The speech-language therapist's role with neonates who have hypoxic-ischaemic encephalopathy

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Abstract

Background	This survey study aimed to describe the role of a sample of speech-language therapists (SLTs) working with neonates with hypoxic-ischaemic encephalopathy (HIE) in neonatal nurseries in South Africa. Research will allow for better understanding of SLTs' role, and effective and timely treatment of this population.
Method	A 21-item previously published online survey was completed by 22 South African SLTs rendering mostly quantitative data. Purposive sampling and snowball sampling were used to recruit participants for the study. Descriptive statistics and qualitative content analysis were used.
Results	An average of five babies with HIE were admitted to NICUs where participants were working. Whole body cooling was used more often than selective head cooling, with no SLTs reporting involvement during cooling. Reported management of feeding difficulties included direct infant treatment to promote oral feeding skills, and caregiver support for optimal breastfeeding and developmentally appropriate stimulation. Most participants (n=21; 95.5%) provide follow-up services to clients with HIE, largely concerning feeding monitoring. Formal and informal feeding assessment methods were used by participants, with most (n=13; 59.1%) participants using the *Neonatal Feeding Assessment Scale*. Management is carefully tailored to the infants' and families' needs. Treatment was influenced by resources available, within the context of sparse management guidelines.
Conclusion	The findings reveal the need for standardised protocols to guide management of this population in the NICU. Additionally, SLTs must strive for holistic management of neonates with HIE as early intervention pre- and post-discharge plays a vital role in mitigating adverse neurodevelopmental outcomes. Results may inform the development of guidelines and may be beneficial for SLTs in low- and middle-income countries involved in the NICU.

Key words	Hypoxic-ischaemic encephalopathy, neonatal intensive care unit / neonatal nurseries, speech-language therapist, role, survey

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Contents

List of abbreviations

ASHA	American Speech-Language-Hearing Association
FEES	Fiberoptic Endoscopic Evaluation of Swallowing
GMA	General Movements Assessment
HIE	Hypoxic-ischemic encephalopathy
HNNE	Hammersmith Neonatal Neurological Exam
HPCSA	Health Professions Council of South Africa
LMICs	Low- and middle-income countries
NeoEAT	Neonatal Eating Assessment Tool
NFAS	Neonatal Feeding Assessment Scale
NICU	Neonatal intensive care unit
NNNS	NICU Network Neurobehavioral Scale
NOMAS	Neonatal Oral Motor Assessment Scale
OPD	Oropharyngeal dysphagia
PIBBS	Preterm Infant Breastfeeding Behaviour Scale
POFRAS	Preterm Oral Feeding Readiness Scale
SASLHA	South African Speech- Language-Hearing Association
SLT	Speech-language therapist
TH	Therapeutic hypothermia
TIMP	Test of Infant Motor Performance
VFSS	Video Fluoroscopic Swallow Study

1. Introduction

The role of the speech-language therapist (SLT) in the neonatal intensive care unit (NICU) and in early communication intervention has been described by the American Speech-Language-Hearing Association (ASHA, 2004) and the South African Speech-Language-Hearing Association (SASLHA, 2017), and can be broadly defined in terms of the following categories (Jenkins, 2021): (1) feeding and swallowing services, including early identification, assessment (clinical and instrumental), and diagnosis of feeding and swallowing disorders, as well as the appropriate management of and intervention for these disorders, (2) communication services, such as monitoring for early signs of communication deficits, assessing, diagnosing, and treating any potential communication disorders and supporting caregivers in creating a stimulating communicative environment, and (3) providing caregiver counselling, educating caregivers and NICU staff on best practice for supporting the early development of communication, feeding, and swallowing skills, and advocating for the role of the SLT in the NICU (Arora et al., 2022; ASHA, 2004; Jenkins, 2021; Krüger et al., 2017; Ross et al., 2017; SASLHA, 2017). Additional roles include collaboration with the family and other members in the interdisciplinary team about decisions regarding assessment and management strategies, assisting with the implementation of mother-infant attachment strategies, maintaining quality control, planning for discharge and follow-up care and documenting treatment outcomes for research purposes (ASHA, 2004).

A prominent population found in the NICU globally are neonates with hypoxic-ischemic encephalopathy [HIE] (Arora et al., 2022). HIE describes a pathological abnormality due to atypical blood and oxygen supply to the neonatal brain during the peripartum period (Park et al., 2023; Yimenicioglu et al., 2022). The majority of cases with HIE occur in low- and middle-income countries (LMICs), due to increased incidence of adverse perinatal events (Ballot et al., 2020; Malan et al., 2022). In LMICs the incidence of HIE is approximately 1.5 - 20.3 per 1 000 live births (Ballot et al., 2020; Chawla, 2024; Greco et al., 2020). Perinatal asphyxia, and subsequent HIE, is also one of the leading causes of infant morbidity and mortality in South Africa (Kali et al., 2015; Malan et al., 2022;

Padayachee & Ballot, 2013). It is important to understand the role of the SLT in treating HIE within the context of the global burden of disease, but also within the context of LMICs such as South Africa (Bruwer, 2016; Padayachee & Ballot, 2013).

The medical management of neonates with HIE in the NICU appears relatively consistent, where possible, across low- and middle-income countries and high-income countries with literature and practice stipulating the benefit of therapeutic hypothermia [TH] (Kali et al., 2015). The therapeutic management protocol by neonatal therapists such as occupational therapists, physiotherapists, and SLTs of neonates with HIE post-cooling is unclear (Perez & Poskey, 2022) therefore research on the role of the SLT with this population is warranted.

Because of South Africa's relatively high prevalence of HIE, SLTs might have a number of infants with HIE on their caseloads (Bruckmann & Velaphi, 2015; Horn, 2013; Krüger et al., 2017; Simiyu et al., 2017). Children who survive are at risk of cognitive and behavioural difficulties, communication and language disorders, oropharyngeal dysphagia and several other pathologies; all of which fall within the scope of the SLT (ASHA, 2004; Malan, 2022; Malan et al., 2022; Malan et al., 2023; SASLHA, 2017; Schreglmann, 2019). This population is at risk of having early breastfeeding difficulties that warrant an SLT's intervention (Arora et al., 2022; Krüger et al., 2019; Senapati & Kakker, 2022; Van Schalkwyk et al., 2020). What is not yet known in South Africa is knowledge pertaining to SLTs' roles with infants with HIE and information on the number of infants with HIE in an SLT's caseload.

Neurological impairment, often associated with neonates born with HIE, could be the cause of many difficulties seen in early breastfeeding skills of infants with HIE (Gupta et al., 2018; Senapati & Kakker, 2022). A few examples include deficits in state regulation, coordination, feeding endurance, inadequate latching-on while breastfeeding, hypotonia and weak primitive reflexes (Krüger et al., 2017; Malan et al., 2023; Senapati & Kakker, 2022). However, literature suggests that the ability to breastfeed may improve over time, which contributes to the idea of the importance of early intervention from an SLT to

encourage optimal breastfeeding development (Krüger et al., 2019; Pérez-Escamilla et al., 2023; Simiyu, 2017). Feeding difficulties with infants with HIE put them at risk for gastrointestinal complications and possible neurological impairments that could cause oropharyngeal dysphagia. The introduction of oral feeding must be timed in a way that ensures safe feeding and promotes the health of infants with HIE (Krüger et al., 2019; Malan et al., 2022; Malan et al., 2023). Research probing the role of the SLT with regard to breastfeeding support for infants with HIE, would thus be valuable.

Neonates with HIE are exposed to prolonged hospital stays with possible separation from their mothers, the influence of prescribed medication, and numerous clinical procedures, which may contribute to inadequate state and subsequent difficulties with sucking and swallowing while breastfeeding (Krüger et al., 2019). Breastfeeding difficulties are linked to increased maternal anxiety, which could lead to negative feeding experiences for both the mother and the infant. This impedes mother-infant bonding and consequently -attachment, ultimately affecting neonatal communication development (Van Schalkwyk et al., 2020), Additionally, infants with HIE are vulnerable to poor breathing, cerebral palsy and seizures, along with other conditions (Greco et al, 2020; Malan et al., 2022; Malan et al., 2023; Merchant & Azzopardi, 2015; Park et al., 2023). Managing the above difficulties and providing intervention falls within the scope of the SLT (ASHA, 2004; SASLHA, 2017).

Since therapeutic hypothermia is a widely accepted treatment strategy for infants with HIE, it is important to consider how these fragile infants feed during treatment (Perez & Poskey, 2022). A standard feeding protocol has not yet been developed for infants with HIE while receiving therapeutic hypothermia (Krüger et al., 2019; Kumar et al., 2023). Despite undergoing therapeutic hypothermia, infants with HIE are at risk for oral feeding difficulties, due to damage to areas of the brain that control oral motor function, such as the brainstem, basal ganglia and cortex (Bozkaya et al., 2023; Gupta et al., 2018). It is important to facilitate feeding support through gastrostomy tube- or home nasogastric tube feeding and to develop a feeding plan with the family and clinician so that infants' hospital stay can be reduced. This will also decrease the burden of healthcare costs and

parental stress (Gupta et al., 2018; Kamity et al., 2021; Markus et al., 2021). Bozkaya et al. (2023) looked at the efficacy of oral motor interventions on feeding outcomes in neonates with HIE receiving therapeutic hypothermia. Results described quicker transitions to full oral feeds, and the importance of including the SLT in the neonatal therapy team, warranting the current research study.

A recent study by Perez and Poskey (2022), provided insight into the perceived role of the neonatal therapist regarding infants with HIE following therapeutic hypothermia; however, the study did not focus on the role of the SLT specifically. Current literature also reveals a paucity of information about the SLT's role with neonates with HIE in South Africa (Bruckmann & Velaphi, 2015; Horn et al., 2013; Krüger et al., 2017; Perez & Poskey, 2022).

Determining the role of the SLT with neonates with HIE is crucial due to the far-reaching effects of HIE, especially in low-resource settings (Dziewas et al., 2017; Malan et al., 2023; Mwatonoka et al., 2022; Tagin et al., 2015; Vegda et al., 2022). Therefore, the research aimed to answer the following research question: *what is the role of a sample of SLTs with neonates with HIE in neonatal nurseries in South Africa?*

A better understanding of the role of SLTs in the NICU with this population can inform early intervention practices. This in turn can provide infants with HIE with an increased chance of optimal and independent functioning; and the potential for functional neurologic improvement (Litt et al., 2018; Malan et al., 2023; Mwatonoka et al., 2022; Park et al., 2023). The established difficulty of oropharyngeal dysphagia (OPD) in neonates with HIE is the responsibility of the SLT in the therapeutic team (Lefton-Greif & Arvedson, 2016; Malan et al., 2022; Malan et al., 2023; Krüger et al., 2019). Since oral feeding competence is a prerequisite for hospital discharge, managing OPD and early breastfeeding challenges as efficiently as possible will reduce the frequency and length of hospitalisation, and decrease the likelihood of readmission, thereby lessening the economic and logistical burden on both the hospital and the family (Attrill et al., 2018; Bozkaya et al., 2023; Dziewas et al., 2017; Edwards et al., 2019; Kamity et al., 2021;

Malan et al., 2022; Malan et al., 2023; Pados et al., 2021). This is especially important when taking into consideration the current increase in survival rates for this population due to early identification and medical advances (Kamity et al., 2021; Lefton-Greif & Arvedson, 2016). Whether these roles translate into what SLTs are currently practising in a South African context, is yet to be established.

Without a clearly defined role, SLTs working with neonates with HIE in the NICU may be undervalued, leading to a lack of appropriate and timely referral, early identification, diagnosis, habilitation, and follow up services (Arora et al., 2022). In LMICs, where early intervention resources are scarce, families may not have access to services after the infant is discharged from the hospital (Malan et al., 2023). Thus, increased awareness of the SLT's role with infants with HIE during this critical time period likely ensures optimal intervention while services are still available to the family.

2. Method

2.1 Aim

To describe the role of a sample of SLTs working with neonates with HIE in neonatal nurseries in South Africa.

2.2 Research design

A quantitative descriptive survey design (Leedy & Ormrod, 2015) was used to examine the SLT's role with neonates with HIE in neonatal nurseries in South Africa. The survey was circulated in an electronic format on social media. The survey was primarily quantitative in nature to allow for the collection of objective data; however, the inclusion of open-ended questions rendered qualitative data, which was used to gain a holistic understanding of the subjective experiences of SLTs in the neonatal setting (Almalki, 2016). Collecting qualitative data in addition to quantitative data strengthened the reliability of the data in a process termed complementarity, where one method's

strengths could make up for the shortcomings of another (Greene et al., 1989).

2.3 Research setting

Data were collected from a group of the Health Professions Council of South Africa registered SLTs with recent work experience in neonatal nurseries in South Africa.

2.4 Population

Relating to the aim of the study, the role of the SLT working with neonates with HIE in the NICU, the population that participated in the research study are qualified SLTs around South Africa working/rendering services in a neonatal nursery, with experience of at least six months within the last five years of working with neonates. This population ensured a sample that would provide a specialist perspective.

2.5 Sample

Non-probability purposive sampling (Leedy & Ormrod, 2015) was used to recruit 22 participants for this study. This type of sampling allowed for participants with specific knowledge relevant to the research study to be selected, which ensured concise and targeted exploration of the topic (Brink et al., 2018; Leedy & Ormrod, 2015). All potential participants were required to meet the inclusion criteria to partake in the research study. A total of 55 responses were recorded, of which four respondents did not meet the inclusion criteria and were thus unable to complete the survey. Additionally, of the 55 total responses, only 22 datasets were fully complete—these respondents constituted this study's sample.

2.6 Inclusion criteria

Participants were included if they complied with the following criteria:

- All participants were required to be qualified speech-language therapists with a bachelor's degree in speech-language pathology or speech-language therapy.

- All participants were required to be registered with the HPCSA (self-reported).
- All participants had to be based in South Africa.
- All participants had to be working/rendering services in a neonatal nursery, with NICU experience of at least six months, or NICU experience within the last five years.

2.7 Participant description

The survey received a total of 55 responses. Out of these responses 22 respondents completed the survey and 29 were incomplete. Four respondents did not meet the inclusion criteria and were excluded from the analysis. One participant was aged 60+ years of age, two aged 50-59 years, 11 aged 30-39 years, and eight aged 20-29 years. Most participants had an average of five to nine years of experience in the NICU. Participants came from the following provinces: Gauteng (n=11; 52.4%), Mpumalanga (n=4; 19%), Kwazulu-Natal (n=3; 14.3%), Eastern Cape (n=1; 4.8%), Western Cape (n=1; 4.8%), Free State (n=1; 4.8%) and Limpopo (n=1, 4.8%). Most participants reported working in units that have 20 beds or more (n=10; 47.6%), with 16 participants (76.2%) having worked in the public sector and six (28.6%) in the private sector.

2.8 Materials and apparatus

An electronic survey, previously published in an article by Perez and Poskey (2022) was utilised for the compilation of a survey for the current research study, given its alignment with a similar research topic and a broader population group. The survey questions were thorough and comprehensive, allowing participants to share their in-depth knowledge about the research topic with researchers. The use of a pre-existing survey proved beneficial, as its validity and reliability had already been established through prior testing for the original research (Nash, 2021).

The current survey (Appendix A) was adapted to only include SLTs as participants and was adapted to the South African context through the question relating to the area

where the participant is working. A question regarding the setting in which the participants gained their experience whether it be in the private or public sector was also added, it was an important aspect to include due to the noticeable difference between the two settings (Nash, 2021; Pinna et al., 2018). The survey was adapted to the above-mentioned points for this study to make it relatable for the participants in their environment (Appendix B).

The survey consisted of open as well as closed-ended questions. Including both types of questions in the survey assisted in gathering various information with open-ended questions. Participants were more willing to complete closed-ended questions as it was time efficient and gave the researchers set data that was easier to code and analyse (Brink et al., 2018; Nash, 2021; Zhou et al., 2017). The survey had 21 questions and was available for six weeks online, via Qualtrics XM, to ensure sufficient time for completion.

2.9 Procedures for data collection

Potential respondents were provided with an information leaflet and informed consent document (Appendix C) and the data were collected through an online survey (Appendix A). The survey for the research study was distributed electronically as this ensured widespread participation (Nash, 2021; Van Selm & Jankowski, 2006). The survey was sent out using the Qualtrics - Experience Management (XM) platform software. The information about the survey was shared on an infographic (Appendix D) and was available on the Qualtrics-XM platform i.e., the description of the survey, the purpose of the research study, including the definition of HIE, informed consent and access to the survey.

Online distribution took place via mailing lists, personal connections of the supervisors and on social media platforms, namely Facebook groups. The snowball sampling technique was used where SLTs could pass on the link to other colleagues in the field (Brink et al., 2018; Johnson, 2014; Leighton et al., 2021; Nash, 2021).

2.10 Ethical considerations

This study was approved by the Research Committee of the Department of Speech-Language Pathology and Audiology, University of Pretoria for the study protocol SLPA2024/02 on 29 February 2024 (Appendix E). A request to utilise the social media platform Facebook, and particularly Facebook groups of speech-language therapists, was sent (Appendix F). Voluntary informed consent was obtained from respondents in an initial question before it was possible to continue with the survey questionnaire. Data were entered into an electronic spreadsheet on a computer, both of which were password-protected. As per the University of Pretoria's guidelines and data management policy, data were uploaded electronically to the University's secure data repository and will be stored for a minimum of 10 years.

2.11 Data analysis

Closed-ended questions, consisting of categorical data (nominal and ordinal data), were analysed using descriptive statistics in which frequency distributions enabled capturing of frequencies and arrangement of these scores from lowest to highest for the quantitative aspects of our data. The qualitative data from the open-ended questions were explored through content analysis and a discussion was conducted to meet a group consensus amongst researchers. As the survey was predominantly closed-ended with a few open-ended questions, triangulation was used to consolidate the qualitative and quantitative data (Brink, 2018; Nash, 2021; Ott & Longnecker, 2015; Voils et al., 2008).

2.12 Reliability and validity

The survey was based on the survey by Perez and Poskey (2022) which has already been published and acknowledged as valid and reliable. Its use of open-ended questions allowed the current best practice to be communicated, making it reliable,

relevant and useful in regard to practical and methodological use (Brink et al., 2018; Perez & Poskey, 2022; Tracy, 2010). Adding to reliability of the questionnaire, it was circulated using Qualtrics, which is well known and secure (Nash, 2021). Closed-ended questions made up most of the survey questions, which guided participants to answer questions more appropriately and with specificity in a structured manner, which contributed to validity (Nash, 2021).

Questions were standardised and identical for each recipient, only being as complex as necessary to contribute towards efficiency. Before data collection began, the survey questionnaire was pretested with three participants who met the inclusion criteria to ensure the design of the survey was functional and appropriate, and the questions were easy to understand and answer. Necessary adaptations to suit the setting in which the research took place were made, use of pre-specified selection criteria and random sampling was carried out to increase appropriateness and validity (Brink et al., 2018; Nash, 2021).

3. Results

Twenty-two participants' responses were analysed. Table 1 outlines characteristics of neonatal intensive care units where participants work at the time of the study. Sixteen participants (72.7%) reported that their NICUs admit five or fewer babies weekly. No participants were involved with infants with HIE during the cooling process.

Table 1

Characteristics of participants' institutions (n = 22)

Characteristic	**n (%)**
***Developmental services provided**	
Speech-language therapy	22 (100%)
Occupational therapy	16 (72.7%)
Physical therapy	16 (72.7%)
Dietician	16 (72.7%)
Other	4 (18.2%)
Music therapy	0
Child life specialist	0
***Average number of babies with HIE admitted weekly**	
Less than/equal to 5	16 (72.7%)
6-8	8 (36.4%)
Unsure	4 (18.2%)
None	2 (9.1%)
***Type of cooling**	
Whole body cooling	14 (63.6%)
Selective head cooling	7 (31.8%)
No cooling	1 (4.6%)

**Note: Participants were able to select more than one option*

Three participants (13.6%) reported using a specific protocol/policy at their institutions for providing neonatal intervention for infants with HIE post-therapeutic cooling, whereas the majority (n=19; 86.4%) do not have a specific protocol or policy. Three participants (13.6%) mentioned the use of a protocol/policy for neonatal intervention in the NICU in which they work. The predominant policy implementation, evident from the two responses received, comprised of reducing possible environmental stressors, feeding readiness preparation, deep touch around the mouth and intra-orally, facilitating non-nutritive

sucking, encouragement of breastfeeding, and use of cup feeding if the infant is still transitioning to breastfeeding and supporting the caregiver with optimal positioning for oral feeds.

Table 2 presents participants' formal assessment methods used with neonates in the NICU. All participants indicated that they assess feeding and swallowing with over half (n=13, 59.1%) using the Neonatal Feeding Assessment Scale (NFAS).

Table 2

Participants' assessment methods (n＝22)

Assessments administered	**n (%)**
The Neonatal Feeding Assessment Scale	13 (59.1%)
Other	6 (27.3%)
NICU Network Neurobehavioural Scale (NNNS)	3 (13.6%)
General Movements Assessment (GMA)	2 (9.1%)
Hammersmith Neonatal Neurological Exam (HNNE)	1 (4.6%)
Test of Infant Motor Performance (TIMP)	1 (4.6%)

**Note: Participants were able to select more than one option*

Out of the 22 participants who indicated the type of formal assessments they administer, six respondents (27.3%) indicated 'other' assessment tools. These assessment tools included: The *Preterm Infant Breastfeeding Behaviour Scale (PIBBS)* (n=1; 3.9%), the *Neonatal Eating Assessment Tool (NeoEAT)* (n=1; 3.9%), the *Neonatal Oral Motor Assessment Scale (NOMAS)* (n=1; 3.9%), the *Preterm Oral Feeding Readiness Scale (POFRAS)* (n=1; 3.9%), informal reflex and tone assessment (n=1; 3.9%) and non-standardised assessment methods (n=1; 3.9%). One response (3.9%) was related to formal assessment tools used by the physiotherapist and occupational therapist.

From responses to an open-ended question in the survey concerning assessment methods, informal, observational, bedside evaluation is the most common method of assessment for feeding and swallowing in this population, as indicated by 90.9% (n=20) of responses and the following statements:

> *"Observational beside assessment, observation of feeding (non-nutritive and nutritive)."* (Participant 15, private sector)

> *"[Non-nutritive suck, nutritive suck] done informally, using pulse oximeter."* (Participant 19, public sector)

Upon analysis of the data, the following categories of assessment emerged. The observation of non-nutritive sucking (n=15; 68.2%) and nutritive sucking (n=14; 63.6%) were the most common methods of assessment reported. Fifteen responses (18.2%) indicated clinical methods of assessment in contrast to only three responses (13.6%) that indicated instrumental methods of assessment such as a video-fluoroscopic swallowing study, a fiberoptic endoscopic evaluation of swallowing (FEES), and a gastro-oesophageal reflux (milk) scan. Areas commonly assessed were infant state (n=5; 22.7%), endurance (n=2; 9.1%), medical stability (n=2; 9.1%), maturation (n=1; 4.6%), and hunger cues (n=1; 4.6%). Additionally, one response (4.6%) indicated inter-professional collaboration with an occupational therapist in the assessment of feeding and swallowing and two responses (9.1%) indicated that reviewing the file was an important part of the assessment process.

Table 3 describes the types of interventions participants reported using when treating infants with HIE.

Table 3

Interventions used by SLTs with Infants who have HIE (n = 22)

***Interventions**	**n (%)**
Feeding and swallowing intervention	22 (100%)

Breastfeeding management and support	21 (95.5%)
Caregiver coaching on feeding	21 (95.5%)
Informational counselling for caregivers	20 (90.9%)
Team discussions/meetings about feeding	20 (90.9%)
Caregiver training/coaching on development	18 (81.8%)
Kangaroo Mother Care (KMC)	18 (81.8%)
Clinical assessment	16 (72.7%)
Developmental care	15 (68.2%)
Positioning	15 (68.2%)
Instrumental feeding and swallowing assessment	14 (63.6%)
NICU staff education, i.e., training or written materials	12 (54.6%)
Team discussions/meetings about discharge	12 (54.6%)
Environmental modifications (lighting, noise, smells, etc.)	10 (45.5%)
Home therapeutic activity plan	5 (22.7%)
Infant massage	2 (9.1%)
Other	0
Frequency of intervention	
Once per day	13 (61.9%)
Every other day	4 (19.1%)
Multiple times daily	2 (9.5%)
Weekly	2 (9.5%)
Every third day	0
Follow up services	
Yes	21 (95.5%)
No	1 (4.5%)

**Note: Participants were able to select more than one option*

Twenty-one respondents indicated that they have follow up services for infants with HIE. These respondents' answers to open ended questions rendered qualitative data on when and how often these follow-up services occur. Results described the

intervals/frequency of future consultations, namely initial, weekly, and monthly consultations, as well as those dependent on other factors.

Initial follow-ups occurring telephonically were reported in two responses (9.5%). Respondents used phone calls after the first five to seven days, and WhatsApp (medium not specified) during the first 48 hours, followed by in-person consultation if necessary as shown in the following comments:

> *"Varies from patient to patient. But usually check in telephonically after 5-7 days discharge and then an in-patient consult if necessary about 7-10 days after discharge"* (Participant 11, private sector)

> *"Via WhatsApp for the first 48 hours, in-person consult if any issues are reported if no issues are reported, follow-up one week post discharge, and then on an "as needed" basis."* (Participant 13, private sector)

Nine participants followed up infants in person weekly (42.9%), with responses ranging from one- and two-week post-discharge as per institution protocol, as required until infant feeding and weight improved. Two responses (9.5%) explicitly indicated weekly reviews followed by greater time between visits, such as once per month or dedicated times as per an infant's needs:

> *"Once a week initially then greater time between visits."* (Participant 7, public sector)

> *"1 week post discharge, needs be basis thereafter."* (Participant 14, private sector)

Monthly reviews included four responses (19.1%) describing once a month follow-ups until two years of age, as required, or according to hospital schedule and protocol. An additional four responses (19.1%) indicated follow-ups every three months, such as in

hospital-based ‘Early Intervention’ clinics with established group therapies beginning from nine months onwards. Three responses (14.3%) indicated review services are coordinated with the medical doctor’s or paediatric outpatient department visits:

> *“High risk baby clinic once every 3 months.”* (Participant 3, public sector)

> *“Follow up on same day as Dr follow up and monthly until 2 yrs old.”* (Participant 4, public sector)

> *“In public, it was once a month. In private only once or twice post discharge.”* (Participant 15, public and private)

Five responses (23.8%) described follow-ups according to be only ‘as needed’, but only after an initial compulsory in-person follow-up session, according to a schedule, or according to infant health and well-being requirements. These included infant feeding abilities and related weight gain, as well as monitoring motor development with two responses (9.5%) specifying physical and occupational therapy services also included:

> *“MDT (multi-disciplinary team)—initially starting with physio and speech for continuation of feeding and motor elements, initially weekly then month.”* (Participant 8, private sector)

Lastly, three responses (14.3%) did not provide specific time frames, but rather indicated that follow-up visits would be considered and scheduled as per the level of care required according to the severity of the infant’s condition, medical aid funding, parental involvement, physical access or proximity to the hospital, and support for follow-up services.

Ten respondents elaborated on reasons why they would not provide follow-up services after discharge from their facility. Seven participants (70%) indicated that infants and families are referred to services closer to where they live or back to their base hospital

as is attested to in the following comment:

> *"Baby may be transferred back to their base hospital."* (Participant 4, public sector)

> *"If the patient lives out of town, we try to find therapy services closer to home."* (Participant 16, private sector)

Four responses (40%) stated that infants would not require follow-up if they were feeding successfully after discharge. Two responses (20%) described that families often cannot attend follow-up appointments due to financial reasons. One response (10%) indicated that families mostly do not return for the follow-up appointment as is seen in the following:

> *"Lots of babies are lost to follow up. Meaning the parents don't bring them back."* (Participant 21, public sector)

An open-ended question asked participants to remark on their perceptions of their assessment and intervention with infants with HIE, and six participants responded. Four responses (66.7%) indicated that intervention varies with this population and should be tailored to each individual case as is attested to in the following quote:

> *"Intervention plan is dependent on each unique child; depending on their presentation."* (Participant 11, public sector)

It was also noted that daily intervention is not always possible due to the influx of cases and low number of professionals to manage the cases. Two responses (33.3%) described the need for inter-professional teamwork to manage cases of infants with HIE. One response (16.7%) indicated that oral feeding preparation should start earlier amongst this population. Another response (16.7%) described that after administering the Thompson score, the infants' progress is monitored:

> *"If the babies are cooled or do have HIE we use [Thompson] scores and monitor them very closely."* (Participant 13, private sector)

Another open-ended question enquired about participants' needs when working with infants with HIE. These interpretations are listed below, along with participants' corroborative statements. Eight (44.4%) participants (n=8) of the 18 respondents who answered the question expressed a need for increased staff and/or material resources, proving to be the most commonly reported need as is shown in the following:

> *"Resources e.g. bottles, pacifiers, nipple shields, [supplemental] nursing systems."* (Participant 3, public sector)

> *"Intensive assessment and intervention if there is enough staff."* (Participant 22, public sector)

Other needs mentioned were related to improving evidence-based research and protocols (n＝6, 33.3%) as is seen in the following quotes:

> *"Need evidence-based guidelines, more research on managing breastfeeding in infants with uncoordinated SSB and disruptive feeding."* (Participant 1 public sector)

> *"A protocol would be helpful to allow [standardised] care instead of relying on doctors recommendations, which can often be delayed."* (Participant 7, private sector)

Participants (n＝4, 22.2%) expressed that ongoing caregiver counselling should be provided and speech-language therapists should be trained with regard to the pathophysiology of HIE in infants and how it affects their overall functioning as is attested to in the following:

“More psychological [counselling] and formal parental support.” (Participant 10, private sector)

“Courses at undergraduate level should really train students on understanding pathophysiology as it great impacts our management of patients." (Participant 11, public sector)

“Early and [continuous] counselling to the parents is needed about possible long term consequences.” (Participant 18, public sector)

4. Discussion

This study explored the perceived role of 22 SLTs working with neonates with HIE, in South African neonatal nurseries. Findings revealed that an average of five infants with HIE were admitted to NICUs where participants were working weekly. In general, whole body cooling was used more often in their units than selective head cooling, with no SLTs reporting any involvement during the therapeutic cooling process. Reported management of this population’s feeding difficulties included direct infant treatment to promote oral feeding skills, and caregiver support for optimal breastfeeding and developmentally appropriate stimulation of the infant, which comprised the bulk of the SLTs’ work. The majority of participants (n=21; 95.5%) indicated that they provide follow-up services to clients with an HIE diagnosis, largely concerning feeding monitoring for appropriate growth and weight gain. Both formal and informal assessment methods for the assessment of feeding difficulties were used by participants. More than half of the participants reported using the Neonatal Feeding Assessment Scale, a formally developed tool appropriate for the South African context. Management was described as being carefully tailored to the infants’ and families’ needs. Additionally, treatment was influenced by the resources available, all within the context of sparse management guidelines.

The majority of responses were about management of feeding difficulties with in-patients. Therapeutic planning for follow-up after discharge was indicated in only 25% (n=5) of the sample. This priority of the management of infant feeding difficulties closely relates to a widely accepted discharge criterion, which is the infant's ability to feed orally (Attrill et al., 2018). Treatment of feeding difficulties and cognitive impairments affecting behaviour, communication, and language all fall within the scope of the SLT (Malan et al., 2023). However, the results of this study illustrated that only a few participants follow up on clients regarding therapeutic neuro-developmental and language management after discharge. This is suboptimal as the neurological and developmental fallouts of HIE, even in mild forms, are extensively documented (Kali et al., 2015; Malan et al., 2022; Padayachee & Ballot, 2013). A possible explanation for this finding may be due to the high prevalence of HIE in South African neonates (Ballot et al., 2020), resulting in many infants with HIE on a South African SLT's case load. With restricted human resources, as is the case in many hospitals (Malan et al., 2023), this may lead to a need to prioritise services with an emphasis on infant survival and treatment of immediate, basic needs, with limited planning for long-term developmental and communicative functioning in the management of infants with HIE.

A second possibility is that the discrepancy between the role of the SLT as described by SASLHA (2017) and the participants' reported follow-up services may stem from deficiencies in undergraduate training, due to limited emphasis on the impact of HIE and the crucial role of the SLT in mitigating adverse long-term effects. Malan et al. (2023) described the need for consistent early intervention including specifically early communication intervention post-discharge for infants with moderate HIE to address pervasive developmental delays. Many respondents in the current study described this implementation of rehabilitative services to address adverse outcomes post-discharge as a 'need' they have regarding treating infants with HIE. Preventative intervention prior to discharge such as caregiver counselling on appropriate infant stimulation to optimise the early language learning opportunity forms part of the SLT's role in neonatal nurseries (SASLHA, 2017). This aspect appears to be overlooked in the early management plan of the study's sample.

These findings underscore the importance of including the pathophysiology of HIE in undergraduate training for students in speech-language pathology, as is already the case at certain universities in South Africa. The BA Speech-Language Pathology degree at the University of Pretoria, for example, has included the pathophysiology of HIE as part of the curriculum since 2020. Furthermore, the importance of the SLT's early management of the long-term neuro-developmental consequences both pre- and post-discharge is also highlighted. In a resource limited setting such as South Africa, it is vital that early intervention begins while the SLT is still in contact with the caregiver in the acute setting, before discharge and subsequent possible 'loss to follow-up' (Malan et al., 2023).

The majority of participants indicated that they use informal, observational, and bedside evaluations to assess the feeding and swallowing capabilities of infants with HIE. These informal assessment methods include non-nutritive sucking, nutritive sucking, infant state, and medical stability. Possible reasons why clinicians use informal assessments more often could be due to the lack of access to formal tools in the low-resource environment, difficulty managing time constraints caused by increased caseloads, and the individualised presentation of each infant with HIE. Within the Sub-Saharan African context, the lack of culturally appropriate formal tools and limited capacity to manage the number of patients may lead to greater reliance on informal assessments to address the unique needs of infants with HIE (Lüdtke et al., 2023). SLTs need to be resourceful because of these factors, thus they often rely on their clinical experience to make decisions with regards to assessing this population. These findings correlate with Perez and Poskey (2022), as both studies indicate a paucity of management guidelines for treating infants with HIE.

Participants reported utilisation of the following standardised assessment tools in the NICU with infants with HIE: Neonatal Feeding Assessment Scale (NFAS), NICU Network Neurobehavioral Scale (NNNS), General Movements Assessment (GMA), Hammersmith Neonatal Neurological Exam (HNNE), the Test of Infant Motor

Performance (TIMP), Neonatal Oral Motor Assessment Scale (NOMAS) amongst others. In South Africa, SLTs often do not have access to all available assessment methods. Formal assessment tools such as the NOMAS requires formal, and often in-person training (Bingham et al., 2012). According to Lefton-Greif and Arvedson (2016), instrumental assessments such as the Video Fluoroscopic Swallow Study (VFSS) and Fiberoptic Endoscopic Evaluation of Swallowing (FEES) are gold-standard tools used to assess swallowing in infants. Unfortunately, these instrumental assessments were reported to be used by only three (13.6%) participants in the current study. This may be due to the limited accessibility of these tools to SLTs in low resourced settings as well as the need for extensive training to obtain reliable interpretation of the results (Coutts, 2019). Undergraduate training of SLTs that include ways to assess this population reliably with limited access to resources would be valuable.

An existing formal assessment option that is feasible in the South African context is the NFAS, a locally developed tool validated against the VFSS that can aid in the evaluation of swallowing abilities in infants in resource-limited settings (Viviers et al., 2017). This tool is included in the undergraduate training of SLTs at institutions, for example the University of Pretoria, and therefore is utilised in the clinical setting. It is encouraging to note that many of the participants in the study are utilising the NFAS in practice. The PIBBS is an additional tool that does not require formal training and can be used to monitor breastfeeding by mothers or clinicians (Nyqvist et al., 1996). The PIBBS is accessible and research has validated the effectiveness of this tool (Jamehdar et al., 2022), but its adoption among SLTs in the study remains limited.

The role of the SLT in feeding management and communication with infants in the NICU has been stipulated by governing bodies, such as ASHA (2004) and SASLHA (2017). SASLHA states that intervention performed by SLTs with high risk infants should include diagnosing and treating feeding disorders, monitoring infant readiness, informational counselling to parents and participation in paediatric follow up clinics. However, the current study found that SLTs working with HIE in the NICU view evidence to be lacking, stating that more research is needed for assessment and management of infants with

HIE. Therefore, there is a need for specialised research to be conducted on this topic. These findings are supported by Krüger et al. (2019) and Kumar et al. (2023) in which it was found that no specialised feeding intervention protocols are in place to aid clinicians in treating infants with HIE.

Standardised protocols for feeding and communication intervention for infants with HIE in the NICU may support therapists in decision-making to create uniform, evidenced-based care in varying contexts. (Kriznik et al., 2019). Within the context of South Africa's high burden of disease, evidence-based protocols for infants with HIE may improve health outcomes of infants, reducing the length of stay and the expenses within the NICU (Malan et al., 2022).

Participants stated that daily intervention may not be possible due to limited staff members and a high number of patients in their daily caseload. Coutts et al.'s (2022) study revealed similar findings describing that an increased number of health care professionals are needed to provide adequate services for the infants at risk of feeding and later cognitive-communication difficulties in the NICU. Participants in the current study also described the need for tailored intervention for infants diagnosed with HIE, which may include including a larger multidisciplinary team. Additionally, over-saturation of the NICU, as found in the results of the current study as well as in Malan's (2022) study, further impacts efficient treatment, stretching both material and human resources. Therefore using standardised protocols to manage infants with HIE, while adapting these protocols and services to the specific needs and context of the patients, would be beneficial.

SLTs have an important role to play in the management of infants with HIE. Management of feeding difficulties appear to be viewed by participants as being the primary concern with less attention being given to early communication development and developmental surveillance. It appears as though clinical experience of the participants and the contextual limitations of their work environment primarily guide their management of infants with HIE. Similar to the results of Perez and Poskey's (2022)

study, the current study found that there is a lack of standardised protocols and policies in place for SLTs working with infants with HIE in the NICU impacting consistency in clinical practice and provision of services (Kriznik et al., 2019). This underscores the need for professional bodies, researchers, and clinicians alike to collaborate and ensure that guiding frameworks are developed to steer SLTs in the decision-making process. Additionally, intervention beyond the hospital period is equally as important to mitigate the long-term adverse developmental outcomes of HIE (Attrill et al., 2018).

4.1 Strengths and limitations

To the researchers' knowledge, this was the first study exploring the role of the SLT with neonates with HIE in a LMIC, namely South Africa, where the prevalence of HIE is higher than in high-income settings. The findings make a valuable contribution towards the management of infants with HIE by increasing the knowledge base and thereby informing clinical practice for SLTs in this low and middle income setting. A limitation is the small sample size, which impacts the generalisability of the findings. The small sample size is however to be expected due to the specialised nature of the research population and the limited number of SLTs working in South Africa.

4.2 Future research

Future research may include a larger sample of SLTs across a spectrum of working contexts and working experience in LMICs. Additionally, a qualitative study probing expert views may also be valuable. Development, trial, and subsequent implementation of guidelines and a standardised protocol can be conducted in a future study to determine the efficacy of protocols within practice. Lastly, research about specific management strategies for feeding and communication intervention for infants with HIE would be valuable.

5. Conclusion

The study set out to identify the role of the SLT in neonatal nurseries in South Africa with neonates with HIE. The majority of the participants indicated involvement in the management of feeding difficulties with only a few participants indicating that they provide follow-up services post discharge. SLTs must strive for more holistic management of this population as early intervention pre- and post-discharge plays a vital role in mitigating adverse neuro-developmental outcomes. In the public hospital setting, the prioritisation of feeding difficulties over other developmental concerns may be linked to limited staff and high caseloads, resulting in minimal follow-up of these high-risk infants. Interestingly, a similar trend was found in private hospitals where individual caseloads may be lower. Services in private healthcare may be more fragmented with less interprofessional collaboration across disciplines, which could impact implementation of follow-up services and lead to loss of infants that follow-up as out-patients. Future research could explore the continuum of care of infants with HIE. The findings also reveal the need for standardised protocols to guide the management of this population in the NICU. The results of the study may help to inform the development of future guidelines and may be beneficial for SLTs in LMICs currently involved in the management of this population in the NICU.

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7. Appendices

Appendix A: Survey Questionnaire

A SURVEY ON THE SPEECH-LANGUAGE THERAPISTS ROLE WITH NEONATES WHO HAVE HYPOXIC ISCHEMIC ENCEPHALOPATHY IN THE NICU

Dear potential respondent,

Title of study: The speech-language therapist's role with neonates who have hypoxic-ischaemic encephalopathy in neonatal nurseries.

As part of an undergraduate research project for the degree BA (Speech-Language Pathology), we are conducting a survey to determine the role of the speech-language therapist (SLT) working with neonates with hypoxic-ischaemic encephalopathy in neonatal nurseries in South Africa. Before data collection can commence, ethical clearance for this study will be sought from the Research Ethics Committee of the Faculty of Humanities, University of Pretoria.

Participation in this study is voluntary. SLTs registered with the Health Professions Council of South Africa (HPCSA), based in South Africa, and working/rendering services in a neonatal nursery, with neonatal intensive care unit (NICU) experience of at least six months, within the last five years, are invited to participate in this survey.

There are 22 questions in the questionnaire and it may take a maximum of 20 minutes to complete. Your responses for this online survey will be kept confidential, and the results of the study will be described in an academic report.

Participation in this study is voluntary and withdrawal is permissible until submission. Answers to previous questions may also be changed up until submission of the questionnaire. Before clicking submit you will be informed

that all responses given will be recorded. Please provide honest answers to all questions. After submission, we will not be able to withdraw your survey from participation.

We thank you for your interest in participating in this study. Should you have other colleagues who may also be interested, feel free to pass on this survey.

Please contact us or our supervisors if you have questions or concerns on any of the email addresses listed below.

Sincerely,

Undergraduate students

Amy de Gouveia

(u21480992@tuks.co.za)

Verity Hindson

(u21520233@tuks.co.za)

Amanda Viljoen

(u10353527@tuks.co.za)

Kyra Wilke

(u21431699@tuks.co.za)

Supervisor and co-supervisor

Dr Esedra Krüger (supervisor)

(esedra.kruger@up.ac.za)

Mrs Bhavani Pillay (co-supervisor)

(bhavani.pillay@up.ac.za)

A SURVEY ON THE SPEECH-LANGUAGE THERAPIST'S ROLE WITH NEONATES WHO HAVE HYPOXIC-ISCHAEMIC ENCEPHALOPATHY IN THE NICU

Questionnaire adapted from Perez & Poskey (2022)

Inclusion criteria

I am a HPCSA registered speech-language therapist rendering services in a neonatal nursery, with neonatal intensive care unit (NICU) experience of at least six months, or NICU experience within the last five years. ☐

I confirm my informed consent to participate in this study. ☐

Survey

1. Please indicate which sector you work in

a. Public healthcare
b. Private healthcare

2. How many years of experience do you have as a speech-language therapist working in the NICU?

a. 5-9 years
b. 10-14 years
c. 15-19 years
d. 20-24 years
e. 25 years or more

3. What is your age?

a. 20-29
b. 30-39
c. 40-49
d. 50-59
e. 60 or older

4. How many beds are in your unit?

a. 1-5
b. 6-10
c. 11-15
d. 16-20
e. More than 20

5. Where do you currently practice?

a. Eastern Cape
b. Free State
c. Gauteng
d. Kwazulu-Natal
e. Limpopo
f. Mpumalanga
g. Northern Cape
h. North-West
i. Western Cape

6. What developmental services does your unit provide?

Check all that apply.

a. Occupational therapy
b. Physical therapy
c. Speech-language therapy
d. Music therapy
e. Child life specialist
f. Dietician
g. Other:

7. On average, how many babies with HIE does your unit have every week?

8. What type of cooling is used with infants with HIE in your unit?

a. Selective head cooling

b. Whole body cooling

c. No cooling

9. Are you involved with infants with HIE during the actual cooling process (infant core body temperature 34°C or less)?

a. Yes

b. No

c. Unsure

10. If yes, what interventions do you provide during cooling? (This question should only be available to respondents who answered 'yes' to question number nine)

11. If not, how soon do you provide services status post therapeutic cooling? (This question should only be available to respondents who answered 'no' in question number nine)

12. What types of interventions do you provide status post therapeutic cooling?

a. Positioning

b. Environmental modifications (lighting, noise, smells, etc)

c. Feeding and swallowing intervention

d. Infant massage

f. Home therapeutic activity plan

g. Clinical assessment

h. Instrumental feeding and swallowing assessment

i. Caregiver training/coaching on development

j. Caregiver coaching on feeding

k. Breastfeeding management and support

l. Informational counselling for caregivers

m. Team discussions/meetings about feeding

n. Team discussions/meetings about discharge

o. NICU staff education, i.e. training or written materials

p. Kangaroo Mother Care (KMC)

q. Developmental care

r. Other:

13. How frequently do you provide interventions?

a. Multiple times daily

b. Once per day

c. Every other day

d. Every third day

e. Weekly

14. What type of formal assessments do you administer? Indicate all that apply.

a. General Movements Assessment (GMA)

b. The Premie-Neuro

c. NICU Network Neurobehavioral Scale (NNNS)

d. Hammersmith Neonatal Neurological Exam (HNNE)

e. Test of Infant Motor Performance (TIMP)

f. The Neonatal Feeding Assessment Scale

g. Other:

15. Do you assess feeding and swallowing?

a. Yes

b. No

16. How do you assess feeding and swallowing?

a.

b. I do not

17. If you do not assess feeding and swallowing, please elaborate. (This question

should only be available to respondents who answered ‘I do not’ for question 16)

18. Is there a specific protocol/policy in place at your institution for providing neonatal intervention for infants with HIE post therapeutic cooling?

a. Yes

i. If yes, please explain:

b. No

19. Do you provide follow up services after discharge from your facility?

a. Yes

i. Please elaborate on when and how often these follow-up services occur

b. No

20. If no, please elaborate on possible reasons (this question should only be available to respondents who answered ‘no’ for question 19)

21. Any other comments in regard to your assessment and intervention with infants with HIE?

22. What needs do you have regarding the work you do with infants who are diagnosed with HIE?

Appendix B: Table of Adaptations to the Published Questionnaire

A SURVEY ON THE SPEECH-LANGUAGE THERAPISTS ROLE WITH NEONATES WHO HAVE HYPOXIC- ISCHAEMIC ENCEPHALOPATHY IN THE NICU:

Questionnaire adapted from Perez & Poskey (2022)

Original question (Perez & Poskey, 2022)	**Question in current study's questionnaire**	**Rationale**
1. What is your discipline? a. Occupational therapy b. Physical therapy c. Speech-language pathology d. Other:	Please indicate which sector you work in a. Public healthcare b. Private healthcare	In the study's inclusion and exclusion criteria it is stated that one should be a speech-language therapist to take part in the questionnaire therefore the original question is not a focus in this study. This new question was added to gain information regarding the work context of the SLT. Practices in private and public healthcare sectors may vary quite significantly (Nash, 2021).
2. How many overall years of experience do you have within your discipline? a. _____	How many years of experience do you have as a speech-language therapist working in the NICU? a. 5-9 years b. 10-14 years c. 15-19 years d. 20-24 years e. 25 years or more	In the study's inclusion and exclusion criteria it is stated that one should be a speech-language therapist who has practised in the NICU for a minimum of 5 years to take part in the questionnaire, therefore the original question is not a focus in this study. The question was changed to a closed-ended question. This was done to make the survey more efficient and because the survey is primarily quantitative.

3. How long have you practised within the NICU? a. _____	How many years of experience do you have as a speech-language pathologist working in the NICU? a. 5-9 years b. 10-14 years c. 15-19 years d. 20-24 years e. 25 years or more	Increased skills, knowledge and training that come with experience in the NICU are believed to enhance the confidence and capabilities of speech-language therapists (Khoza-Shangase et al., 2022; Nash, 2021).
4. How many beds are in your unit?	How many beds are in your unit? a. 1-5 b. 6-10 c. 11-15 d. 16-20 e. More than 20	The question was changed to a closed-ended question. This was done to make the survey more efficient and because the survey is primarily quantitative.
5. Where do you currently live and practice? a. Australia b. Canada c. New Zealand d. United Kingdom e. United States of America f. Other:	Where do you currently practice? a. Eastern Cape b. Free State c. Gauteng d. Kwazulu-Natal e. Limpopo f. Mpumalanga g. Northern Cape h. North-West i. Western Cape	Within the study's inclusion and exclusion criteria it is stated that one should be a South African speech-language therapist to take part in the questionnaire.

6. What developmental services does your unit provide? Check all that apply. a. Occupational therapy b. Physical therapy c. Speech therapy d. Music therapy e. Child life specialist f. Other:	What developmental services does your unit provide? Check all that apply. a. Occupational therapy b. Physical therapy c. Speech-language therapy d. Music therapy e. Child life specialist f. Dietician g. Other:_____	This question was slightly adapted to make the question more comprehensive.
7. Approximately, how many hypoxic ischemic encephalopathy (HIE) cases are admitted to your unit annually? a. _____	On average, how many babies with HIE does your unit have every week?	This question was changed because SLTs might not have knowledge about the number of cases admitted to their units annually.
8. What type of cooling is used on infants with HIE in your unit? a. Selective head cooling b. Whole body cooling	What type of cooling is used with infants with HIE in your unit? a. Selective head cooling b. Whole body cooling c. No cooling	This question was slightly adapted to make the question more comprehensive.
9. Are you involved with HIE infants during the actual cooling process (infant core body temperature 34ºC or less)?	Are you involved with infants with HIE during the actual cooling process (infant core body temperature 34ºC or less)?	This question was slightly adapted to make the question more comprehensive.

a. Yes b. No	a. Yes b. No c. Unsure	
10. If yes, what interventions do you provide during cooling? a. Positioning b. Environmental modifications (lighting, noise, smells, etc) c. Other:	If yes, what interventions do you provide during cooling? (This question should only be available to respondents who answered 'yes' to question number nine.)	This question was changed to an open ended question to provide an opportunity for participants to expand on their view.
12. What types of interventions do you provide status post therapeutic cooling? a. Positioning b. Environmental modifications (lighting, noise, smells, etc.) c. Feeding d. Infant massage e. Caregiver education f. Home therapeutic activity plan g. Other:	What types of interventions do you provide status post therapeutic cooling? a. Positioning b. Environmental modifications (lighting, noise, smells, etc) c. Feeding and swallowing intervention d. Infant massage f. Home therapeutic activity plan g. Clinical assessment	This question was slightly adapted to make the question more comprehensive.

	h. Instrumental feeding and swallowing assessment i. Caregiver training/coaching on development j. Caregiver coaching on feeding k. Breastfeeding management and support l. Informational counselling for caregivers m. Team discussions/ meetings about feeding n. Team discussions/ meetings about discharge o. NICU staff education, i.e. training or written materials p. Kangaroo Mother Care (KMC) q. Developmental care r. Other:	
13. How frequently do you provide interventions? a. _____	How frequently do you provide interventions? a. Multiple times daily b. Once per day c. Every other day d. Every third day e. Weekly	The question was changed to a closed-ended question because the survey is primarily quantitative.

14. What type of formal assessments do you administer? a. General Movements Assessment (GMA) b. The Premie-Neuro c. NICU Network Neurobehavioral Scale (NNNS) d. Hammersmith Neonatal Neurological Exam (HNNE) e. Test of Infant Motor Performance (TIMP) f. Other:	What type of formal assessments do you administer? Indicate all that apply. a. General Movements Assessment (GMA) b. The Premie-Neuro c. NICU Network Neurobehavioral Scale (NNNS) d. Hammersmith Neonatal Neurological Exam (HNNE) e. Test of Infant Motor Performance (TIMP) f. The Neonatal Feeding Assessment Scale g. Other:	This question was slightly adapted to make the question more comprehensive.
15. Do you provide formal feeding assessments? a. Yes What formal feeding assessments do you administer? b. No	Do you assess feeding and swallowing? a. Yes b. No	The question was changed to a closed-ended question because the survey is primarily quantitative.

16. When do you administer formal assessments? a. _____	How do you assess feeding and swallowing? a. _____+ b. I do not	This question was removed as we cannot be certain that all respondents provide this service and this does not allow participants to specify whether or not they use formal assessments. This new question was added to gather more in-depth information.
Added	17. If you do not assess feeding and swallowing, please elaborate. (This question should only be available to respondents who answered 'I do not' for question 16.)	This open-ended question was added to gather more in-depth information.
Added	20. If no, please elaborate on possible reasons. (This question should only be available to respondents who answered 'no' for question 19.)	This question was added to gather more in-depth information related to the scope of the study.
Added	22. What needs do you have regarding the work you do with infants who are diagnosed with HIE?	This question was added to gather more in-depth information related to the scope of the study.

Appendix C: Respondent Information Leaflet and Informed Consent Letter

RESPONDENT INFORMATION LEAFLET AND INFORMED CONSENT LETTER

Study title: The speech-language therapist's role with neonates who have hypoxic-ischaemic encephalopathy in neonatal nurseries.

Contact details: Amy de Gouveia (u21480992@tuks.co.za); Verity Hindson (u21520233@tuks.co.za); Amanda Viljoen (u10353527@tuks.co.za); Kyra Wilke (u21431699@tuks.co.za); Dr Esedra Krüger (supervisor) (esedra.kruger@up.ac.za); Mrs Bhavani Pillay (co-supervisor) (bhavani.pillay@up.ac.za)

Dear potential respondent,

We are conducting research as part of an undergraduate group project in the Research methodology for healthcare sciences 300 (RHC300) module at the University of Pretoria. If you are working/rendering services in a neonatal nursery, with neonatal intensive care unit (NICU) experience of at least six months, or NICU experience within the last five years, you are invited to participate in this survey.

Purpose of the study

Care for neonates with hypoxic-ischaemic encephalopathy (HIE) must be timely, targeted, and clearly defined for all members of the early intervention team. Whilst the role of the other therapists and medical professionals is more clearly stipulated, that of the speech-language therapist (SLT) is not,

particularly within the South African context. Thus, this study aims to explore and describe the role of the SLT working with neonates with hypoxic-ischaemic encephalopathy in neonatal nurseries in South Africa.

What is expected from respondents

SLTs working/rendering services in a neonatal nursery, with NICU experience of at least six months, or NICU experience within the last five years, you are invited to participate in this electronic survey. Participation in the study is voluntary, with the 22 question survey taking approximately 20 minutes to complete. Answers can be changed and withdrawal possible until submission of the questionnaire. Once submitted, answers cannot be changed and respondents can no longer withdraw from the study. Answers must be honest as far as possible and the results of the survey will be described in an academic research report.

Ethical approval

Ethical approval for this study will be sought from the Research Ethics Committee of the Faculty of Humanities, University of Pretoria. This study will follow the ethical principles of autonomy, beneficence and non-maleficence, justice, and confidentiality, to protect the rights of respondents.

Your rights and participation in the study

Participation in this study is voluntary and withdrawal will not result in any negative consequences. There are no incentives for participation in this study.

What are the risks involved in the procedures?

Respondents will not be at risk of harm when participating in this study. Discomfort is minimised with the questionnaire taking no longer than 15 minutes to complete. All responses will be kept confidential.

Confidentiality

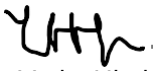
All responses will be kept confidential, and the reporting of data in the academic research report will not include any identifiable information about participants. Data will be entered into an electronic spreadsheet on a password-protected computer. Furthermore, the data will be uploaded

electronically to the University of Pretoria's secure data repository and stored for a minimum of 10 years.

Queries

If you have any questions, concerns, or require additional information please feel free to contact any one of the researchers via email: Amy de Gouveia at u21480992@tuks.co.za, Verity Hindson at u21520233@tuks.co.za, Amanda Viljoen at u10353527@tuks.co.za, and Kyra Wilke at u21431699@tuks.co.za. Alternatively you can contact the supervisor Dr Esedra Krüger at esedra.kruger@up.ac.za, or co-supervisor Mrs Bhavani Pillay at bhavani.pillay@up.ac.za.

Amy de Gouveia



Verity Hindson

Amanda Viljoen

Kyra Wilke

Dr E Krüger

Mrs B

INFORMED CONSENT TO PARTICIPATE IN THE STUDY

(to appear on landing page of online survey)

I hereby confirm that I understand how this study will be conducted with my participation. I have obtained and read the relevant written information about the study, and have had the opportunity to ask questions and seek further understanding. I am aware that the responses I give will be reported on, but identifiable (personal or professional) information will be kept confidential.

I understand that I am able to change my answers and/or withdraw my consent to participate in the study until submission. Once I have submitted the questionnaire, I will be unable to change any answers or withdraw from the study. I confirm that I am willing to participate in this study.
Furthermore, a copy of this informed consent agreement can be requested.

Appendix D: Infographic

ATTENTION NICU SLTs

Invitation to be a participant in a research study

AIM

The aim of this research study is to describe the SLTs role with neonates who have hypoxic-ischaemic encephalopathy.

WHO CAN PARTICIPATE?

- SLTs in South Africa that are registered with the HPCSA.
- SLTs working/rendering services to infants who have hypoxic-ischaemic encephalopathy in a neonatal nursery.
- SLTs with NICU experience of at least six months within the last five years.

ONLINE SURVEY

Survey Link:
https://qualtricsxm6ql7tzldz.qualtrics.com/jfe/form/SV_d53ttahBFZQIrsy

RESEARCHERS

STUDENT RESEARCHERS
- Amanda Viljoen u10353527@tuks.co.za
- Amy de Gouveia u21480992@tuks.co.za
- Kyra Wilke u21431699@tuks.co.za
- Verity Hindson u21520233@tuks.co.za

RESEARCH SUPERVISOR
- Dr Esedra Krüger esedra.kruger@up.ac.za

IF YOU MEET ALL OF THE CRITERIA:

- Please scan the QR code/ follow the link to fill in the online survey (it will take less than 10 minutes to complete).
- Additional information and consent documents are available on the survey.
- If you have any queries about the study please feel free to contact the researchers.

Thank you!

Department of Speech-Language Pathology and Audiology, University of Pretoria.

Appendix E: Ethical Clearance

UNIVERSITEIT VAN PRETORIA
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Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Humanities 100. Since 1919

Department of Speech- Language Pathology and Audiology

29 February 2024

Dear Researchers,

Project:	The speech-language therapist's role with neonates who have hypoxic-ischemic encephalopathy
Researchers:	Amy de Gouveia (u21380992); Verity Hindson (u2152033); Amanda Viljoen (u10353527); Kyra Wilke (u2141699)
Supervisors:	Dr E Kruger, Ms B Pillay
Department:	Department of Speech-Language Pathology and Audiology
Reference Number:	SLPA2024/02

Thank you for the application submitted to the Research Committee of the Department of Speech-Language Pathology and Audiology, Faculty of Humanities. We have the pleasure of informing you that the above application was approved on 29 February 2024.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal.

We wish you success with the project.

Sincerely

Prof Lidia Pottas
Chair: Departmental Research Committee

Prof J van der Linde
HEAD: DEPARTMENT OF SPEECH-LANGUAGE PATHOLOGY AND AUDIOLOGY
UNIVERSITY OF PRETORIA

Room 7.22, Level 7, Humanities Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Email makone.maja@up.ac.za | www.up.ac.za

Appendix F: Permission Request Letters to Post on Local Facebook Groups

UNIVERSITEIT VAN PRETORIA
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Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Humanities 100
Since 1919

24/10/2023

Dear Group Administrator

The speech-language therapist's role with neonates who have hypoxic-ischaemic encephalopathy.

We are a group of undergraduate students conducting research at the University of Pretoria. Our study aims to describe the speech-language therapist's (SLTs) role with neonates who have hypoxic-ischaemic encephalopathy. The study is conducted through an online survey that should not take longer than 20 minutes to complete. We would like to ask permission to post the infographic and link to the online survey on your Facebook group at the beginning of 2024. The data collected during this research study will be kept strictly confidential and will be stored securely.

If there are any queries about the research study, please feel free to contact the supervisors, Dr Krüger at esedra.kruger@up.ac.za or Mrs Pillay at bhavani.pillay@up.ac.za, respectively.

You can also contact the research students: Amy de Gouveia at u21480992@tuks.co.za, Verity Hindson at u21520233@tuks.co.za, Amanda Viljoen at u10353527@tuks.co.za, Kyra Wilke at u21431699@tuks.co.za.

Yours sincerely,

Amy de Gouveia, Verity Hindson, Amanda Viljoen and Kyra Wilke- Undergraduate Speech-Language Pathology students

Dr Esedra Krüger
Supervisor

Mrs Bhavani Pillay
Supervisor

I Karyn Casey (full name) hereby give permission to the researchers to post on the Facebook group South African Audiologists and Speech-Language Therapists (name) an infographic and online survey link for the purpose of a research study at the University of Pretoria.

Signature

25/10/2023
Date

Organizational Stamp

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24/10/2023

Dear Group Administrator

The speech-language therapist's role with neonates who have hypoxic-ischaemic encephalopathy.

We are a group of undergraduate students conducting research at the University of Pretoria. Our study aims to describe the speech-language therapist's (SLTs) role with neonates who have hypoxic-ischaemic encephalopathy. The study is conducted through an online survey that should not take longer than 20 minutes to complete. We would like to ask permission to post the infographic and link to the online survey on your Facebook group at the beginning of 2024. The data collected during this research study will be kept strictly confidential and will be stored securely.

If there are any queries about the research study, please feel free to contact the supervisors, Dr Krüger at esedra.kruger@up.ac.za or Mrs Pillay at bhavani.pillay@up.ac.za, respectively.

You can also contact the research students: Amy de Gouveia at u21480992@tuks.co.za, Verity Hindson at u21520233@tuks.co.za, Amanda Viljoen at u10353527@tuks.co.za, Kyra Wilke at u21431699@tuks.co.za.

Yours sincerely,

Amy de Gouveia, Verity Hindson, Amanda Viljoen and Kyra Wilke- Undergraduate Speech-Language Pathology students

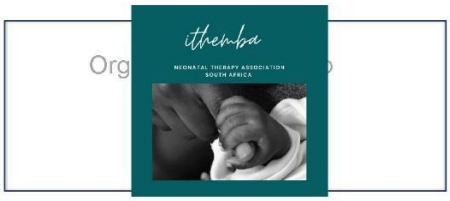
Dr Esedra Krüger
Supervisor

Mrs Bhavani Pillay
Supervisor

I Andrea Fourie (full name) hereby give permission to the researchers to post on the Facebook group iThemba Neonatal Therapy (name) an infographic and online survey link for the purpose of a research study at the University of Pretoria.

Signature

04 December 2023
Date



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24/10/2023

Dear Group Administrator

The speech-language therapist's role with neonates who have hypoxic-ischaemic encephalopathy.

We are a group of undergraduate students conducting research at the University of Pretoria. Our study aims to describe the speech-language therapist's (SLTs) role with neonates who have hypoxic-ischaemic encephalopathy. The study is conducted through an online survey that should not take longer than 20 minutes to complete. We would like to ask permission to post the infographic and link to the online survey on your Facebook group at the beginning of 2024. The data collected during this research study will be kept strictly confidential and will be stored securely.

If there are any queries about the research study, please feel free to contact the supervisors, Dr Krüger at esedra.kruger@up.ac.za or Mrs Pillay at bhavani.pillay@up.ac.za, respectively.

You can also contact the research students: Amy de Gouveia at u21480992@tuks.co.za, Verity Hindson at u21520233@tuks.co.za, Amanda Viljoen at u10353527@tuks.co.za, Kyra Wilke at u21431699@tuks.co.za.

Yours sincerely,

Amy de Gouveia, Verity Hindson, Amanda Viljoen and Kyra Wilke- Undergraduate Speech-Language Pathology students

Dr Esedra Krüger
Supervisor

Mrs Bhavani Pillay
Supervisor

I Annelie Bezuidenhout (full name) hereby give permission to the researchers to post on the Facebook group Allied Health in SA (name) an infographic and online survey link for the purpose of a research study at the University of Pretoria.

Signature

27 - 10 - 2023
Date

Organizational Stamp