general NICU
In a particular section of NICU
In a specialized unit for NAS
In a general nursery
“Rooming-In” with caregiver
In (other, please describe:) _____

If they have answered “In your general NICU”, “In a particular section of NICU”, “In a general nursery”, “Rooming-In” with caregiver”, or “In (other, please describe:) _____” above, respondent will be directed to Question 63.

If they have answered “In a specialized unit for NAS” above to “Are infants with NAS in your hospital, select all that apply:” then the following questions (61 & 62) will appear.

Page 15: **Section 2: Environmental Description**

61. What is the number of NAS beds in your specialized unit: ____
62. Estimate the occupancy of your NAS unit over the last 3 months:
Drop Down: 0%, 1-20%, 21-50%, 51-75%, 76-100%

Page 16: **Section 3: Respondent Demographics**

63. What is your highest level of education?

Drop Down: Master's degree, Doctoral degree

64. Gender:

Drop Down: Male, Female, Non-binary/ third gender, Transgender, Prefer not to disclose

65. Indicate any types of NAS education/training you have received, please select all that apply: Graduate Coursework, Graduate Clinic Placement, Post-Graduate Clinic Placement, CEU, None, Other, please describe: _____

66. Indicate any types of Pediatric Feeding or Swallowing education/training you have received, please select all that apply: Graduate Coursework, Graduate Clinic Placement, Post-Graduate Clinic Placement, CEU, None, Other, please describe: _____

67. How many years have you been employed as a speech-language pathologist? Please Select:

Drop Down: 0-5 years, 6-10 years, 11-15 years, 16-20 years, 21-25 years, 26-30 years, 31 or more years

68. How many years have you been working with infants in a hospital? Please Select:

Drop Down: 0-5 years, 6-10 years, 11-15 years, 16-20 years, 21-25 years, 26-30 years, 31 or more years

69. Please share any additional comments and experiences related to infants with NAS and their feeding skills. Please do not include any identifying information:

Appendix F

Survey Recruitment Letter

Subject Line: Survey of the Perceptions of Neonatal Intensive Care Unit Speech-Language Pathologists

Body Text:

Dear Hospital-Based Speech-Language Pathologists,

I would like to invite you to participate in my survey! My name is Lauren Fabrize and I am currently working on my master's degree in speech-language pathology at East Tennessee State University (ETSU). I am conducting a research study for my master's thesis.

The purpose of this study is to gather information on your experience as a hospital-based speech-language pathologist (SLP), particularly as it pertains to infants diagnosed with Neonatal Abstinence Syndrome (NAS). Results from this survey will be disseminated and describe current SLPs' practices for infants with NAS and how intervention might differ from other NICU populations.

The survey will take approximately 20-25 minutes to complete. Since this research is focused on your perspectives, there are no risks involved.

By completing this survey, you are giving your consent to participate in this research study. Your participation in this study is completely voluntary. You may skip any questions you do not wish to answer or simply exit the online survey at any time if you wish to remove yourself entirely. Declining to participate or opting to discontinue participation will not have any negative effects on you or your place of employment. All responses are anonymous. Although your rights and privacy will be maintained, the ETSU IRB and our team members have access to the study records.

If you have research-related questions or problems, you may contact Lauren Fabrize at fabrize@etsu.edu. You may also contact my research mentor, Dr. Kerry Proctor-Williams, at williamk@etsu.edu. Also, the chairperson of the Institutional Review Board at East Tennessee State University is available at (423) 439-6054 if you have questions regarding your rights as a research subject. If you have questions or concerns about the research and want to talk to someone independent of the research team or you cannot reach the study staff, you may call an IRB Coordinator at (423) 439-6055 or (423) 439-6002.

To access the survey, please select this link: <https://www.surveymonkey.com/r/37ZP7J9>

We thank you for your time.

Sincerely,

Lauren Fabrize, B.S.

Primary Investigator - Graduate Student/Clinician
Department of Audiology and Speech-Language Pathology
College of Clinical and Rehabilitative Health Sciences
East Tennessee State University
fabrize@etsu.edu

Under the mentorship of Drs. Proctor-Williams & Louw
Department of Audiology and Speech-Language Pathology
College of Clinical and Rehabilitative Health Sciences
East Tennessee State University

Appendix G

Modified Special Interest Group (SIG) Recruitment Letter

Hello, thank you for your time and attention to this request. My name is Lauren Fabrize and I am a speech-language pathology master's student completing a thesis at East Tennessee State University.

I invite you to participate in my survey! The purpose of this study is to gather information on your experience as a hospital-based speech-language pathologist (SLP), particularly as it pertains to infants diagnosed with Neonatal Abstinence Syndrome (NAS). Results from this survey will be disseminated and describe current SLPs' practices for infants with NAS and how intervention might differ from other NICU populations.

Your participation in this study is completely voluntary. You may skip any questions you do not wish to answer or simply exit the online survey at any time if you wish to remove yourself entirely. Since this research is focused on your perspectives, there are no risks involved. The survey will take approximately 20-25 minutes of your time. On December 20th, 2018 ETSU IRB approved this study.

To access the survey, please select this link: <https://www.surveymonkey.com/r/37ZP7J9>

Thank you for your time and expert input.

Sincerely,

Lauren Fabrize, B.S.
Primary Investigator - Graduate Student/Clinician
Department of Audiology and Speech-Language Pathology
College of Clinical and Rehabilitative Health Sciences
East Tennessee State University
fabrize@etsu.edu

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VITA

LAUREN E. FABRIZE

- Education: Master of Science, Speech-Language Pathology,
East Tennessee State University, Johnson City, Tennessee, 2019
- Bachelor of Science, Communication Sciences & Disorders,
James Madison University, Harrisonburg, Virginia, 2016
- Professional Experience: Graduate Clinician, East Tennessee State University, 2017- 2019
- Presentations: Detty, K., Fabrizze, L., Louw, B., Trifiro, M., & Weiner, J. (2019, April). *Clinician-Research Collaboration: Determining Research Interests & Needs of Clinicians in the Tri-Cities, Tennessee*. Poster presented at the 2019 Appalachian Student Research Forum, Johnson City, TN.
- Fabrizze, L. (2019, April). *Neonatal Intensive Care Unit Speech-Language Pathologists' Perceptions of Infants with Neonatal Abstinence Syndrome*. Oral presented at the 2019 Appalachian Student Research Forum, Johnson City, TN.
- Detty, K., Fabrizze, L., Louw, B., Trifiro, M., & Weiner, J. (2018, November). *Clinician-Research Collaboration: Determining Research Interests & Needs of Clinicians in the Tri-Cities, Tennessee*. Poster presented at the 2018 Annual Convention of the American Speech-Language-Hearing Association (ASHA), Boston, MA.
- Honors and Awards: First Place, Masters Social Sciences Poster Presentation for "Clinician-Research Collaboration: Determining Research Interests & Needs of Clinicians in the Tri-Cities, Tennessee" at the 2019 Appalachian Student Research Forum (2019)
- ASLP Research Endowment Scholarship (2018)
- GPSA Transportation Funding (2018)
- East Tennessee State University NSSLHA Funding (2018)
- George L. Carter Scholarship (2017, 2018)