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Swallowing, feeding, developmental outcomes and associated factors of South African infants with hypoxic-ischaemic encephalopathy

by

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ACKNOWLEDGEMENTS

"Trust in the Lord with all your heart and lean not on your own understanding; in all your ways submit to him and He will make your paths straight."
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LIST OF ABBREVIATIONS

AAP:	American Academy of Pediatrics
ABC:	Adaptive Behaviour Composite
ACOG:	American College of Obstetricians and Gynecologists
AGA:	Appropriate for gestational age
APGAR:	Appearance, pulse, grimace, activity, and respiration
ARV:	Anti-retroviral
ASHA:	American Speech-Language-Hearing Association
BFHI:	Baby Friendly Hospital Initiative
CDC:	Centers for Disease Control and Prevention
CP:	Cerebral palsy
CPAP:	Continuous positive airway pressure
EBM:	Expressed breast milk
HELIX trial:	Hypothermia for Moderate or Severe Encephalopathy in Low- and Middle-Income Countries trial
HIE:	Hypoxic-ischaemic encephalopathy
HIC:	High-income country
HIV:	Human immunodeficiency virus
HPCSA:	Health Professions Council of South Africa
IDDSI:	International Dysphagia Diet Standardisation Initiative
IQR:	Interquartile range
LGA:	Large for gestational age
LMIC:	Low- and middle-income country
MDT:	Multi-disciplinary team
MRI:	Magnetic resonance imaging
NE:	Neonatal encephalopathy
NFAS:	Neonatal Feeding Assessment Scale
NNS:	Non-nutritive sucking
NS:	Nutritive sucking

NVD:	Normal vaginal delivery
OPD:	Oropharyngeal dysphagia
OT:	Occupational therapist
$PaCO_2$:	Partial pressure of carbon dioxide
PAS:	Penetration-Aspiration Scale
PPV:	Positive pressure ventilation
PROM:	Premature rupture of membranes
RITLS:	Rossetti Infant-Toddler Language Scale
SASLHA:	South African Speech-Language-Hearing Association
SD:	Standard deviation
SGA:	Small for gestational age
SLP:	Speech-language pathologist
SLT:	Speech-language therapist
SMS:	Short message service
SPSS:	Statistical Package for Social Sciences
SSB:	Suck-swallow-breathe
TH:	Therapeutic hypothermia
UNICEF:	United Nations International Children's Emergency Fund
VFSS:	Video-fluoroscopic swallow study
WHO:	World Health Organisation
WMA:	World Medical Association

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PUBLICATIONS AND RESEARCH OUTPUTS

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The findings of Chapter 4 were presented orally by R. Malan at the Early Childhood Voices Conference hosted by Charles Sturt University, Australia, 5-9 December 2022.

The findings of Chapter 4 were also accepted for an oral presentation by R. Malan at the Feeding Matters 10th International Pediatric Feeding Disorder Conference, 13-14 April 2023.

The findings of Chapter 5 were presented by R. Malan in the form of a poster at the Association of Medical Councils of Africa 24th Annual Conference held at Sun City Resort, South Africa, 2-6 October 2022.

ABSTRACT

Background: Hypoxic-ischaemic encephalopathy **(**HIE) is a significant cause of mortality and neurological impairment among infants, especially in low- and middle-income countries (LMICs). Associated problems may include swallowing, feeding, and developmental difficulties but there is a lack of research in the field.

Aim: To describe South African infants with HIE regarding swallowing, feeding, development and associated factors.

Method: Three prospective studies were conducted at an academic hospital in Tshwane over 24 months. Data were collected in the 29-bed neonatal unit and developmental assessments were conducted on an outpatient basis. Firstly, a comparative design described and compared factors associated with mild and moderate HIE among 46 infants. Secondly, a longitudinal cohort design described the evolution of swallowing and feeding among 29 infants with all stages of HIE initially and at discharge from hospital. Correlational research explored the relationship between oropharyngeal dysphagia (OPD) severity and length of hospitalisation. Thirdly, a case series described the swallowing and feeding of four infants with moderate HIE and their development at six and 12 months.

Results and discussion: Management factors and clinical tests differed significantly between mild and moderate HIE in Study 1. Significant factors included resuscitation duration ($p=0.011$); time to spontaneous respiration ($p=0.012$); admission and highest Thompson scores ($p<0.001$); and five- ($p=0.012$) and ten-minute ($p=0.022$) APGAR scores. Approximately two-thirds of Study 2 participants displayed OPD symptoms regardless of HIE severity, suggesting that infants with all grades of HIE should receive early intervention by a speech-language therapist (SLT). Significantly fewer OPD symptoms occurred at discharge compared to initial assessment ($p=0.004$). The correlation between OPD severity and length of hospitalisation was not significant ($p=0.052$). All participants with moderate HIE in Study 3 displayed atypical outcomes

throughout infancy, including OPD during hospitalisation. Everyone went home on oral feeds, but some breastfeeding difficulties persisted due to non-optimal states of alertness and aspiration on fast-flowing liquids. Developmental delays emerged in various domains by six-months' age for all Study 3 participants. Communication abilities were relatively spared at this age. Developmental delays persisted among all participants at 12 months but occurred in different areas than in the six-months assessment. Increased communication delays were evident at 12 months. Research strengths included investigating different HIE severity grades and describing evolving swallowing, feeding and developmental profiles over time.

Conclusion: A deeper understanding of South African infants with HIE was obtained. The importance of early SLT involvement in mitigating infants' swallowing, feeding, and communication difficulties was highlighted. The need for dynamic assessment was established. A continuous route of early intervention is proposed, from birth to school-going age.

Keywords: Hypoxic-ischaemic encephalopathy; mild, moderate, and severe hypoxic-ischaemic encephalopathy; modified Sarnat staging; Thompson score; low-and-middle-income countries; South Africa; neonate; infant; oropharyngeal dysphagia; swallowing; feeding; development; factors

CHAPTER 1: INTRODUCTION

1.1 Aim of the chapter

Chapter 1 introduces hypoxic-ischaemic encephalopathy (HIE) as one of the most common causes of neonatal encephalopathy (NE) and discusses its severity and prevalence with special reference to low- and middle-income countries (LMICs) such as South Africa. The chapter also examines therapeutic hypothermia (TH) and its application in LMICs, as TH is the main neuro-protective strategy used to reduce mortality and morbidity associated with HIE. Current knowledge of associated factors, swallowing, feeding, and developmental outcomes of infants with HIE are presented. Deficiencies in the understanding of this heterogenous population are highlighted, and three research questions are posed at the end of the chapter. This is followed by an explanation of the terminology used in the thesis and an outline of the thesis chapters.

1.2 Introduction

Despite advances in medical care, rates of neurological compromise among neonates remain high (Haffner & Sankovic, 2022; Szakmar et al., 2019). HIE is a significant cause of neurological compromise and results in significant mortality and varying morbidity, including swallowing, feeding, and developmental difficulties (Aker et al., 2020; Arvedson et al., 2020; Egharevba et al., 2018). Although rates of HIE have greatly decreased in high-income countries (HICs) in recent years, HIE remains a problem in LMICs such as South Africa, where prevalence rates of the condition are up to 20 times higher (Ballot et al., 2020; Kawakami et al., 2021). Despite this, there is a paucity of research regarding the burden of HIE in LMICs (Egharevba et al., 2018).

1.3 Neonatal encephalopathy (NE)

NE is a general term used to describe clinical signs of disturbed brain function in neonates at or beyond 35 weeks gestational age in the earliest days after delivery (American Academy of Pediatrics [AAP], 2014). It is most noticeably manifested by a depressed level of consciousness, reduced spontaneous movement, respiratory

difficulty, abnormal tone and posturing, and disturbed cranial nerve function. It is also frequently associated with seizures (AAP, 2014; Volpe, 2012; Wu, 2021). NE can be caused by a variety of conditions, some of which remain unexplained; therefore, the term does not make assumptions about aetiology or pathophysiology (Wu, 2021). Typical causes of NE include HIE, intercranial haemorrhage, hypoglycaemia, severe hyperbilirubinaemia (kernicterus), metabolic disorders, malignant epileptic syndromes, neurodegenerative disorders, intercranial infections, protozoan infections (toxoplasmosis), trauma, and genetic conditions (Martinez-Biarge et al., 2013; Volpe, 2012).

1.4 Hypoxic-ischaemic encephalopathy (HIE)

HIE describes a pathological pattern that occurs due to impaired oxygen supply to the foetal brain during the intra- or peripartum period (Douglas-Escobar & Weiss, 2015; James & Patel, 2014; Volpe, 2012). When occurring with signs of encephalopathy, there are certain clinical markers that imply the presence of HIE (Douglas-Escobar & Weiss, 2015; Kurinczuk et al., 2010). These include APGAR scores <5 at 5 and 10 minutes, or evidence of foetal acidemia [arterial umbilical cord blood gas or radial artery blood gas done within 60 minutes of delivery with a pH <7.0 or a base deficit ≥12 mmol/L] (AAP, 2014; Douglas-Escobar & Weiss, 2015; Shankaran et al., 2005). Specific patterns of brain injury and multi-system organ involvement are also associated with HIE (AAP, 2014; Douglas-Escobar & Weiss, 2015; Wu, 2021). Patterns of brain injury typically affect the cerebral cortex, basal ganglia, thalamus, and brain stem or cerebral white matter, especially in parasagittal watershed distributions (Quattrochi et al., 2016; Volpe, 2018). Multi-system organ involvement may include renal injury, hepatic injury, haematologic abnormalities, cardiac dysfunction, gastrointestinal injury, and metabolic derangements (AAP, 2014).

Defining the severity of encephalopathy associated with hypoxic ischaemia is important to predict affected neonates' long-term outcomes (Volpe, 2018). Sarnat and Sarnat (1976) originally classified HIE according to stages 1 (mild), 2 (moderate) and 3 (severe). The Sarnat stages provided the basis for simpler scoring systems such as the modified Sarnat score and the Thompson score, both of which are commonly used today [Volpe, 2018] (See Table 1.1).

Table 1.1

Modified Sarnat and Thompson scores (Shalak et al., 2003; Shankaran et al., 2005; Thayyil et al., 2017; Thompson et al., 1997)

Scoring system	Categories/ elements assessed	Application
Modified Sarnat score	**1. Level of consciousness** Normal = alert, Mild = hyperalert, Moderate = lethargic, Severe = stupor/ coma **2. Spontaneous activity** Normal = changes position when awake, Mild = normal or decreased, Moderate = decreased, Severe = absent **3. Posture** Normal = predominantly flexed, Mild = mild flexion of distal joints, Moderate = moderate flexion of distal joints, complete extension, Severe = decerebrate[a] **4. Tone** Normal = normal strong flexor tone, Mild = normal or slightly increased, Moderate = hypotonia (focal or general), Severe = flaccid **5. Primitive reflexes** **Suck:** Normal = strong, Mild = weak, Moderate = weak +/- bite, Severe = absent **Moro:** Normal = complete, Mild = exaggerated, Moderate = incomplete, Severe = absent **6. Autonomic dysfunction** **Pupils:** Normal = 2.5-4.5 mm (in light) / 1.5-2.5 (in dark) Mild = dilated, Moderate = constricted, Severe = deviated/ dilated/ non-reactive to light **Heart rate:** Normal = 100-160, Mild = tachycardia, Moderate = bradycardia, Severe = variable **Respiration:** Normal = regular, Mild = hyperventilation, Moderate = periodic breathing, Severe = apnoea/ requiring ventilation)	Encephalopathy is defined by at least one abnormal sign for three of the six categories. The number of signs determines the severity of encephalopathy. Many therapeutic hypothermia trials (discussed in Section 1.5) have used the score to assess neonates within the first six hours of life to determine those at greatest risk of abnormal developmental outcomes (Shankaran et al., 2005; Thayyil et al., 2017). It is recommended that the Modified Sarnat score be repeated every 1-2 hours within the first six hours of life to identify neonates with progressive encephalopathy (Martinello et al., 2017).
Thompson score	**1. Level of consciousness** 0 = normal, 1 = hyperalert, 2 = lethargic, 3 = comatose **2. Posture** 0 = normal, 1 = fisting, 2 = strong, distal flexion, 3 = decerebrate **3. Tone** 0 = normal, 1 = hypertonia, 2 = hypotonia, 3 = flaccid **4. Suck** 0 = normal, 1 = poor, 2 = absent +/- bite **5. Moro** 0 = normal, 1 = partial, 2 = absent **6. Grasp** 0 = normal, 1 = poor, 2 = absent **7. Respiration** 0 = normal, 1 = hyperventilation, 2 = brief apnoea, 3 = apnoea, often requiring ventilation **8. Seizures** 0 = none, 1 = infrequent, 2 = frequent **9. Fontanelle findings** 0 = normal, 1 = full, not tense, 2 = tense	Each of the nine signs is scored according to severity. Scoring is performed daily until a score of 0 is achieved or the neonate is discharged home. The highest score and the score on day seven of life are used for prognostication. In some studies, the Thompson score has been used in the first six hours of life to determine eligibility for therapeutic hypothermia (Kali et al., 2016; Thoresen et al., 2016; Weeke et al., 2017).

[a] *Exaggerated extensor posturing of the extremities, indicative of brain injury (Whitney & Alastra, 2021).*

Typically, neonates with a Thompson score of 10 or less are considered to have mild HIE according to the Sarnat stages; those who score 11-14 are considered to have moderate HIE; and those who score above 14 are considered to have severe HIE (Thompson et al., 1997). However, recent evidence indicates that a Thompson score of 0-4 is aligned with a normal modified Sarnat score; a score of 5-6 is aligned with a mild modified Sarnat score; a score of 7-11 is aligned with moderate modified Sarnat score; and a score of 14 or more is aligned with a severe modified Sarnat score (Chansarn et al., 2021).

Estimates of HIE prevalence rates vary greatly. In HICs, it is estimated that HIE is diagnosed in 1 to 3/1000 live births (Acun et al., 2022; Parker et al., 2018; Shipley et al., 2021). In LMICs such as South Africa, HIE occurs with an estimated prevalence of 2.3 to 20/1000 live births (Bruckmann & Velaphi, 2015; Horn et al., 2013; Montaldo et al., 2015; Padayachee & Ballot, 2013). Rates of HIE may be even higher in rural areas where increased rates of home births occur and where health care facilities are often under-resourced (Ballot et al., 2020).

1.5 Therapeutic hypothermia (TH)

TH is currently the main neuro-protective strategy available for neonates with HIE and should be initiated within six hours after birth (Coetzee, 2018; Shankaran, 2010). TH is provided to neonates born near term (usually ≥36 weeks' gestation) and entails maintaining the neonate's core body temperature at between 33°C and 34°C for 72 hours, with slow re-warming thereafter (Shankaran et al., 2005). Both whole-body cooling and selective head cooling have proven to be effective methods of providing TH, for which servo-controlled devices, frozen gel packs and phase-changing materials can be used (Prashantha et al., 2019).

TH is the standard of care for moderate and severe HIE in HICs, as it has been found to be an effective method of reducing death and childhood disability among affected neonates (Marlow et al., 2021). Despite the therapeutic drift towards offering TH to neonates with mild HIE, there is currently insufficient evidence to campaign for its use among this population (Goswami et al., 2020). This is because neonates with mild HIE were previously thought to have similar developmental outcomes as their typical

peers, and the benefits of implementing TH may be insufficient to outweigh some of its associated risks [such as coagulopathy, cardiac arrhythmias, thrombocytopaenia, subcutaneous fat necrosis, and mother-neonate separation] (Goswami et al., 2020). Previous reports may have underestimated the effect of mild HIE on development, but more research into TH for neonates with mild HIE is required (Goswami et al., 2020).

Another area of debate is whether to implement TH in LMICs. Earlier research in South Africa suggested that it is safe and feasible to implement TH in resource-limited settings, if there is sufficient monitoring and support (Kali et al., 2016). However, data from the Hypothermia for Moderate or Severe Encephalopathy in LMICs (HELIX) trial conducted in South Asia revealed no significant differences in disability between cooled and uncooled survivors and showed that mortality was higher in the cooled group (Thayyil et al., 2021). The authors of the HELIX trial argued that even when the same TH resources were available in LMICs and HICs, population differences between the two settings rendered TH unfeasible in LMICs (Thayyil et al., 2021). Despite the controversy surrounding the implementation of TH, it has been offered in South Africa with reasonable outcomes for many years (Ballot et al., 2021). It has therefore been recommended that more research be conducted to determine which populations will benefit most from this treatment modality (Ballot et al., 2021).

1.6 Factors associated with HIE

For effective service delivery, any multi-disciplinary team (MDT) working with HIE requires a thorough understanding of the factors associated with this condition. Such factors, which may indicate potential causal pathways or denote the severity of the condition, may differ for HICs and LMICs (McIntyre et al., 2021). Factors associated with HIE are divided into biological and environmental factors (see Table 1.2). Biological factors include antepartum, intrapartum, and maternal influences (Bruckman & Velaphi, 2015; Martinez-Biarge et al., 2013). Although past publications broadly claim that social factors are related to the presence of HIE, few studies investigated the specific environmental factors related to the condition (Antonucci et al., 2014; Milsom et al., 2002). The dated nature of older studies, their use of retrospective designs and the absence of universally accepted HIE definitions further limit the usefulness of previous research on the factors associated with HIE (Badawi

et al., 1998a; Badawi et al., 1998b; Butt et al., 2008; Ellis et al., 2000; Futrakul et al., 2006; Ibrahim & Asmaa, 2016). Moreover, few studies compared factors between HIE severity types, often grouping infants with moderate and severe HIE together, or comparing survivors and non-survivors (Bruckmann & Velaphi, 2015; Padayachee & Ballot, 2013).

Table 1.2

Biological and environmental factors associated with HIE

Biological factors			Environmental factors
Antepartum factors	Intrapartum factors	Inherent maternal factors	
• **Lack of antenatal care** (Ibrahim & Asmaa, 2016[a]) • **Male gender** (Ibrahim & Asmaa, 2016) • **Gestational age greater than 41 weeks** (Martinez-Biarge et al., 2013[a]; Namusoke et al., 2018[a]) • **Intra-uterine growth restriction** (Yadav & Damke, 2017[a])	(Martinez-Biarge et al., 2013; Ibrahim & Asmaa, 2016; Namusoke et al., 2018): • **Premature rupture of membranes** (greater than 24 hours between rupture of the membranes and delivery) • **Meconium-stained amniotic fluid** • **Sentinel events** (uterine rupture, placental abruption, cord prolapse, foetal exsanguination and maternal collapse) • **Shoulder dystocia** (delivery requiring manipulation of the shoulders for them to be released) • **Tight wrapping of the umbilical cord around the neck** • **Failed vacuum delivery** • **Abnormal foetal heart rate** • **Prolonged second stage of labour** (Bruckmann & Velaphi, 2015[b]): • **Prolonged second stage of labour** • **Low APGAR score at 10 minutes** • **Resuscitation factors** (need for adrenaline or chest compressions, or onset of respiration after 20 minutes) • **Metabolic acidaemia** Padayachee & Ballot, 2013[b]): • **Foetal distress** • **Need for resuscitation after birth** • **Mode of delivery** (elective caesarean section associated with improved outcomes)	(Bruckmann & Velaphi, 2015): • **Eclampsia** • **Cephalopelvic disproportion**	• **Single maternal marital status** (Milsom et al., 2002[a]) • **Lower socio-economic status** (Yadav & Damke, 2017)

[a] Ibrahim and Asmaa (2016); Martinez-Biarge and colleagues (2013); Milsom and colleagues (2002); Namusoke and colleagues (2018) and Yadav and Damke (2017) investigated factors associated with HIE.

[b] Bruckmann and Velaphi (2015) and Padayachee and Ballot (2013) investigated factors associated with poorer outcomes of HIE (such as death and severe HIE).

1.7 Mortality and developmental disability

HIE is the main cause of death and permanent neurological impairment among full-term neonates globally (Liu et al., 2020). It is also the most important cause of cerebral palsy (CP) in sub-Saharan Africa (Ballot et al., 2020). Even in the absence of CP, survivors of HIE may have increased risk of cognitive, communicative, behavioural, sensory, psychological, and memory problems, with adverse outcomes occurring in almost 50% of affected neonates (Adhearne et al., 2016; Ballot et al., 2020; De Vries & Jongmans, 2013; Pin et al., 2009). Mild sequelae of HIE may include learning difficulties, attention deficit disorders, delayed entry into primary school, language delay, or fine motor dysfunction (Shankaran et al., 2012; De Vries & Jongmans, 2013). Severe sequelae may include epilepsy, CP, vision or hearing impairment, and severe cognitive or developmental disorders (Pin et al., 2009; Wu et al., 2021).

Outcomes among individuals with HIE vary greatly, therefore neurological prognostication from an early age is essential for the development of treatment plans, parent counselling, and decision making (Rasmussen et al., 2016). For those who need it the most, prognostication may also facilitate early intervention during infancy when neuroplasticity is thought to be the greatest (Mizuno & Ueda, 2005). Later outcomes of neonates with mild and severe HIE are often effectively predicted through early rating systems such as the modified Sarnat stages or Thompson score (Adhikhari & Rao, 2017; Murray et al., 2009). However, the outcomes of neonates with moderate HIE are less certain, and significant diversity exists among this group (Adhikhari & Rao, 2017; De Vries & Jongmans, 2013; Robertson & Perlman, 2006; Van Handel et al., 2007). Earlier studies suggest that abnormal long-term outcomes occur in 100% of neonates with severe HIE, in 32% of neonates with moderate HIE and in 0% of neonates with mild HIE (Pin et al., 2009). However, a growing body of evidence is emerging to indicate that the outcomes of neonates with mild HIE are not typical (Conway et al., 2018).

With the implementation of TH among neonates with moderate and severe HIE in HICs, rates of moderate to severe disability among the affected population at the ages of 18-24 months dropped to 25-30% (Adhearne et al., 2016). In South Africa, similar figures were found, as approximately one-third of neonates with moderate and severe

HIE who had received TH presented with developmental disability at the ages of 18-24 months (Mbatha et al., 2021). Another local study reported reduced rates of language impairment, CP and cognitive delay in neonates who received TH, although the study's primary objective was not to determine the effect of TH on developmental outcomes (Ballot et al., 2020). The improvement found in these studies may be offset by the uncertainty surrounding the use of TH in LMICs (Thayyil et al., 2021).

1.8 Early sucking, swallowing, and feeding

Apart from the threat of mortality and long-term developmental difficulties among survivors, infants with HIE are also at significant risk for developing oropharyngeal dysphagia (OPD) and gastrointestinal complications (Arvedson et al., 2020). Recently, it was found that 89% of infants with HIE displayed at least one symptom of OPD, such as falling asleep during feeding, short sucking bursts, oral-motor difficulties, absence of frequent swallowing, coughing, nostril-flaring, and visible oral secretions (Krüger et al., 2019). Elsewhere it was found that a third of infants with HIE required long-term feeding tubes due to severe feeding difficulties (Martinez-Biarge et al., 2012). This figure rose to 91% when associated with injuries to the basal ganglia, thalamus, and pons (Martinez-Biarge et al., 2012).

OPD among infants with HIE is thought to be predominantly due to deep nuclear grey matter, brain stem, and cranial nerve nuclei involvement, but contribution of the cerebral cortex and corticobulbar disturbance is also possible (Arvedson et al., 2020; Volpe, 2018). Specifically, disturbances of muscle tone, poor coordination of movement, impaired functioning of neuromuscular units, poor state regulation and/or reduced feeding endurance may affect swallowing and feeding among these infants (Arvedson et al., 2020; Genna et al., 2013; Krüger et al., 2017). Additional contributing factors may include drowsiness associated with neurological compromise, the sedation effect of medication, and the implementation of TH (Arvedson et al., 2020; Craig et al., 2020; Krüger et al., 2019). The ideal early feeding regime for neonates with HIE on TH has not yet been sufficiently described, and since there is a lack of evidence on providing enteral or parenteral nutrition during TH, variable practice results (Ojha et al., 2019). TH may also interfere with early bonding between mother and neonate, which could affect oral feeding readiness (Ojha et al., 2019; Craig et al.,

2020). Gastrointestinal complications among the HIE population may be associated with decreased perfusion and motility in the gastrointestinal tract (Thornton et al., 2014).

Consequences of OPD may include malnutrition, aspiration, difficulties administering medication, behavioural difficulties, reduced health status and poor quality of life for infants and their families (Arvedson et al., 2020; Martinez-Biarge et al., 2012). OPD also lengthens hospital stay, increases the number of emergency room visits, and raises the costs of medical equipment and treatment – all of which place strain on healthcare resources. (Dziewas et al., 2017). Early intervention could help to lessen these negative effects and may contribute to improved progression of oral feeding skills (Jadcherla et al., 2017; Leder et al., 2016).

Speech-language therapists (SLTs) are central in assessing, diagnosing, and providing intervention for OPD among affected infants (Lefton-Greif & Arvedson, 2016; Walker, 2021). As infants with HIE often have complicated feeding profiles, SLTs require specialist knowledge of this population (Lefton-Greif & Arvedson, 2016). Unfortunately, there is a lack of understanding of the neural mechanisms that underlie both normal and disordered swallowing and feeding, and research on OPD in infants with HIE remains vague (Humbert & German, 2013; Jadcherla et al., 2017). Even though some research on OPD in infants with HIE is emerging, studies using validated and standardised assessment tools are lacking and instrumental evaluations such as video-fluoroscopic swallow studies (VFSSs) are limited (Audag et al., 2016; Krüger et al., 2019). VFSSs may recognise subtle symptoms of OPD (such as silent aspiration), which may result in earlier management and possible prevention of associated negative consequences (Arvedson et al., 2020; Audag et al., 2016). Serial assessment of OPD is also rarely found in the relevant research, even though neonates present with rapidly changing anatomical and physiological subsystems that continue to mature throughout hospitalisation (Jensen et al., 2017; Krüger et al., 2019; Lau, 2015).

1.9 Problem statement and rationale

HIE involves a profound burden of disease and remains a significant cause of infant mortality and disability, even with advances in medical care and the widespread use

of TH, the main neuro-protective strategy for the condition (Ballot et al., 2020; Douglas-Escobar & Weiss, 2015). This is especially true in LMICs such as South Africa, where the incidence of HIE is high, under-resourcing and lack of access to appropriate health facilities are pervasive, and where uncertainty exists about the implementation of TH. Early intervention for infants with HIE is essential due to the condition's adverse effect on infant outcomes, as well as the negative consequences it poses for individuals, their families, health care resources, and society (Jamison et al., 2013). SLTs have an integral role to play in providing some of the earliest interventions to this population, as they can address swallowing, feeding and developmental issues from the neonatal stage (American Speech-Language-Hearing Association [ASHA], 2016; South African Speech-Language-Hearing Association [SASLHA], 2017). Besides neurological prognostication, knowledge of associated factors and an acute understanding of the swallowing, feeding and developmental profiles of infants with HIE are important to provide effective evidence-based early intervention. However, the heterogeneity of infants with HIE renders prognostication challenging and further information about the swallowing, feeding and developmental profiles of this population is essential. Past research either grouped HIE severity grades together or focused on those infants with the most severe outcomes while neglecting more subtle forms of the condition (Rasmussen et al., 2016). Moderate HIE was particularly neglected and therefore it is imperative that the needs of this large and variable group of individuals be addressed. As infants are dynamic beings with rapidly changing physiological systems, a deeper understanding of the evolution of swallowing, feeding and development among neonates with HIE is required.

1.10 Research questions

The over-arching research question that emerged from the literature review was formulated as follows: "What are the swallowing, feeding, developmental outcomes and associated factors of infants with HIE in South Africa?" To answer this main question, the following three research questions were posed:

(i) What are the factors associated with mild and moderate HIE in neonates?

The first part of the study was a necessary starting point to work towards the main research aim, as its findings provided a foundation for an improved understanding of the diverse HIE population. Understanding the factors that characterise neonates with mild and moderate HIE was especially important, as the risk profiles of these two groups are less clear than that of their counterparts with severe HIE.

(ii) How do the swallowing and feeding abilities of neonates with HIE evolve during their hospital stay?

The second part of the study set out to describe the swallowing and feeding abilities of neonates with HIE during hospitalisation. Serial assessment of OPD was important, as neonates present with rapidly changing anatomical and physiological subsystems. Among other findings, this sub-study highlighted the heterogeneity of neonates with moderate HIE, which contributed to the rationale for the third part of the study.

(iii) What are the outcomes of infants with moderate HIE and how do they evolve over time; from their early swallowing and feeding abilities to their later developmental outcomes at six and 12 months?

The aim of the third sub-study was to describe the evolution of outcomes among the heterogeneous group of infants with moderate HIE, from hospitalisation to the ages of six and 12 months. The study provided a detailed report of the unique swallowing and feeding profiles of neonates with moderate HIE and took matters one step further by describing their developmental outcomes later in infancy.

Each of the three research questions was answered by implementing an appropriate research design and method, as described in Chapter 2. The findings of the sub-studies were submitted as articles to peer-reviewed journals (submission details are also provided in Chapter 2).

1.11 Terminology used in the thesis

The terminology as used and applied in the thesis is explained next.

- **Early intervention**

  Early intervention describes services and supports that are available for infants and young children at risk of developmental delays and disabilities, as well as for their families, during the crucial early years (often 0-5 years) when neuroplasticity is thought to be the greatest (Centers for Disease Control and Prevention [CDC], 2019; Kohli-Lynch et al., 2019). Benefits may be seen in child development, educational achievements, and even financial earnings later in life (Kohli-Lynch et al., 2019).

- **Exclusive breastfeeding**

  Exclusive breastfeeding is the situation in which an infant receives only breast milk from their mother or wet nurse. No other liquids or solids are given, except medications, vitamins, or minerals in syrup or droplet form (World Health Organisation [WHO], 2009). Exclusive breastfeeding may include direct breastfeeding (sucking directly from the breast) or receiving breast milk via other methods such as cup or bottle (WHO, 2009).

- **Feeding**

  Feeding is a broad term that refers to the process of getting food and liquid into the mouth (Arvedson et al., 2020). It includes gathering food and liquid for intake, sucking or chewing, and swallowing (Arvedson & Brodsky, 2002; Arvedson et al., 2020). For this study, feeding refers to the process of orientating towards the food source (i.e., rooting and latching), sucking, and swallowing milk.

- **Infant**

  An infant is a young child ≤12 months of age. Where used in this study, the term encompasses the neonatal stage.

- **Neonate**

  A neonate is usually defined as a child <28 days of age (WHO, 2022). However, for this study, the term neonate may include any neonate receiving care from birth in the neonatal high care unit of the hospital, even if they are older than 28 days.

- **Oropharyngeal dysphagia**

  Oropharyngeal dysphagia refers to an impairment in any of the components of the oral preparatory, oral (propulsive), and/or pharyngeal phases of swallowing (Arvedson et al., 2020; Benfer et al., 2013).

- **Speech-language therapist (SLT)**

  The term “speech-language therapist” is used throughout this thesis to refer to professionals who work within the profession of Speech-Language Therapy and who are registered with a relevant regulatory body (Health Professions Council of South Africa [HPCSA], 2017). Only in Chapter 4, the term is replaced with “speech-language pathologist,” as this was a requirement of the journal in which the article was accepted for publication.

- **Sucking**

  Sucking refers to an infant’s rhythmical mouth and tongue movements (Wolf & Glass, 1992). It can be classified as either non-nutritive or nutritive in nature (Da Costa et al., 2008; Poore & Barlow, 2012). Non-nutritive sucking (NNS) comprises a series of rhythmical compressions followed by pauses where no nutrient is consumed (Barlow, 2009; Poore & Barlow, 2012). Nutritive sucking (NS) involves the consumption of a nutrient such as milk and occurs at approximately half the rate of NNS (Barlow, 2009; Da Costa et al., 2008; Poore & Barlow, 2012).

- **Suck-swallow-breathe (SSB) coordination**

  Successful feeding depends on an infant’s ability to rhythmically coordinate sucking, swallowing, and breathing, to allow for safe transport of the milk bolus from the oral cavity to the digestive system while minimising the duration of airflow interruption (Lau et al., 2003; Mizuno & Ueda, 2005; Sakalidis & Geddes, 2016; Sigendonk et al., 2014).

- **Swallowing**

  In neonates, swallowing refers to the process by which the milk bolus is transported from the mouth to the stomach while keeping the airway protected (Arvedson et al., 2020; Sigendonk et al., 2014). (A distinction is made between feeding and swallowing in this study). Swallowing is commonly divided into

three main phases, namely oral, pharyngeal, and oesophageal (Viswanathan & Jadcherla, 2020). In neonates:

(i) the oral phase includes bolus formation by sucking;

(ii) the pharyngeal phase includes transport of the bolus towards the oesophagus by eliciting the pharyngeal swallow reflex in coordination with upper oesophageal opening while ensuring airway protection; and

(iii) the oesophageal phase of swallowing includes transport of the bolus towards the stomach through peristalsis (Viswanathan & Jadcherla, 2020).

1.12 Outline of chapters in the thesis

The chapters presented in the thesis are outlined below:

Chapter 1- Introduction

The first chapter provides background information and a rationale for the current study based upon relevant research. Chapter 1 also provides a list of relevant terminology.

Chapter 2- Methodology

The second chapter presents the methods of each of the three sub-studies contained in this thesis. Research aims, context, designs, sampling, participant selection criteria, materials and apparatus, as well as data collection and analysis procedures are described. The relevant ethical considerations, reliability, and validity are also discussed.

Chapter 3- South African neonates with mild and moderate hypoxic-ischaemic encephalopathy

The third chapter consists of the article based upon the first study. It was published in the *South African Journal of Child Health* in September 2022.

Chapter 4- Evolution of swallowing and feeding abilities of neonates with hypoxic-ischaemic encephalopathy during hospitalisation: a case series

The fourth chapter consists of the article based upon the second study. It was accepted for publication in the *International Journal of Speech-Language Pathology* on 6 November 2022 and was published online on 29 November 2022.

Chapter 5- Evolution of feeding and developmental outcomes in infants with moderate hypoxic-ischemic encephalopathy

The fifth chapter is based upon the third study. It was submitted to *Early Child Development and Care* on 20 July 2022 and is currently under review.

Chapter 6- Discussion, implications, and conclusions

Chapter 6 discusses the important findings of each of the three sub-studies presented in this thesis, as well as the clinical and theoretical implications of the main study. A critical evaluation of the project is provided and recommendations for future research are presented.

CHAPTER 2: METHODOLOGY

2.1 Aim of the chapter

The second chapter provides detailed descriptions of the methodology used to conduct the research. The main study consisted of three sub-studies, each with distinct methodologies. Aspects related to the research objectives, context, designs, sampling, participant selection criteria, materials and apparatus, data collection, data analysis, ethical considerations, validity, and reliability are discussed.

2.2 Aim of the research project

To describe South African infants with HIE regarding swallowing, feeding, developmental outcomes and associated factors.

2.3 Objectives

1. To describe and compare factors associated with mild and moderate HIE in a sample of South African neonates.

2. To describe the evolution of swallowing and feeding abilities of neonates with HIE during their hospital stay, using a validated and standardised assessment tool and VFSS. To do this, the following sub-aims were developed:

   (i) To describe and compare the swallowing and feeding abilities of neonates at introduction of oral feeds and at discharge from hospital;

   (ii) To describe the swallowing and feeding abilities of affected neonates according to HIE severity and

   (iii) To explore the relationship between OPD severity and length of hospitalisation among affected neonates.

3. To describe the evolution of outcomes among infants with moderate HIE; from their early swallowing and feeding abilities during hospitalisation, to their later developmental outcomes at six and 12 months.

2.4 Research studies

Three different sub-studies were conducted to reach the main aim of the study. Each of the studies has either been submitted or has already been accepted for publication in accredited, peer-reviewed journals. Their titles, objectives, journals, and publication status are summarised in Table 2.1.

Table 2.1

Summary of studies

Study	**1**	**2**	**3**
Title	South African neonates with mild and moderate hypoxic-ischaemic encephalopathy	Evolution of swallowing and feeding abilities of neonates with hypoxic-ischaemic encephalopathy during hospitalisation: a case series	Evolution of feeding and developmental outcomes in infants with moderate hypoxic-ischaemic encephalopathy
Objectives	To describe and compare factors associated with mild and moderate HIE in a sample of South African neonates	To describe the evolution of swallowing and feeding abilities of neonates with HIE during their hospital stay, using a validated and standardised assessment tool and VFSS.	To describe the evolution of outcomes among infants with moderate HIE; from their early swallowing and feeding abilities during hospitalisation, to their later developmental outcomes at six and 12 months.
Journal	South African Journal of Child Health	International Journal of Speech-Language Pathology	Early Child Development and Care
Publication status	Published September 2022	Accepted and published online November 2022	Submitted July 2022
Chapter in thesis	3	4	5

2.5 Research context

Data were collected at a single site: an urban tertiary academic hospital in Tshwane, South Africa. More specifically, data were collected in the 29-bed neonatal unit of the hospital. Additionally for the third study, developmental assessments of participants were conducted at the hospital on an outpatient basis at the ages of six and 12 months. The hospital is a Baby Friendly Hospital Initiative (BFHI)-accredited facility. BFHI recognises the importance of breastfeeding for the growth, development, and health of infants, and encourages and supports exclusive breastfeeding for all infants, with the use of expressed breast milk or donor human milk via cup as an alternative where necessary (WHO & United Nations International Children's Emergency Fund [UNICEF], 2018). The BFHI also supports mothers who are HIV-positive and on

antiretroviral (ARV) therapy to continue breastfeeding their infant exclusively for the first six months of life (National Department of Health, 2015).

2.6 Research design

Data for all three sub-studies were prospectively collected over a period of 24 months. For the first study, a comparative research design was used to describe and compare factors among neonates with mild and moderate HIE. For the second study, a case series design was used. Specifically, a longitudinal cohort study described the evolution of swallowing and feeding abilities of neonates with HIE during hospitalisation. Correlational research explored the relationship between OPD severity and length of hospitalisation. For the third study, a case series design was also implemented to describe the early swallowing and feeding abilities of neonates with moderate HIE and their developmental outcomes at six and 12 months. Case series designs follow a group of individuals with a similar diagnosis over a period of time and are often a useful first step when researching complex populations (Kooistra et al., 2009; Saul & Norbury, 2021).

2.7 Sampling procedure

All neonates with HIE meeting criteria who were available at the study site and whose guardians consented to participation were consecutively included in the sample as they were admitted to the neonatal unit. Study 1 included participants with mild and moderate HIE. Study 2 included participants with mild, moderate, and severe HIE and Study 3 included participants with moderate HIE. Where participants' HIE severity met criteria for multiple studies, they were included in all the applicable studies to which their legal guardians consented and for which they remained in hospital.

Table 2.2 depicts the sample sizes for the three studies. For Studies 1 and 2, a statistician was consulted and power analyses were conducted using the G*Power version 3.1.9.4.to determine the sample sizes required for statistical analyses. For a level of significance of 0.05, Study 1's achieved power was 0.839 and Study 2's achieved power was 0.813, both of which were above the minimally acceptable achieved power of 0.8 (Cohen, 1992). For Study 3, all participants with moderate HIE meeting inclusion criteria were consecutively recruited between October 2018 and

June 2019 as they were admitted to the neonatal unit (Kooistra et al., 2009). The sample size was therefore determined by the number of participants recruited during this time period. The sample size was small and only included four participants for a case series design. However, the study was the first of its kind, utilised stringent inclusion criteria, and as far as known, generated new data that were not available elsewhere at the time.

2.8 Participant selection criteria

The inclusion and exclusion criteria for the studies are listed below. The sample sizes and participant characteristics are indicated in Table 2.2.

2.8.1 Participant inclusion criteria

For all three studies:

- Participants had to be born ≥37 weeks' gestation. Gestation was confirmed by a neonatologist, using the most reliable available information, in order of preference being- ultrasound conducted before 22 weeks' gestation, sure dates (first date of the last normal menstrual period) or new Ballard score (American College of Obstetricians and Gynecologists [ACOG], 2017).
- Participants had to be diagnosed with HIE as confirmed by a neonatologist. For the studies, NE was suspected to be secondary to an acute peri- or intrapartum event if **BOTH** criteria (i) and (ii) were met (AAP, 2014; Shankaran et al., 2005):

  (i) The presence of **at least ONE** of the following signs consistent with an acute intra- or peripartum event:

    - APGAR scores <5 at 5 and 10 minutes, **OR**
    - Evidence of foetal acidaemia: Arterial umbilical cord blood gas or radial artery blood gas done on the neonate within 60 minutes of delivery with a pH <7.0 or a base deficit ≥12 mmol/L.

  (ii) The presence of NE (disturbed neurological function manifesting as an abnormal level of consciousness or seizures, which may also be accompanied

by difficulty establishing or maintaining respiration, decreased tone and/or primitive reflexes).

- Encephalopathy was graded according to the six categories of the modified Sarnat stages (Shalak et al., 2003). Mild encephalopathy was defined as ≥1 abnormal category (Prempunpong et al., 2018). Moderate or severe encephalopathy was defined as ≥3 abnormal categories; the number of moderate or severe signs determined the extent of their encephalopathy (Shankaran et al., 2005). If moderate and severe signs were equally distributed, encephalopathy grading was based upon the participant's level of consciousness (Shankaran et al., 2005). Modified Sarnat scores were performed during the first six hours of life. If there was progression of the disease among mild participants within this time frame, the worse staging was assigned to participants to determine their eligibility for TH.
    - Study 1 required participants with mild (stage 1) and moderate (stage 2) HIE.
    - Study 2 required participants with mild (stage 1), moderate (stage 2), and severe (stage 3) HIE.
    - Study 3 required participants with moderate (stage 2) HIE.
- For the third study, participants were additionally required to attend follow-up appointments at the hospital's high-risk clinic at the ages of six and 12 months.

2.8.2 Participant exclusion criteria

Participants were excluded from all studies if they were diagnosed with:

- Genetic syndromes or major congenital abnormalities
- Metabolic disease
- Meningitis
- Structural brain abnormalities
- Intracerebral or intraventricular haemorrhage
- Congenital hydrocephalus
- Cerebrovascular incident

Table 2.2

Study sample sizes and participant characteristics

Study	1	2	3
Sample size	**N=46** Mild HIE n=13 Moderate HIE n=33	**N=29** Mild HIE n=7 Moderate HIE n=19 Severe HIE n=3	**N=4** (all participants = moderate HIE)
Participant characteristics	Male n=29 (63.0%) Mean gestational age 38.8 weeks [standard deviation (SD)=1.50] Mean birth weight 3081.2g (SD=466.59)	Male n=18 (62.1%) Mean gestational age 38.9 weeks (SD=1.45) Mean birth weight 3138.6g (SD=504.23)	Male n=2 (50.0%) Mean gestational age 38.75 weeks (SD=2.22) Mean birth weight 2869.0g (SD=457.49)

2.9 Materials and apparatus

For the first study, a checklist (Appendix A) was compiled to capture biological and environmental factors obtained from participants' clinical records. Biological factors included antepartum, intrapartum, and maternal factors, as well as mode of delivery and birth complications (Badawi et al., 1998a; Bruckman & Velaphi, 2015). Environmental factors included parental marital and employment status, whether participants lived in urban, peri-urban or rural areas, and whether they were born at the hospital where the study was conducted (Badawi et al., 1998a; Grandjean et al., 2016; Ibrahim & Asmaa, 2016).

For Studies 2 and 3, each participant was assessed twice using the Neonatal Feeding Assessment Scale [NFAS] (Viviers et al., 2016). The NFAS (Appendix B) was developed in the South African context and is a valid and reliable tool for describing neonatal feeding skills (Viviers et al., 2017; Viviers et al., 2019). It assesses six diagnostic areas related to swallowing and feeding: physiological functioning; neonatal state; stress cues; motor performance; oral anatomy and primitive reflexes; and signs and symptoms of OPD (Viviers et al., 2019). It also provides a composite score that indicates whether OPD is present (Viviers et al., 2019).

Also for Studies 2 and 3, a VFSS was conducted within seven days of initial NFAS administration, using the CombiDiagnost R90 remote-controlled fluoroscopy system (Koninklijke Philips N.V., Netherlands). A checklist based upon guidelines by Arvedson and Brodsky (2002) was used in conjunction with the Penetration Aspiration Scale [PAS] (Rosenbek et al., 1996) to interpret the VFSS (Appendix C).

For Study 3, the Vineland Adaptive Behavior Scales, Third Edition [Vineland-3] (Sparrow, 2016) was used to assess participants' communication development, daily living skills, socialisation, and motor development. Sub-domains included receptive and expressive language, personal, interpersonal, play, gross and fine motor development. The Vineland-3 Comprehensive Interview Form was completed (Appendix D). The Rossetti Infant-Toddler Language Scale [RITLS] (Rossetti, 2006) was utilised for additional assessment of participants' communication development, including their interaction-attachment, pragmatics, gesture, play, language comprehension and language expression skills (Appendix E). The Vineland-3 scales and RITLS have both been used successfully to assess development in South African studies previously (Dettman et al., 2007; Du Toit et al., 2021; Stevens et al., 2017; Van der Linde et al., 2016; Wrigglesworth et al., 2021).

2.10 Data collection procedures

For Study 1, clinical records of all participants were prospectively reviewed by the researcher. The biological and environmental factors identified in the records were captured on a checklist (Appendix A). For Studies 2 and 3, each participant was assessed twice using the NFAS during a typical feeding session: once when they were deemed medically ready for the introduction of oral feeds by the treating paediatrician and once on the day of discharge home. Each VFSS was conducted within seven days of initial NFAS administration. Participants were positioned supine at 20˚ and a commercially prepared non-ionic contrast solution was administered via a Tommee Tippee 260ml 0m+ bottle with a standard wide-neck teat. If participants were unable to extract the solution from the teat due to sucking difficulties, it was administered via a syringe or cup. The lateral view was first used. Participants were initially screened for a series of up to 20 suck-swallow-breath cycles and were then screened intermittently during continued drinking to conduct "fatigue testing" (Weir et al., 2011). The anterior-posterior view was then used to assess symmetry and to scan the oesophagus for bolus transit. Views were first assessed in real-time, followed by frame-by-frame analysis. Total radiation time did not exceed two minutes (Arvedson et al., 2008). Both the VFSS checklist and PAS were completed by two SLTs registered with the Health Professions Council of South Africa (HPCSA), with experience in the assessment and management of paediatric OPD. All VFSSs were

independently reviewed by two radiologists also registered with the HPCSA. All professionals were blinded to participants' NFAS results and participant characteristics such as HIE severity. There was 100.0% agreement between the SLTs' and radiologists' findings.

After discharge, all participants in Study 3 were given dates to attend developmental assessments at the hospital on an outpatient basis at the ages of six and 12 months. Dates were coordinated with participants' check-ups at an MDT high-risk clinic to minimise the time and cost associated with travel to and from the hospital. The MDT included a paediatrician, nurse, SLT, audiologist, and occupational therapist (OT). Dietitians and physiotherapists were available on a consultation basis. Measures taken to ensure reasonable follow-up rates included Short Message Service (SMS) appointment reminders and telephone calls to caregivers the day before the appointment. All participants (100.0%) attended their six- and 12-month follow-up appointments. The goals of the clinic were to detect impairment, inform parents, promote early intervention, and discover changes in outcomes (Robertson & Perlman, 2006). Intervention provided included caregiver education regarding developmental stimulation and modelling of appropriate techniques. Techniques broadly included establishing sensitive, responsive interactions between caregivers and infants; establishing joint attention; provision of stimulating materials; and scaffolding infants' behaviours (Guralnick, 2017). If needed, appropriate and timely referrals were made for more frequent treatment. At both the six- and 12-month developmental assessments, the Vineland-3 Comprehensive Interview Form was completed first through caregiver interview. The RITLS was then completed by observing or eliciting various behaviours among participants, or by using caregivers' reports thereof.

2.11 Data analysis

SPSS statistical software package version 26.0 (IBM Corp., USA) was used for all statistical analyses. For Study 1, factors from participants' clinical records comprised categorical and continuous variables; the Shapiro-Wilk test was used to test normality among the latter (Field, 2018). Since normality was not detected, non-parametric tests were used. Chi-square and Fisher's exact tests compared categorical data, and Mann-Whitney tests compared continuous data between mild and moderate groups.

The NFAS and VFSS were both scored using a binary yes/no system for Studies 2 and 3. All items were scored “yes” if symptoms were present and “no” if symptoms were absent. Composite scores were obtained. In the NFAS, the composite score indicated whether OPD was present. In the VFSS, the composite score determined how many symptoms of OPD were evident, reflecting OPD severity. A PAS score of one to eight was assigned to participants during VFSSs, based upon the amount of penetration or aspiration found. For Study 2, descriptive statistics were obtained. McNemar’s test for paired nominal binary data compared participants’ performance on the NFAS initially versus discharge. Nonparametric Spearman’s rank-order correlations investigated correlations between the number of combined OPD symptoms and length of hospital stay. In the study, p-values less than 0.05 indicated statistical significance. However, Bonferroni adjustments were applied where variables were tightly related and adjusted levels of significance were indicated where relevant (Barnett et al., 2022). As is appropriate when using nonparametric tests, medians and interquartile ranges (IQR) were reported as measures of location and spread.

For Study 3, descriptive statistics were obtained for participants’ NFAS and VFSS outcomes. Vineland-3 test items were scored using a three-point rating scale (0= never, 1= sometimes, 2= usually), reflecting the frequency with which participants performed behaviours without prompting or assistance (Pepperdine & McCrimmon, 2017). Participants’ performance in developmental domains (communication, daily living skills, socialisation, and motor skills) was expressed as standard scores (mean=100; SD=15). Participants’ performance in developmental sub-domains (receptive and expressive language, personal, interpersonal, play, gross and fine motor development) was expressed as v-scale scores [mean=15; SD=3] (Sparrow et al., 2016). Scores from each domain and sub-domain were interpreted according to the following adaptive levels: adequate (<1 SD), moderately high (≥+1 SD), moderately low (≥-1 SD), high (≥+2 SD), or low [≥-2 SD] (Sparrow et al., 2016). Adaptive levels indicated participants’ developmental strengths or focal delays in specific areas. Participants’ strengths included areas in which their development was interpreted as moderately high or high. Participants’ delays included areas in which their development was interpreted as moderately low or low. An overall standard

score, called the Adaptive Behaviour Composite (ABC) was calculated by adding the standard scores from the communication, daily living skills, and socialisation domains. An infant was considered to have an overall developmental delay if the ABC score was one or more standard deviations below the mean [≥-1 SD] (Sparrow et al., 2016). Focal delays in specific domains or sub-domains did not necessarily add up to an overall developmental delay, as the ABC score is an average of the developmental domains. Information obtained through observation, elicitation or caregiver report carried equal weight when scoring test items across the six developmental domains of the RITLS (Rossetti, 2006). Domains were considered delayed if a participant fell two or more three-month categories below their chronological age level (Rossetti, 2006). Assessment of the gesture domain only started at the 9-12 month level.

2.12 Research ethics

All studies were conducted within the framework of ethical principles set out by the World Medical Association (WMA) Declaration of Helsinki (2013). The principles that were applied to the studies are described in Table 2.3.

Table 2.3

Ethical principles applied to the studies (WMA, 2013)

Principle	Application to the study
Research should only be conducted if the importance of the objective outweighs the risks and burdens to participants. All risks should be satisfactorily managed.	There were minimal risks associated with the studies. Radiation doses in paediatric VFSSs pose an acceptable risk to infants; the mean dose associated with a VFSS is 0.08mSv, which is well below the recommended annual limit of 1mSv for children (Weir et al., 2011). To limit participants' radiation exposure, the total radiation time to which participants were exposed did not exceed two minutes (Arvedson, 2008). All other data collection was conducted during participants' typical feeding times. Developmental assessments correlated with participants' check-up dates, to minimise unnecessary travel to and from the hospital. In doing so, potential discomfort or inconvenience was minimised.
The legal guardians of all participants should be informed regarding research aims, methods, sources of funding, conflicts of interest, institutional affiliations, anticipated benefits and potential risks, as well as possible discomfort, post-study provisions, and any other relevant aspects.	All legal guardians of participants were given a form (Appendix F) explaining the purpose of the study, what participation would entail, participant rights, risks, potential discomfort, benefits of the study, and post-study provisions such as further management. The information form was available in English, Afrikaans and Sepedi. Guardians were also verbally informed of the above information in a language that they understood. The researcher conveyed the information in English and Afrikaans. Where interpretation was needed, assistance was received from staff members from the Department of Speech Therapy and Audiology at the site who were competent in the other main languages spoken in Tshwane [Sepedi, Setswana and Zulu] (Statistics South Africa, 2011).
Voluntary informed consent must be obtained from the legal guardian of each participant. If written consent is not possible, non-written consent must be formally documented and witnessed.	Voluntary informed consent was obtained from the guardian of each potential participant, using an informed consent form (Appendix F). Consent was either obtained in writing or verbally, and was documented and witnessed by a staff member working in the neonatal unit. Each guardian was informed that they have the right to withdraw from the study at any time without negative consequences for themselves or the participant. Furthermore, refusal to participate in the study did not affect the participant's hospital care.
Every effort should be made to protect participants' rights to privacy and confidentiality.	The researcher took all necessary precautions to protect participant information. Numbers were assigned to participants in lieu of their names on all forms utilised during data collection, and the researcher was the only individual who had access to participant information. No identifying information was used in any reports or presentations stemming from research findings.
Research should only be carried out by individuals with appropriate scientific education, training, and qualifications.	The researcher is an SLT who is registered with the HPCSA and has nine years' post-graduate experience working with paediatric dysphagia. The only clinical assessment which was not conducted by the researcher was the VFSS, which was conducted by two trained hospital-based SLTs with experience in paediatric VFSSs and who are also registered with the HPCSA. Additionally, the diagnosis of HIE, grade of encephalopathy (using the modified Sarnat score), and Thompson scores were all performed or confirmed by a qualified neonatologist who is registered with the HPCSA.
Post-study provisions will be made available to all research participants needing intervention as deemed beneficial in the study.	Any participants who were found to have difficulties such as OPD or developmental delays were referred for SLT, OT, Physiotherapy or other appropriate interventions.
Approval should be obtained by the relevant research ethics committee before the study begins.	Prior to the start of data collection, approval to conduct research was obtained from the hospital (Appendix G) and the Faculty of Health Sciences Research Ethics Committee [protocol number 390/2018] (Appendix H).

Researchers have the responsibility to make the results of their study publicly available and should be accountable for the completeness and accuracy of their reports.	Each of the studies has either been submitted or has already been accepted for publication in accredited, peer-reviewed journals. The researcher also accepts responsibility for reporting all findings fully and honestly.

2.13 Reliability and validity

Several factors contributed to the validity and reliability of the studies. A qualified neonatologist confirmed the gestation of all participants, established their HIE diagnoses according to stringent inclusion criteria, and confirmed their encephalopathy grading according to the modified Sarnat stages. The same neonatologist also confirmed the Thompson scores calculated for all participants and determined whether other diagnoses were present to exclude potential participants from the study sample. Consistent data collection procedures were followed as all three studies were conducted at a single site with a strict management protocol for infants with HIE. The researcher had a Master's degree in Speech-Language Pathology and nine years' post-graduate experience in paediatric dysphagia. She collected data for all three studies. All participants for Studies 2 and 3 also received daily oral sensorimotor intervention by the same SLT for their swallowing and feeding difficulties during hospitalisation. After discharge, all Study 3 participants furthermore attended the same MDT high-risk clinic where similar intervention techniques were followed. Additionally, the prospective nature and consecutive inclusion of participants implemented in Studies 2 and 3 increased the external validity of their case series designs (Kooistra et al., 2009).

Preliminary investigations into the psychometric properties of the NFAS have proven that it is a valid tool for describing neonatal feeding skills and that it shows acceptable inter-rater reliability (Viviers et al., 2017; Viviers et al., 2019). Furthermore, the VFSS is considered the gold standard for dysphagia assessment (Audag et al., 2016). Two SLTs who were blinded to the NFAS results and participant characteristics analysed the VFSSs of participants using the valid and reliable PAS and a checklist compiled from paediatric dysphagia literature (Araújo et al., 2014; Arvedson, 2008; Arvedson & Brodsky, 2002; Bours et al., 2008; Rosenbek et al., 1996). All VFSSs were independently reviewed by two radiologists who were also blinded to the NFAS results and participant characteristics. There was 100.0% agreement between the SLTs' and radiologists' findings. The Vineland-3 and RITLS are both suitable for assessing developmental functioning. The Vineland-3 is a valid and reliable norm-referenced tool (Pepperdine & McCrimmon, 2017). The RITLS, although criterion-referenced, is a tool that has been used successfully in numerous previous studies, including studies

conducted in South Africa (Van der Linde et al., 2016; Stevens et al., 2017; Dettman et al., 2007).

CHAPTER 3: SOUTH AFRICAN NEONATES WITH MILD AND MODERATE HYPOXIC-ISCHAEMIC ENCEPHALOPATHY

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The article, including its language and referencing style, is written according to the journal manuscript guidelines.

3.1 Abstract

Background: Clear risk profiles of neonates with mild and moderate hypoxic-ischaemic encephalopathy (HIE) are lacking.

Objective: To describe and compare factors associated with mild and moderate HIE in South African neonates.

Methods: A prospective, comparative design was used to describe factors among South African neonates with mild (n=13) and moderate (n=33) HIE in an urban, tertiary academic hospital. HIE diagnosis and encephalopathy grading were conducted using the modified Sarnat stages. Thompson scores were recorded. Participants' clinical records were reviewed to identify factors. Descriptive data were obtained. Chi-square and Fisher's exact tests were used to compare categorical data, and Mann-Whitney tests were used to compare continuous data between groups.

Results: Significant differences were found between groups' admission ($p<0.001$) and highest Thompson scores ($p<0.001$). The mild group's APGAR scores were significantly higher than that of the moderate group at five ($p=0.012$) and 10 minutes ($p=0.022$). Duration of resuscitation ($p=0.011$) and time to spontaneous respiration ($p=0.012$) also differed significantly between groups. Significantly more moderate than mild participants received therapeutic hypothermia (TH) ($p<0.001$).

Conclusion: Clinical tests and management factors differed significantly between groups. The findings provide the multidisciplinary team with an increased understanding of the heterogeneous HIE population and add to existing evidence for identifying neonates eligible for TH in resource-limited settings.

Key words: Hypoxic-ischaemic encephalopathy, modified Sarnat staging, mild versus moderate hypoxic-ischaemic encephalopathy, APGAR scores, resuscitation, Thompson score, low-and-middle-income countries, South Africa

3.2 Introduction

Hypoxic-ischaemic encephalopathy (HIE) is the fifth leading cause of death in children under five years globally and is a significant problem in low-and-middle-income countries (LMICs).[1,2] Among survivors, HIE is a significant cause of cerebral palsy, seizures, sensory impairment, learning difficulties, cognitive or behavioral fallouts, and communication difficulties.[2-4] HIE, therefore, has a profound burden of disease.[2]

The HIE population is heterogeneous, with different clinical pictures and recovery patterns.[3,4] Using the modified Sarnat stages and/or Thompson score, HIE can be graded as mild, moderate or severe.[5-7] This can contribute to long-term prognostication, clinical decision-making and parent counselling because individual outcomes are often linked with severity of the neonatal condition.[3] Owing to the high incidence of HIE in LMICs and associated health concerns, the multi-disciplinary team (MDT) requires a thorough understanding of HIE across severity types. Factors such as lack of antenatal care, intra-uterine growth restriction, prolonged second stage of labour, meconium-stained amniotic fluid, eclampsia and lower socio-economic status were previously linked to HIE in LMICs.[8-10] However, gaps in research, including dated studies, retrospective designs and lack of universally accepted HIE definitions,

exist. Also, few studies compared factors between severity types, often grouping moderate and severe infants together or comparing survivors and non-survivors.[8,11]

Severe HIE has previously been researched and it is widely accepted that this neonatal group is at a significantly higher risk of mortality and major neurodevelopmental impairment.[4,8,11] Conversely, neonates with moderate HIE are more variable and their outcomes more difficult to predict.[4] Similarly, neonates with mild HIE frequently escape attention, despite mild HIE being more prevalent than moderate and severe HIE in many contexts and there being evidence suggesting adverse neurological and long-term developmental outcomes in this group.[12] This study aimed to describe and compare factors associated with mild and moderate HIE in a sample of South African neonates.

3.3 Methods

A prospective, comparative design was used to describe factors among 46 neonates with mild and moderate HIE during admission to the 29-bed neonatal high care unit of an urban tertiary academic hospital in South Africa between October 2018 and January 2020. Approval to conduct the study was obtained (protocol number 380/2018).

Neonatal encephalopathy was suspected to be secondary to an acute peri- or intrapartum event if participants presented with encephalopathy (disturbed neurological function manifested as an abnormal level of consciousness or seizures, possibly accompanied by respiratory difficulties and decreased tone and/or primitive reflexes), **and** had APGAR scores <5 at 5 and 10 minutes, **or** had evidence of fetal acidemia (arterial umbilical cord blood gas or radial artery blood gas done within 60 minutes of delivery with a pH <7.0 or a base deficit ≥12 mmol/L).[13,14] Encephalopathy grading was performed using the modified Sarnat stages and was confirmed by a neonatologist.[6] Serial modified Sarnat scores were performed during the first six hours of life and if there was progression of disease, the worse staging was assigned to the participant. Thompson scores were conducted daily until day 10 of life. Participants' first, highest and day seven Thompson scores were recorded where available.[7] Eligible neonates were born ≥37 weeks' gestation, using the most reliable

information available, in order of preference being: ultrasound before 22 weeks' gestation, sure dates or new Ballard score. [15] Non-probability purposive sampling was used to recruit neonates meeting inclusion criteria.

Neonates with genetic syndromes, major congenital abnormalities, metabolic disease, meningitis, structural brain abnormalities, intracerebral or intraventricular haemorrhage, congenital hydrocephalus or perinatal stroke were excluded. Sixty-two neonates with mild or moderate HIE were identified. Sixteen were excluded for: lack of consent (n=7), demise before consent (n=2), meningitis (n=5), maternal myasthenia gravis (n=1) and Down syndrome (n=1). Forty-six participants were included in the study; 28.3% (n=13) had mild HIE and 71.7% (n=33) had moderate HIE.

Participants' clinical records were prospectively reviewed, and a checklist of factors related to the neonate and mother was used to capture data.[8,9,16] The SPSS statistical software package version 26.0 (IBM Corp., USA) was used for all statistical analyses, except for the power calculation, which was done using the G*Power version 3.1.9.4 (Heinrich Heine Universität, Düsseldorf). Factors from participants' clinical records comprised categorical and continuous variables and, for the latter, the Shapiro-Wilk test was used to test normality.[17] As normality was not detected, non-parametric tests were used. Chi-square and Fisher's exact tests were used to compare categorical data, and Mann-Whitney tests were used to compare continuous data between mild and moderate groups. For a level of significance of 0.05, the study's achieved power was 0.839, which is above the minimally acceptable achieved power of 0.8.[18]

3.4 Results

Participants (n=46) were divided into two groups based on whether they had mild (n=13) or moderate (n=33) HIE. Admission and highest Thompson scores were recorded for 44 participants (Table 3.1). The mild group had significantly lower admission ($p<0.001$) and highest Thompson scores ($p<0.001$) than the moderate group. Day seven scores were recorded for the minority of the sample (n=5; 10.9%).

Table 3.1

Admission, highest and day seven Thompson scores of participants

	Scores, mean (SD) median			
Thompson Score	**Overall**	**Mild**	**Moderate**	**p-value**
Admission*	8.6 (3.71) 8.0	5.4 (2.71) 5.0	9.8 (3.33) 10.0	<0.001
Highest*	9.2 (3.92) 9.5	5.5 (2.61) 5.0	10.6 (3.42) 10.5	<0.001
Day 7†	6.8 (4.15) 7.0	6.5 (7.78) 6.5	7.0 (2.00) 7.0	1.000

** Overall (n=44); mild (n=12); moderate (n=32).*

† Overall (n=5); mild (n=2); moderate (n=3).

Factors investigated were categorised as follows: antepartum, intrapartum, maternal, environmental and management factors.

Antepartum factors

Most participants were male (n=29; 63.0%), with a median gestation of 38.5 weeks. Antepartum factors did not differ significantly between groups (Table 3.2)

Table 3.2

Antepartum factors of participants

Factors	**Overall (n=46), n (%)***	**Mild (n=13), n (%)***	**Moderate (n=33), n (%)***	**p-value**
Male	29 (63.0)	11 (84.6)	18 (54.5)	0.090
Gestational age, weeks, mean (SD) median	38.8 (1.50) 38.5	38.7 (1.38) 38.0	38.9 (1.56) 39.0	0.763
Birth weight, grams, mean (SD) median	3081.2 (466.59) 3097.5	3128.5 (438.32) 3300.0	3062.6 (482.53) 3009.0	0.575
Anthropometry				1.000
SGA	7 (15.2)	2 (15.4)	5 (15.2)	
AGA	38 (82.6)	11 (84.6)	27 (81.8)	
LGA	1 (2.2)	0 (0.0)	1 (3.0)	
Twins	5 (10.9)	3 (23.1)	2 (6.1)	0.128
Antenatal care				1.000
Received	23 (50.0)	6 (46.2)	17 (51.5)	
Not received	3 (6.5)	1 (7.7)	2 (6.1)	
Not specified	20 (43.5)	6 (46.2)	14 (42.4)	

**Unless otherwise stated.*

SGA (small for gestational age); AGA (appropriate for gestational age); LGA (large for gestational age).

Intrapartum factors

Intrapartum factors included clinical tests like APGAR scores, arterial pH and base deficit values (Table 3.3). The mild group's APGAR scores were significantly higher than that of the moderate group at five (p=0.012) and 10 minutes (p=0.022).

Table 3.3

Clinical tests conducted on participants

	Values, mean (SD) median			
Factors	**Overall (n=46)**	**Mild (n=13)**	**Moderate (n=33)**	**p-value**
APGAR at 1 min	3.7 (1.83) 3.0	4.4 (2.26) 4.0	3.4 (1.58) 3.0	0.173
APGAR at 5 mins	6.0 (1.65) 6.0	6.9 (1.66) 7.0	5.7 (1.53) 6.0	0.012
APGAR at 10 mins	7.4 (1.60) 8.0	8.7 (1.03) 9.0	7.1 (1.58) 7.0	0.022
Arterial pH	7.1 (0.15) 7.1	7.1 (0.09) 7.1	7.1 (0.17) 7.1	0.235
Base deficit, mmol/L	18.2 (3.49) 17.9	17.5 (2.68) 16.8	18.5 (3.77) 18.1	0.374

Mode of delivery and birth complications were also investigated but did not differ significantly between groups (Table 3.4). Sentinel events included the second twin being retained for more than one hour (n=2) and placental abruption (n=1). Birth complications other than those in Table 3.4 included breech presentation (n=6); transfer during labour (n=3); poor maternal effort (n=2); uncooperative mother (n=2); aspiration of blood by neonate (n=2); failed induction of labour (n=1); low-lying placenta (n=1); antepartum haemorrhage (n=1); prolonged latent stage of labour (n=1); maternal seizure at birth (n=1); eclampsia (n=1); and one case where the participant was born in the Casualty Department of a referring hospital. Some participants presented with more than one birth complication.

Table 3.4

Mode of delivery and birth complications

Factors	Overall (n=46), n (%)	Mild (n=13), n (%)	Moderate (n=33), n (%)	p-value
Mode of delivery				
NVD	19 (41.3)	8 (61.5)	11 (33.3)	0.104
Assisted delivery*	10 (21.7)	1 (7.7)	9 (27.3)	0.240
Caesarean section	19 (41.3)	5 (38.5)	14 (42.4)	1.000
Birth complications				
Cephalopelvic disproportion	5 (10.9)	2 (15.4)	3 (9.1)	0.612
PROM	0 (0.0)	0 (0.0)	0 (0.0)	Not applicable
Meconium-stained amniotic fluid	17 (37.0)	5 (38.5)	12 (36.4)	1.000
Nuchal cord	1 (2.2)	0 (0.0)	1 (3.0)	1.000
Failed vacuum delivery*	2 (4.3)	1 (7.7)	1 (3.0)	0.490
Fetal distress	11 (23.9)	1 (7.7)	10 (30.3)	0.141
Prolonged second stage of labour	16 (34.8)	4 (30.8)	12 (36.4)	1.000
Sentinel events	3 (6.5)	1 (7.7)	2 (6.1)	1.000

** Two participants (one from each group) experienced failed vacuum (-assisted) deliveries and required caesarean sections.*

NVD (normal vaginal delivery); PROM (premature rupture of membranes).

Maternal factors

Maternal factors did not differ significantly between groups (Table 3.5). The median maternal age was 27.0 years (minimum 15.0 years, maximum 44.0 years). Seven mothers (15.2%) were teenagers (<20 years), and four (8.7%) were of advanced maternal age (≥35 years). Most mothers were primigravida (n=31; 67.4%), with 53.8% of mild participants' (n=7) and 72.7% of moderate participants' mothers (n=24) following this trend. Nine mothers (19.6%) were HIV positive; all of them used antiretrovirals (ARVs) during pregnancy. Two mothers used other medications; one used methyldopa and the other used herbal medication. Two mothers had urinary tract infections, and one reported green vaginal discharge during pregnancy. The following maternal diseases were recorded: obesity (n=2); pre-eclampsia (n=2); gestational diabetes mellitus (n=2); drug-induced jaundice (n=1); elevated low-density lipoprotein (LDL) cholesterol (n=1); and gestational hypertension (n=1).

Table 3.5

Maternal factors of participants

Factors	Overall (n=46), n (%)*	Mild (n=15), n (%)*	Moderate (n=31), n (%)*	p-value
Age, years, mean (SD) median	27.1 (6.49) 27.0	26.4 (5.14) 27.0	27.4 (7.02) 27.0	0.716
Parity†, mean (SD) median	1.5 (1.01) 1.0	1.7 (0.89) 1.0	1.5 (1.06) 1.0	0.322
HIV status				1.000
Positive	9 (19.6)	2 (15.4)	7 (21.2)	
Negative	37 (80.4)	11 (84.6)	26 (78.8)	
Use of other medication‡	2 (4.3)	2 (15.4)	0 (0.0)	Not applicable
Infection	3 (6.5)	1 (7.7)	2 (6.1)	1.000
Disease	9 (19.6)	3 (23.1)	6 (18.2)	0.698
Fever	1 (2.2)	0 (0.0)	1 (3.0)	1.000

**Unless otherwise stated.*

†Parity only indicated in 45 participants' records, therefore overall (n=45); mild (n=12), moderate (n=33).

‡Refers to medication other than antiretrovirals (ARVs).

Environmental factors

Few clinical records reflected environmental factors such as parental marital or employment status. Participants came from urban (n=36; 78.3%) and peri-urban areas (n=9; 19.6%) and were mostly born at the hospital where the study was conducted (n=33; 71.7%). Statistically significant differences were not observed between groups.

Management factors

Thirty-six participants (78.3%) (eight mild (61.5%) and 28 moderate (84.8%)) required resuscitation at birth. Two participants (4.3%) received naloxone. No significant differences existed between groups' components of resuscitation (Table 3.6). Resuscitation duration differed significantly between groups (p=0.011). Overall, the median resuscitation duration was three minutes, with the moderate group requiring longer resuscitation than the mild group (median 5.0 minutes v. median 0.0 minutes). Length of time to spontaneous respiration was recorded in 20 participants' files and also differed significantly between groups (p=0.012), with the moderate group experiencing longer times to spontaneous respiration than the mild group (median 5.0 minutes v. median 0.0 minutes).

Table 3.6

Components of resuscitation received by participants

Component	Overall (n=46), n (%)	Mild (n=13), n (%)	Moderate (n=33), n (%)	p-value
Initial stabilisation only	7 (15.2)	0 (0.0)	7 (21.2)	0.166
PPV	34 (73.9)	8 (61.5)	26 (78.8)	0.276
Chest compressions	8 (17.4)	1 (7.7)	7 (21.2)	0.409
Adrenaline	5 (10.9)	1 (7.7)	4 (12.1)	1.000

PPV (positive pressure ventilation).

Thirty-six participants (78.3%) received whole-body therapeutic hypothermia (TH), where core body temperature was kept at 33.5°C - 34.5°C for 72 hours using servo-controlled methods (n=33; 91.2%) or frozen gel packs (n=3; 8.3%). Significantly more moderate (n=32; 97.0%) than mild participants (n=4; 30.8%) received TH (p<0.001). Overall, ten participants (21.7%) did not receive TH; nine (90.0%) did not meet eligibility criteria and one participant (10.0%) was too unstable.

3.5 Discussion

Of the 46 participants, 28.3% (n=13) presented with mild and 71.7% (n=33) presented with moderate HIE. Although it is often estimated globally that 50.0% of neonates with HIE are mild,[1,12] the distribution of HIE in this study is similar to other South African findings, where moderate and severe categories account for greater proportions of the HIE population.[8] This study used the modified Sarnat stages and not Thompson scores to grade participants.[5-7] Although Thompson scoring has limitations and may be influenced by factors such as TH and sedation,[19] this study suggests that allocating Thompson scores remains important, as demonstrated by the significant differences between groups for admission and highest Thompson scores. Furthermore, the median admission and highest Thompson scores for the mild (5.0 and 5.0) and moderate groups (10.0 and 10.5) are similar to a recent publication that suggests that the mild modified Sarnat stages align with a Thompson score of 5-6 and that the moderate modified Sarnat stages align with a Thompson score of 7-13.[20]

When comparing factors between mild and moderate groups, neither biological factors such as antepartum and maternal factors, mode of delivery and birth complications, nor environmental factors differed significantly. Management factors such as

resuscitation duration and length of time to spontaneous respiration, and clinical tests such as five- and 10-minute APGAR scores were the only factors that could distinguish the two groups.

Similar to Padayachee and Ballot,[11] the median gestation of participants was 38.5 weeks. The majority of study participants were male (n=29; 63.0%), which is comparable with other studies in LMICs.[8,9] As with other African studies, most mothers were primigravida (n=31; 67.4%).[8,10,11] The median maternal age was 27.0 years, which is higher than that of other studies.[8,9,11] This may reflect the global pattern of increasing maternal age.[21] Seven participants (15.2%) were born to teenage mothers, and four (8.7%) to mothers of advanced age. Childbearing during these years may pose increased risks to mothers and neonates.[21]

The median birth weight was 3097.5g, and 82.6% (n=38) of participants had appropriate growth for gestational age. Only 15.2% (n=7) of participants were small for gestational age (SGA). This differs from other studies where intra-uterine growth restriction was the most common antepartum factor associated with HIE.[22] Of the entire sample, 19.6% (n=9) were born to mothers who were HIV positive; this is lower than the reported prevalence of 25.9% among neonates with HIE.[8] All affected mothers in the study took ARVs during pregnancy. Only 50% (n=23) of mothers attended antenatal care; this is much less than mothers of infants with HIE in other South African studies, where 95.6% and 68.0% received antenatal care respectively.[8,11] This difference may be due to poor record-keeping.

This study found that both five- and 10-minute APGAR scores were significantly associated with HIE severity, while previous studies only reported a significant association between the 10-minute APGAR score and severity of HIE.[8,23] An arterial cord or radial pH level taken within 60 minutes after birth of **less than** 7.0, often plays a key role in identifying an intrapartum hypoxic event.[13] However, the median pH levels of both groups **exceeded** 7.0 in this study. As arterial blood gas analysis provides a representation of a neonate's respiratory and metabolic status, one of the factors contributing to the arterial pH exceeding 7.0 in this study may be secondary to a low partial pressure of arterial carbon dioxide ($PaCO_2$) influencing pH levels in spontaneously breathing acidotic infants.[24]

The proportion of participants requiring resuscitation increased as HIE severity increased, and resuscitation duration and length of time to spontaneous respiration were significantly higher for the moderate group. Although the need for resuscitation at birth and resuscitation components such as the need for chest compressions or adrenaline were previously significantly associated with poorer outcomes in neonates with HIE, these were not significantly associated with HIE severity in the present study.[8,11]

TH was the main neuro-protective strategy implemented among participants, and as expected, significantly more moderate participants received TH. As per international recommendations and the neonatal unit's protocol, participants with moderate HIE received TH routinely, unless too unstable (n=30; 96.8%). Although there are currently no recommendations for providing TH to neonates with mild HIE, four participants with mild HIE inadvertently received TH (30.8%). This trend is reflected in numerous studies from other countries.[25]

There is a paucity of literature on neonates with mild HIE, and neonates with moderate HIE are variable, with outcomes that are difficult to predict.[4] Obtaining clearer risk profiles of neonates with mild v. moderate HIE may help the MDT better understand these populations, to utilise resources such as TH more effectively.

Study limitations include no participants living in rural areas and incomplete information on participants' environmental factors, antenatal care and day seven Thompson scores. Future research should use complete clinical records and should include participants living in rural areas. Large-scale prospective studies in LMICs are also warranted to further investigate factors associated with different stages of HIE. The potential for early factors associated with HIE to predict later outcomes should also be explored.

3.6 Conclusion

This study used strict inclusion criteria and prospective methods to describe and compare factors associated with mild and moderate HIE, two distinct severity types with less clear risk profiles than their severe counterparts. Results showed significant differences between the groups, confirming the value of performing various clinical

measures. Management factors such as resuscitation duration, length of time to spontaneous respiration and TH, and clinical tests such as five- and 10-minute APGAR scores differed significantly between participants with mild and moderate HIE. Conversely, other biological and environmental factors could not distinguish groups. Admission and highest Thompson scores were significantly lower in participants with mild compared to moderate HIE, indicating that performing the Thompson score remains important. These findings provide the MDT with an increased understanding of the heterogeneous HIE population and adds to existing evidence for identifying neonates eligible for TH in resource-limited settings.

3.7 Declaration

None.

3.8 Acknowledgements

None.

3.9 Author contributions

RM conceptualised the project, collected and analysed the data, and wrote this article. JV, AK and EK conceptualised the project, and assisted with writing and editing. MC assisted with participant identification, data collection and editing. MAG analysed the data, compiled statistics, and assisted with editing.

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None.

3.11 Conflicts of interest

None.

3.12 References

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CHAPTER 4: EVOLUTION OF SWALLOWING AND FEEDING ABILITIES OF NEONATES WITH HYPOXIC-ISCHAEMIC ENCEPHALOPATHY DURING HOSPITALISATION: A CASE SERIES

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4.1 Abstract

Purpose: To describe the evolution of swallowing and feeding abilities of neonates with hypoxic-ischaemic encephalopathy (HIE) during hospitalisation.

Method: A longitudinal cohort study was used. Twenty-nine participants [median age 39.0 weeks (IQR=2.0 weeks)] with mild (n=7), moderate (n=19) and severe HIE (n=3) were included. Clinical swallowing and feeding assessments were conducted at introduction of oral feeds and at discharge using the Neonatal Feeding Assessment Scale (NFAS). Video-fluoroscopic swallow studies (VFSSs) supplemented the NFAS before discharge.

Results: Approximately two-thirds of participants showed symptoms of oropharyngeal dysphagia (OPD) during initial NFAS and VFSS. Significantly fewer OPD symptoms occurred at discharge NFAS ($p=0.004$). Endurance during non-nutritive sucking ($p<0.001$) and nutritive sucking ($p<0.001$) significantly improved. Nine participants (31.0%) demonstrated penetration or aspiration. Most aspiration events were silent (60%). Instrumental assessment identified pharyngeal phase dysphagia more effectively than bedside evaluation. High proportions of participants displayed OPD symptoms regardless of HIE severity. The correlation between OPD severity and length of hospitalisation ($p=0.052$) was not significant.

Conclusion: All grades of HIE should be considered for early intervention by speech-language pathologists before discharge. Findings may be valuable to neonatal feeding teams.

Key words: Hypoxic-ischaemic encephalopathy; mild, moderate, and severe hypoxic-ischaemic encephalopathy; neonate; oropharyngeal dysphagia; swallowing and feeding

4.2 Introduction

Neonatal hypoxic-ischaemic encephalopathy (HIE) is a central nervous system disorder that occurs in approximately 1 to 20/1000 live births in high-income and lower- and middle-income countries (LMICs) respectively (Acun et al., 2022; Montaldo et al., 2015; Shipley et al., 2021). Not only does the condition have a profound burden of disease due to high rates of mortality and long-term neurodevelopmental disability, but it commonly also results in oropharyngeal dysphagia (OPD) among affected neonates (Arvedson et al., 2020; Ballot et al., 2020). This may be caused by disturbances of muscle tone, poor coordination of movement, impaired function of neuromuscular units, poor state regulation and/or reduced feeding endurance (Arvedson et al., 2020; Genna et al., 2013; Krüger et al., 2017). A recent study found that 89% of neonates with HIE displayed at least one symptom of OPD (Krüger et al., 2019). Another study reported that one-third of infants with HIE required long-term feeding tubes due to severe feeding difficulties (Martinez-Biarge et al., 2012). This

proportion increased to 91% when injuries to the basal ganglia, thalamus and pons existed (Martinez-Biarge et al., 2012).

HIE can be graded as mild, moderate, or severe (Sarnat & Sarnat, 1976; Shalak et al., 2003). The numerous health concerns associated with HIE may lead to complicated feeding profiles in affected neonates with all grades of the condition, prompting healthcare professionals such as speech-language pathologists (SLPs) working with OPD to require specialist knowledge of this population (Lefton-Greif & Arvedson, 2016). Consequences of OPD may include malnutrition, aspiration, difficulties administering medication, behavioural abnormalities, reduced health status and poor quality of life for neonates and their families (Arvedson et al., 2020; Martinez-Biarge et al., 2012). OPD also places strain on healthcare resources by increasing length of hospital stay, number of emergency room visits and increased costs of medical equipment and treatment (Dziewas et al., 2017). Evidence-based early intervention contributes to improved progression of swallowing and feeding skills and may assist in mitigating the negative effects associated with OPD (Jadcherla et al., 2017; Leder et al., 2016). However, research on OPD in both typical and high-risk infants remains limited (Arvedson et al., 2020). Some research on OPD among neonates with HIE is emerging, but studies using validated and standardised assessment tools are lacking, and gold-standard instrumental evaluations of this population are needed (Audag et al., 2016; Krüger et al., 2019). Importantly, video-fluoroscopic swallow studies (VFSSs) may recognise subtle symptoms of OPD, including silent aspiration, resulting in earlier management and possible prevention of associated negative consequences (Arvedson et al., 2020; Audag et al., 2016). Serial assessment of OPD is rarely found in the relevant research, even though neonates present with rapidly changing anatomical and physiological subsystems that continue to mature throughout hospitalisation (Jensen et al., 2017; Krüger et al., 2019; Lau, 2015). A deeper understanding of the evolution of swallowing and feeding among neonates with HIE, from introduction of oral feeds to discharge, may increase efficacy of SLP service delivery and may facilitate timely development of discharge feeding plans for this vulnerable population.

This study set out to describe the evolution of swallowing and feeding abilities of neonates with HIE during their hospital stay, using a validated and standardised assessment tool and VFSS. Specifically, the following sub-aims were developed:

(i) To describe and compare the swallowing and feeding abilities of neonates at introduction of oral feeds and at discharge from hospital;

(ii) To describe the swallowing and feeding abilities of affected neonates according to HIE severity and

(iii) To explore the relationship between OPD severity and length of hospitalisation among affected neonates.

4.3 Method

4.3.1 Study design and setting

A longitudinal cohort study described the swallowing and feeding abilities of neonates with HIE consecutively admitted to the 29-bed neonatal unit of an urban tertiary academic hospital in South Africa during the course of their hospitalisation. The study was conducted between October 2018 and October 2020.

4.3.2 Ethical considerations

All pre-approvals and permissions were obtained from the University of Pretoria Research Ethics Committee (protocol number 380/2018). The study did not change any aspect of participants' routine care. Written informed consent was obtained from the legal guardian of each participant prior to the start of data collection.

4.3.3 Participants and recruitment

Neonates independently diagnosed with HIE by a neonatologist according to hospital protocol were recruited for the study. Eligible participants had to be born ≥37 weeks' gestation as confirmed by a neonatologist, using the most reliable information available. Early ultrasound is considered the most accurate method of determining gestational age; where this information was not available due to a lack of resources, sure dates or the new Ballard score were used (Lee et al., 2017). The new Ballard

score estimates gestational age by examining and rating physical and neuromuscular maturity characteristics in the neonate (Ballard et al., 1991).

Neonatal encephalopathy was suspected to be secondary to an acute peri- or intrapartum event if participants presented with encephalopathy (disturbed neurological function manifested as an abnormal level of consciousness or seizures, possibly accompanied by respiratory difficulties and decreased tone and/or primitive reflexes), in addition to at least one of the following criteria: i) APGAR scores <5 at 5 and 10 minutes, or ii) evidence of foetal acidemia (arterial umbilical cord blood gas or radial artery blood gas done within 60 minutes of delivery with a pH <7.0 or a base deficit ≥12 mmol/L) [American Academy of Pediatrics (AAP), 2014; Shankaran et al., 2005]. Encephalopathy grading was performed by a neonatologist using the modified Sarnat stages (Shalak et al., 2003). The modified Sarnat stages were scored according to six categories related to encephalopathy (Shalak et al., 2003; Shankaran et al., 2005). Each category was scored as normal, mild, moderate, or severe according to pre-defined signs (Shalak et al., 2003). Mild encephalopathy was defined as ≥1 abnormal category (Prempunpong et al., 2018). Moderate or severe encephalopathy was defined as ≥3 abnormal categories; the number of moderate or severe signs determined the extent of encephalopathy (Shankaran et al., 2005). If moderate and severe signs were equally distributed, the participant's staging was based upon the level of consciousness (Shankaran et al., 2005). Modified Sarnat scores were performed during the first six hours of life. If there was progression of the disease among mild participants within this time frame, the worse staging was assigned to participants to determine eligibility for therapeutic hypothermia (TH).

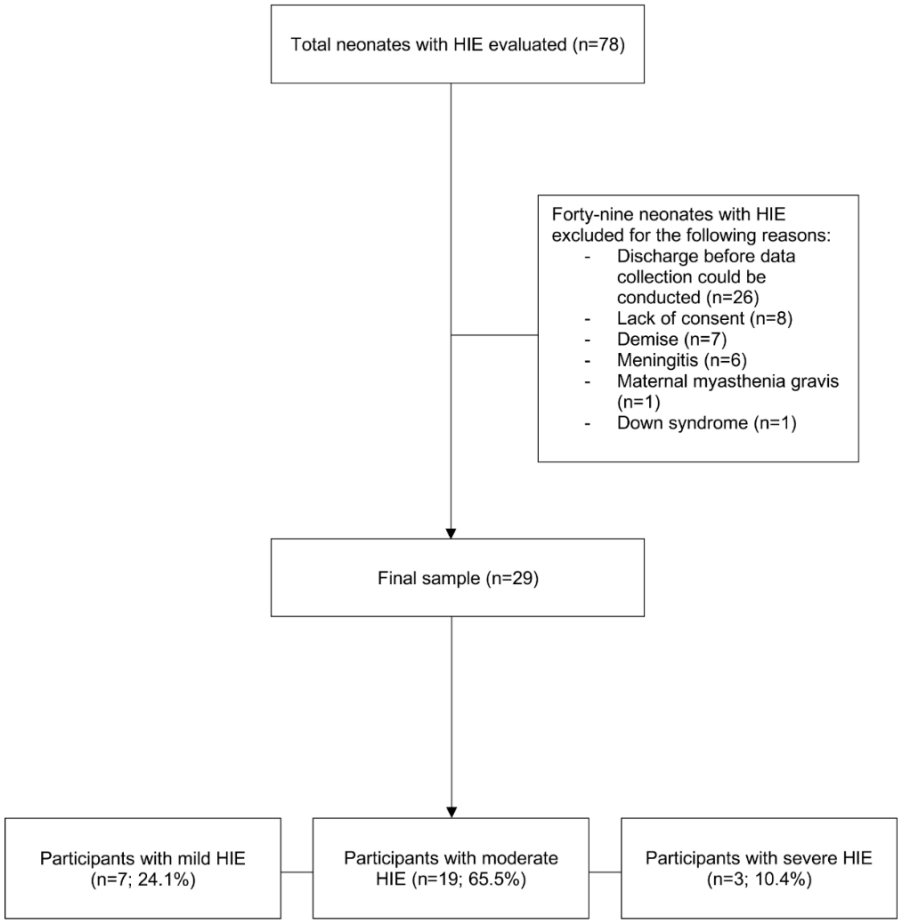
All participants with moderate and severe HIE received TH, as it is the standard of care for these grades of severity [Table 4.1] (Goswami et al., 2020). One participant with mild HIE inadvertently received TH; this mimics a recent therapeutic drift toward offering TH to mildly affected neonates, despite there being insufficient evidence for the use of TH in this population (Goswami et al., 2020). Depending on the availability of TH equipment, high-cost devices (servo-controlled methods) or low-cost devices (cloth-covered ice packs) were offered to participants under intensive care. Low-cost devices such as ice packs have proven to be plausible substitutes for servo-controlled

devices, as similar outcomes have been found among neonates receiving the two treatment modalities previously (Kinoshita et al., 2021; Rossouw, 2015).

Participants were excluded if they presented with genetic syndromes or major congenital abnormalities, metabolic disease, meningitis, structural brain abnormalities, intracerebral or intraventricular haemorrhage, congenital hydrocephalus or perinatal stroke (see Figure 4.1 for Consort-flow diagram). Neonates were not excluded based on HIV exposure, due to a current lack of evidence that this affects neonatal swallowing and feeding abilities (Krüger et al., 2019). All participants received daily oral sensorimotor intervention by the same SLT since the introduction of oral feeds.

Figure 4.1

Consort-flow diagram indicating the inclusion and exclusion of participants



4.3.4 Data collection

Once participants were deemed medically ready for introduction of oral feeds by the treating paediatrician (see Supplemental File 4.1 for criteria), they were referred for SLP services and assessed using the Neonatal Feeding Assessment Scale [NFAS] (Viviers, 2016) on the same day. The NFAS was re-administered on the day each participant was discharged to allow for serial assessment.

NFAS findings were supplemented with VFSSs prior to discharge from hospital. VFSSs could not be conducted on the same day as NFAS administration, due to challenges surrounding the availability of equipment, staff shortages, and high patient loads which commonly occur in LMICs such as South Africa (Ostrofsky & Seedat, 2016). During the VFSS, participants were positioned supine at 20˚ and commercially prepared non-ionic contrast solution was administered via a Tommee Tippee 260ml 0m+ bottle with standard wide-neck teat. If participants were unable to extract the solution from the teat due to sucking difficulties, it was administered via a syringe or cup. The lateral view was first used. Participants were initially screened for a series of up to 20 suck-swallow-breath cycles and were then screened intermittently during continued drinking to conduct "fatigue testing" (Weir et al., 2011). The anterior-posterior view was then used to assess symmetry and to scan the oesophagus for bolus transit. Views were first assessed in real-time, followed by frame-by-frame analysis. Total radiation time did not exceed two minutes (Arvedson et al., 2008). A VFSS checklist and PAS were completed by two SLPs registered with the Health Professions Council of South Africa (HPCSA), having experience in assessment and management of paediatric OPD. VFSSs were independently reviewed by two radiologists also registered with the HPCSA. All professionals were blinded to participants' NFAS results and participant characteristics such as HIE severity. There was 100.0% agreement between the SLPs' and radiologists' findings.

4.3.5 Materials and apparatus

The NFAS assesses the following areas related to swallowing and feeding: physiological functioning; neonatal state; stress cues; motor performance; oral anatomy and primitive reflexes; and signs and symptoms of OPD (Viviers et al., 2019). It also provides a composite score that indicates whether OPD is present (Viviers et

al., 2019). Preliminary investigations into the psychometric properties of the NFAS have proven that it is a valid tool for describing neonatal feeding skills and that it shows acceptable inter-rater reliability (Viviers et al., 2017; Viviers et al., 2019).

VFSSs were conducted using the CombiDiagnost R90 remote controlled fluoroscopy system (Koninklijke Philips N.V., Netherlands). A data collection sheet based upon guidelines by Arvedson and Brodsky (2002) was used with the Penetration Aspiration Scale (PAS) (Rosenbek et al., 1996) for VFSS interpretation. The PAS was created for reliable quantification of penetration or aspiration during VFSSs (Rosenbek et al., 1996).

4.3.6 Data analysis

The NFAS and VFSS were both scored using a binary yes/no system. All items were scored “yes” if symptoms were present and “no” if symptoms were absent. Composite scores were obtained. In the NFAS, the composite score indicated whether OPD was present. In the VFSS, the composite score determined how many symptoms of OPD were evident, reflecting OPD severity. A PAS score was assigned to participants during VFSSs, reflecting the amount of penetration or aspiration found (Rosenbek et al., 1996). A score of one indicated no penetration or aspiration; scores of two to five indicated penetration; and scores of six to eight indicated aspiration (Rosenbek et al., 1996).

IBM Statistical Package for the Social Sciences (SPSS), Version 26.0 (IBM Corp, 2019) was used for all statistical analyses. Descriptive statistics were obtained. McNemar’s test for paired nominal binary data compared participants’ performance on the NFAS initially versus discharge. Nonparametric Spearman’s rank-order correlations investigated correlations between the number of combined OPD symptoms and length of hospital stay. In the study, p-values less than 0.05 indicated statistical significance. However, Bonferroni adjustments were applied where variables were tightly related and adjusted levels of significance were indicated where relevant. As is appropriate when using nonparametric tests, medians and interquartile ranges (IQR) were reported as measures of location and spread.

4.4 Results

Twenty-nine participants were included in the study, of which 24.1% had mild HIE (n=7), 65.5% had moderate HIE (n=19) and 10.4% had severe HIE (n=3). Table 4.1 displays participant characteristics. The median age at initial NFAS assessment and introduction of oral feeds was 5.0 days [IQR=4.0 days] (see Supplementary file 4.1 for more information). Most participants were assessed during breastfeeding (n=13; 44.8%), cup feeding (n=8; 27.6%) or breastfeeding supplemented with cup (n=7; 24.1%). Bottle feeding was assessed once (3.5%) due to early maternal decision to formula feed exclusively.

Table 4.1

Participant characteristics

	Overall (N=29)	**Mild participants (n=7)**	**Moderate participants (n=19)**	**Severe participants (n=3)**
Male, n (%)	18 (62.1)	5 (71.4)	12 (63.2)	1 (33.3)
Gestational age, median (IQR)	39.0 (2.0)	40.0 (1.5)	39.0 (2.0)	39.0 (1.5)
Birth weight median, (IQR)	3143.0 (779.0)	3300.0 (367.5)	3140.0 (796.5)	3100.0 (271.0)
Mode of delivery:				
Normal vaginal delivery, n (%)	11 (37.9)	2 (28.6)	7 (36.8)	2 (66.7)
Assisted delivery, n (%)	5 (17.2)	0 (0.0)	4 (21.1)	1 (33.3)
Caesarean section, n (%)	13 (44.8)	5 (71.4)	8 (42.1)	0 (0.0)
Maternal age, median (IQR)	28.0 (10.0)	28.0 (1.0)	27.0 (9.5)	33.0 (2.5)
Neonatal seizures[a]	4 (13.8)	0 (0.0)	1 (5.3)	3 (100.0)
Therapeutic hypothermia[b], n (%) of which:	23 (79.3)	1 (14.3)	19 (100.0)	3 (100.0)
Servo-controlled methods, n (%)	18 (78.3)	1 (100.0)	14 (73.7)	3 (100.0)
Frozen gel packs, n (%)	5 (21.7)	0 (0.0)	5 (26.3)	0 (0.0)

[a]Participants who demonstrated seizures during hospitalisation were placed on anticonvulsant medications. The severe participants (n=3) were discharged home on these medications. The moderate participant (n=1) no longer required these medications by discharge.

[b]Core body temperature was maintained at 33.5°C - 34.5°C for 72 hours. Thereafter, re-warming occurred at rates of 0.5°C per hour until normal ranges of 36.5°C – 37.5°C were achieved.

The discharge NFAS was conducted on the day participants went home. The median age at discharge was 12.00 days (IQR=7.0 days). As all participants were born in hospital, age at discharge equaled length of hospitalisation. Everyone went home on full oral feeds when they were feeding safely and efficiently, as well as demonstrating appropriate growth patterns for their age. Twenty participants (69.0%) were discharged on exclusive breastfeeding; five participants (17.2%) had breastfeeding supplemented with expressed breast milk (EBM) via cup; one participant (3.5%) had cup feeding of EBM; and three participants (10.3%) were discharged on bottle feeding. Among all three participants, reasons for bottle feeding included maternal decision to formula feed exclusively.

The NFAS divides symptoms of OPD into six diagnostic areas. It is possible for neonates to have symptoms of OPD in more than one area. Eighteen participants (62.1%) initially presented with OPD in at least one NFAS diagnostic area, but an overall diagnosis of OPD was only given to three participants (10.3%). Upon discharge, five participants (17.2%) presented with OPD symptoms in at least one NFAS diagnostic area, but an overall diagnosis of OPD was only given to one participant (3.4%). There were significantly fewer signs and symptoms of OPD among participants at discharge compared to initial assessment (p=0.004). Table 4.2 displays the frequency with which OPD symptoms occurred within the diagnostic areas, across HIE grades initially and at discharge.

Table 4.2

Frequency of OPD symptoms within the NFAS diagnostic areas across HIE grades: Initial vs discharge assessment (N=29)

Diagnostic area	Initial assessment				Discharge assessment				p-values of the McNemar test (Overall: initial vs discharge)
	Mild participants (n=7) Frequency (%)	Moderate participants (n=19) Frequency (%)	Severe participants, (n=3) Frequency (%)	Overall (N=29) Frequency (%)	Mild participants, (n=7) Frequency (%)	Moderate participants, (n=19) Frequency (%)	Severe participants, (n=3) Frequency (%)	Overall (N=29) Frequency (%)	
Physiological functioning	0 (0.0)	5 (26.3)	2 (66.7)	7 (24.1)	0 (0.0)	2 (10.5)	0 (0.0)	2 (6.9)	p=0.063
Neonatal state	2 (28.6)	6 (31.6)	0 (0.0)	8 (27.6)	0 (0.0)	3 (15.8)	0 (0.0)	3 (10.3)	p=0.063
Stress cues	0 (0.0)	1 (5.3)	0 (0.0)	1 (3.4)	0 (0.0)	1 (5.3)	0 (0.0)	1 (3.4)	p=1.000
Motor performance	0 (0.0)	2 (10.5)	2 (66.7)	4 (13.8)	0 (0.0)	2 (10.5)	1 (33.3)	3 (10.3)	p=1.000
Oral anatomy and primitive reflexes	1 (14.3)	1 (5.3)	2 (66.7)	4 (13.8)	0 (0.0)	1 (5.3)	0 (0.0)	1 (3.4)	p=0.250
Signs and symptoms of OPD	2 (28.6)	5 (26.3)	3 (100.0)	10 (34.5)	0 (0.0)	1 (5.3)	0 (0.0)	1 (3.4)	**p=0.004***
Overall diagnosis of OPD	0 (0.0)	1 (5.3)	2 (66.7)	3 (10.3)	0 (0.0)	1 (5.3)	0 (0.0)	1 (3.4)	p=0.611

**Significant at 5% level of significance.*

NFAS assessment of physiological functioning included observing respiratory status. Initially, abnormal respiratory patterns occurred among six participants (20.7%). Stridor persisted in one participant upon discharge home (3.4%). Eight participants (27.6%) presented with non-optimal states of alertness at introduction of oral feeds. This number decreased to five participants (17.2%) at discharge. Four participants (13.8%) were on anticonvulsant medications but displayed adequate alertness for oral feeding during both NFAS assessments. Table 4.3 presents the oral reactions elicited and OPD symptoms evaluated as part of the NFAS initially and at discharge. Since the variables per subscale in Table 4.3 are tightly related, Bonferroni adjustments were applied. The “oral reactions elicited”, “non-nutritive sucking skills”, “nutritive sucking skills”, “behavioural responses,” and “symptoms of OPD” subscales have 7, 8, 6, 9 and 14 items, respectively. The adjusted levels of significance to which the p-value was compared were therefore 0.007, 0.006, 0.008, 0.006 and 0.004, respectively. At discharge, significant improvement was observed in endurance during non-nutritive sucking [NNS] ($p<0.001$) and nutritive sucking [NS] ($p<0.001$)

Table 4.3

Oral reactions elicited, and signs and symptoms of OPD: Initial vs discharge NFAS assessment (N=29)

Domain	Initial assessment, frequency (%)	Discharge assessment, frequency (%)	p-values of the McNemar test (Initial vs discharge)
Oral reactions elicited (7 items)[a]			
Transverse tongue	27 (93.1)	28 (96.6)	p=1.000
Strong sucking	25 (86.2)	27 (93.1)	p=0.500
Jaw clenching	23 (79.3)	26 (89.7)	p=0.250
Tongue protrusion	21 (72.4)	28 (96.6)	p=0.025
Rooting	27 (93.1)	29 (100.0)	p=0.500
Santmyer reflex	24 (82.8)	25 (86.2)	p=1.000
Palmomental (Babkin) reflex	23 (79.3)	26 (89.7)	p=0.250
Signs and symptoms of OPD			
Non-nutritive sucking (NNS) skills (8 items)[b]			
< 10-20 sucks per burst cycle	8 (27.6)	6 (20.7)	p=0.500
Reduced endurance	17 (58.6)	3 (10.3)	**p<0.001***
Reduced lip closure	2 (6.9)	2 (6.9)	p=1.000
Reduced tongue cupping	3 (10.3)	2 (6.9)	p=1.000
Reduced anterior-posterior tongue movement	3 (10.3)	2 (6.9)	p=1.000
Reduced sucking strength	5 (17.2)	2 (6.9)	p=0.250
Uncoordinated suck-swallow-breathe (SSB) rhythm	6 (20.7)	2 (6.9)	p=0.125
Abnormal breathing pattern	6 (20.7)	2 (6.9)	p=0.125
Nutritive sucking (NS) skills (6 items)[c]			
< 10-20 sucks per burst cycle	11 (37.9)	8 (27.6)	p=0.453
Reduced endurance	19 (65.5)	2 (6.9)	**p<0.001***
Reduced lip closure	5 (17.2)	2 (6.9)	p=0.250
Lack of timely initiation of sucking	5 (17.2)	0 (0.0)	p=0.063
Reduced sucking strength	5 (17.2)	1 (3.4)	p=0.125
Uncoordinated SSB rhythm	7 (24.1)	2 (6.9)	p=0.031
Behavioural responses (9 items)[d]			
Refusal of nipple/teat/syringe/cup	2 (6.9)	0 (0.0)	p=0.500
Refusal of finger/pacifier	3 (10.3)	0 (0.0)	p=0.500
Tongue thrusting	2 (6.9)	0 (0.0)	p=0.500

Jaw clenching	0 (0.0)	0 (0.0)	Not applicable
Jaw thrusting	1 (3.4)	0 (0.0)	p=1.000
Lip retraction	1 (3.4)	0 (0.0)	p=1.000
Arching of back and neck	0 (0.0)	0 (0.0)	Not applicable
Turning head away	0 (0.0)	0 (0.0)	Not applicable
Emesis	1 (3.4)	0 (0.0)	p=1.000
Symptoms of OPD (14 items)[e]			
Lack of timely initiation of sucking	5 (17.2)	1 (3.4)	p=0.125
Weak sucking	5 (17.2)	1 (3.4)	p=0.125
Absent sucking	1 (3.4)	1 (3.4)	p=1.000
Uncoordinated tongue movement	3 (10.3)	1 (3.4)	p=0.500
Poor lip closure resulting in excessive anterior spillage	3 (10.3)	2 (6.9)	p=1.000
Multiple attempts to initiate pharyngeal swallow	1 (3.4)	0 (0.0)	p=1.000
Gurgling during/after swallow	3 (10.3)	0 (0.0)	p=0.250
Coughing during/after swallow	3 (10.3)	0 (0.0)	p=0.250
Choking during/after swallow	1 (3.4)	0 (0.0)	p=1.000
Teary eyes during/after swallow	0 (0.0)	0 (0.0)	Not applicable
“Wet” respiratory sounds	3 (10.3)	0 (0.0)	p=0.250
“Wet” vocal sounds	2 (6.9)	0 (0.0)	p=0.500
Suspected delayed pharyngeal swallow	5 (17.2)	2 (6.9)	p=0.250
Absent pharyngeal swallow	0 (0.0)	0 (0.0)	Not applicable

[a] *Bonferroni adjusted level of significance* = 0.007.

[b] *Bonferroni adjusted level of significance* = 0.006.

[c] *Bonferroni adjusted level of significance* = 0.008.

[d] *Bonferroni adjusted level of significance* = 0.006.

[e] *Bonferroni adjusted level of significance* = 0.004.

**Statistically significant at the specified Bonferroni adjusted level of significance.*

The median age at VFSS was 10.5 days (IQR=4.5 days). Twenty participants (69.0%) presented with OPD symptoms during VFSSs. Supplementary file 4.2 displays the frequency with which OPD symptoms occurred during VFSSs across HIE grades. Nine participants (31.0%) demonstrated penetration or aspiration during VFSSs (penetration n=4, 13.8%; aspiration n=5, 17.2%). All participants who aspirated presented with moderate HIE. Three out of five participants (60.0%) displayed silent aspiration. Causes of penetration/aspiration included disorganisation of the participant at the beginning of the VFSS (n=1; 3.4%), and excessive drowsy or crying states (n=2; 6.9%). Four participants (13.8%) demonstrated aspiration during the swallow due to reduced endurance during fatigue testing. Disorganised tongue movements (n=1; 3.4%) and delayed pharyngeal swallows (n=3; 10.3%) also emerged during fatigue testing. Compensatory techniques were beneficial for two out of nine cases (22.2%) where penetration/aspiration occurred; for one participant, slow external pacing of liquid presentation eliminated penetration and for another, thickening liquids to a slightly thick consistency (IDDSI Level 1) eliminated aspiration.

Difficulties in the oesophageal phase of swallowing were found among 23 participants (79.3%). Slow oesophageal clearance and retrograde movement of the bolus from lower- to upper- oesophagus were noted among 14 (48.3%) and 20 (69.0%) participants, respectively. VFSS composite scores reflecting the number of combined OPD symptoms within individual participants were obtained. Overall, the median composite score was 2.0 (IQR=3.0). The median composite score for mild participants was 3.0 (IQR=3.0), for moderate participants was 1.0 (IQR=2.0), and for severe participants was 4.0 (IQR=1.0). Using the VFSS composite score as a reflection of OPD severity, no statistically significant correlations were found between OPD severity and length of hospitalisation (p=0.052).

4.5 Discussion

Approximately two-thirds of participants displayed swallowing and feeding difficulties in at least one area at the introduction of oral feeds (n=18; 62.1%) and during VFSSs (n=20; 69.0%), reinforcing OPD as a concern among neonates with HIE. Fortunately, participants' swallowing and feeding skills generally improved during hospitalisation and by discharge, significantly fewer signs and symptoms of OPD occurred (p=0.004).

Specifically, endurance during NNS ($p<0.001$) and NS ($p<0.001$) significantly improved. Improvements may be due to neonates' dynamic anatomical and physiological subsystems, neurological recovery, and early SLT intervention during admission (Jensen et al., 2017; Lau, 2015). All participants went home on full oral feeds, with most receiving either exclusive breastfeeding or EBM feeds. This is positive as oral feeding may have stimulatory effects on neurodevelopment and because breastfeeding and breast milk have significant benefits for infant health and development (Binns et al., 2016; Jadcherla et al., 2017).

Common initial difficulties identified during NFAS assessment included reduced sucking endurance, short sucking bursts, and uncoordinated SSB rhythm. These findings correspond with previous observations of infants with neurological impairment (Arvedson et al., 2020; Krüger et al., 2019). Abnormal breathing patterns and reduced tongue reactions were also found. Breathing difficulties may have implications for successful oral feeding, increasing the neonate's risk for aspiration (Arvedson, 2008). Diminished oral reactions and reflexes may indicate neurological immaturity (Modrell & Tadi, 2021). Non-optimal states of alertness for oral feeding commonly occurred at initial assessment and persisted among five participants (17.2%) at discharge. These states included light sleep, drowsy and crying states, with three participants (10.3%) falling asleep during feeding. Drowsiness during oral feeds may be attributed to neurological compromise (Genna et al., 2013; Krüger et al., 2019). Although the participants who received anticonvulsant medications displayed adequate states of alertness for oral feeding, it is important to note that these medications may have a sedation effect, consequently impacting neonatal swallowing and feeding. More research in this area may be needed.

Despite significant changes in participants' swallowing and feeding, five participants (17.2%) still presented with OPD in at least one NFAS diagnostic area at discharge. Persistent OPD symptoms mostly included short sucking bursts. This relates to previous findings that neonates with HIE had significantly more single sucks and short sucking bursts than healthy controls (Krüger et al., 2019). Persistent OPD symptoms at discharge have the potential to impact upon feeding, possibly resulting in reduced health and nutritional status, reduced quality of life and increased chance of hospital

re-admissions (Arvedson et al., 2020; Dziewas et al., 2017; Martinez-Biarge et al., 2012). This highlights the need for continuous monitoring by SLPs to prevent secondary complications.

Although contextual limitations existed, a benefit of this study included the instrumental evaluation of OPD among neonates with HIE. Delayed swallows occurred among all three grades of HIE and constitute one of the most common abnormalities observed in infants with dysphagia (Arvedson et al., 2020). The fact that the VFSS identified considerably more delayed swallows than the NFAS shows that clinical evaluation alone may be insufficient. Nine participants demonstrated penetration or aspiration (31.0%) and most aspiration events (60.0%) occurred without participant response. This concurs with findings that aspiration in infants with neurologic impairment is typically silent and highlights the importance of conducting gold-standard VFSSs (Audag et al., 2016; Velayutham et al., 2017; Weir et al., 2011). Causes of penetration and aspiration included disorganisation of the neonate at the beginning of the VFSS, as well as excessive drowsy and crying states. Additionally, four participants (13.8%) demonstrated aspiration due to reduced endurance during fatigue testing, underscoring the need for this manner of assessment during VFSSs.

Neonates with different grades of HIE demonstrated diverse swallowing and feeding abilities. Initial OPD symptoms occurred most frequently for severe participants. This is unsurprising, since neonates with severe HIE have the highest risk for adverse outcomes (Schreglmann et al., 2019). OPD severity was also greatest for neonates with severe HIE. They had a median VFSS composite score of 4.0 (IQR=1.0). Only one persistent difficulty was noted among the severe group at discharge; this occurred in the motor performance area. These findings may indicate the potential for neonates with severe HIE to recover neurologically and respond to early intervention. However, only participants with severe HIE who survived hospitalisation were included in the study; findings may not be representative of all severely affected neonates. More research in this field is required. Participants with mild HIE also experienced OPD symptoms during the initial NFAS administration. However, by discharge, no mild participants displayed OPD signs. Although neonates with mild HIE are generally considered lower risk than their moderate and severe counterparts, these findings

highlight that they do remain at risk for adverse outcomes, especially in the short-term (Krüger et al., 2017; Prempunpong et al., 2018). Participants with moderate HIE demonstrated OPD symptoms across the greatest variety of areas. This group had the fewest OPD symptoms during VFSSs but constituted the bulk of participants displaying penetration/aspiration. Moderate participants also had persistent difficulties across all NFAS areas at discharge. Evidently, the current research supports the notion that the outcomes of neonates with moderate HIE are variable and may be difficult to predict (De Vries & Jongmans, 2013). The high proportions of participants with HIE displaying OPD symptoms regardless of severity indicate that neonates with all grades of HIE should be considered for early SLP intervention. It is important to note that the way neonates with different grades of HIE are managed may independently impact swallowing and feeding. This may include intubation and ventilation which are associated with an increased risk for OPD (Tutor, 2022). Additionally, neonates with mild HIE do not usually receive TH. As restrictions on oral feeding are often implemented during TH, this group may subsequently be introduced to oral feeds sooner than their moderate and severe counterparts (Craig et al., 2020; Goswami et al., 2020).

Earlier research has consistently found that the presence of OPD is associated with extended length of hospital stay (Attrill et al., 2018; Dziewas et al., 2017). This link has also been described among neonates with HIE, although studies did not make statistical inferences about the associations (Gupta et al., 2018; Krüger et al., 2017). The current study appeared to be the first to investigate the correlation between OPD severity and length of hospitalisation among neonates with HIE. However, a significant correlation was not found between these variables ($p=0.052$). Although it is possible that the mere presence of OPD is related to length of hospital stay and that OPD severity plays a lesser role, it was previously suggested that early identification and management of OPD may decrease length of hospitalisation (Attrill et al., 2018). Therefore, the early introduction of oral feeding and involvement of the SLP as soon as participants were medically stable may have played a role in mitigating the effect of OPD severity on length of hospital stay. In settings where outpatient support is available to complete transition to oral feeding, OPD severity may also have a smaller

association with length of hospitalisation. Findings may be limited by a small sample size and should be further explored in future research using more participants.

4.6 Limitations

Common resource limitations in LMICs were highlighted in the study. These included a lack of availability of equipment such as early ultrasound, a lack of trained medical personnel, and poor maternal access to healthcare, which in some cases necessitated the use of sure dates or the new Ballard score to determine gestational age (Lee et al., 2017). Although a qualified neonatologist oversaw the administration of the new Ballard score, which may improve the validity of this clinical assessment, it should be noted that the Ballard score may over- or underestimate gestational age and may therefore affect interpretations of swallowing and feeding (Lee et al., 2017). Neuroimaging tools such as magnetic resonance imaging (MRI) are also costly and were not available for all participants. The relationship between patterns of brain injury and OPD could therefore not be determined.

Additional study limitations include a small sample size and unequal distribution of participants with mild, moderate, and severe HIE in the study sample. Neonates with mild HIE who were discharged from the hospital before data collection could be completed or neonates with severe HIE who demised were not included in the study. Future research should include more equally distributed grades of HIE and a larger sample size, to allow for more effective comparisons.

4.7 Clinical implications

A high proportion of neonates displayed OPD regardless of HIE severity. Neonates with all grades of HIE should be considered for early intervention by SLPs, who are uniquely equipped to manage swallowing and feeding difficulties in a neonatal feeding team. Although significantly fewer signs and symptoms of OPD were found among neonates with HIE at discharge compared to initial assessment, 17.2% of neonates still presented with OPD when they went home. SLPs should thus optimally use opportunities during hospitalisation for early intervention and parent coaching before families are discharged and dispersed to areas where early intervention services may be scarce. Using VFSSs identified symptoms of pharyngeal phase dysphagia more

effectively than clinical evaluation alone. Most aspiration events among participants were silent and may have been missed otherwise. The value of instrumental dysphagia evaluation is therefore highlighted. The role of early SLP intervention in mitigating the effect of OPD severity on length of hospitalisation remains important.

4.8 Conclusion

This study provided a comprehensive description of the evolution of swallowing and feeding abilities of neonates with HIE during hospitalisation, using a validated and standardised assessment tool and instrumental evaluation. Findings may be beneficial to neonatal feeding teams. Further well-designed experimental studies on neurological recovery, early establishment of oral feeds, and length of hospitalisation are also warranted, since the ideal early feeding regime for neonates with HIE on TH has not yet been described (Chandrasekaran et al., 2021). Intervention for OPD among neonates with HIE should similarly be investigated since this was not included in the current study.

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4.10 Declaration of interest

The authors report no conflict of interest.

4.11 Funding

No external funding was received for conducting this study.

4.12 Disclosure statement

The authors report that there are no competing interests to declare.

4.13 Data availability

All data are stored securely in the University of Pretoria repository. Due to the nature of the research, data cannot be made publicly available to ensure privacy of participants.

4.14 Author contributions

Conceptualisation (RM, JV, AK and EK); Method (RM, JV, AK, EK, ZL and KK); Formal analysis and investigation (RM and MG); Writing (RM); Supervision (JV, AK and EK)

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Supplementary file 4.1

Criteria for participants to be deemed medically ready for introduction of oral feeds

	Criteria	Definition
1.	**Therapeutic Hypothermia (TH)**	The participant should not currently be on TH. (TH should either have been completed and the participant fully rewarmed, or TH should not have been received).
2.	**Respiratory stability**	The participant should display a stable respiratory rate at 35-60 breaths per minute
		The participant should not currently be on mechanical ventilation or continuous positive airway pressure (CPAP).
3.	**Cardiac stability**	The participant should display a stable heart rate at 100-160 beats per minute

Participants were first assessed using the NFAS upon admission to the neonatal unit if they did not receive TH (n=6; 20.7%) or upon completion of TH if they did (n=23; 79.3%), unless they were mechanically ventilated (n=3; 10.3%) or on continuous positive airway pressure [CPAP] (n=3; 10.3%) at the time. Among participants who were ventilated or on CPAP, the first assessment was conducted 24 hours after it was discontinued.

Supplementary file 4.2

Frequency of oropharyngeal dysphagia (OPD) symptoms found during video-fluoroscopic swallow study (VFSS) across hypoxic-ischaemic encephalopathy (HIE) grades (N=29)

VFSS findings	Mild participants (n=7) Frequency (%)	Moderate participants, (n=19) Frequency (%)	Severe participants (n=3) Frequency (%)	Overall (N=29) Frequency (%)
Oral phase				
Reduced labial closure/anterior spillage of the bolus	1 (14.3)	2 (10.5)	3 (100.0)	6 (20.7)
Disorganised/weak tongue movements	1 (14.3)	3 (15.8)	3 (100.0)	7 (24.1)
Residue on tongue	2 (28.6)	5 (26.3)	1 (33.3)	8 (27.6)
Residue in lateral sulci	0 (0.0)	1 (5.3)	0 (0.0)	1 (3.4)
Residue on palate	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Pharyngeal phase				
Premature loss of bolus posteriorly into pharynx	2 (28.6)	0 (0.0)	0 (0.0)	2 (6.9)
Reduced velopharyngeal closure	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Delayed pharyngeal swallow	3 (42.9)	6 (31.6)	2 (66.7)	11 (37.9)
Reduced epiglottic closure	1 (14.3)	2 (10.5)	0 (0.0)	3 (10.3)
Limited hyolaryngeal elevation and/or excursion	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Residue on posterior pharyngeal wall	1 (14.3)	3 (15.8)	0 (0.0)	4 (13.8)
Pooling in the valleculae[a]	1 (14.3)	0 (0.0)	1 (33.3)	2 (6.9)
Pooling in the pyriform sinuses[a]	2 (28.6)	0 (0.0)	1 (33.3)	3 (10.3)
Penetration/aspiration before swallow	0 (0.0)	2 (10.5)	0 (0.0)	2 (6.9)
Penetration/aspiration during swallow[d]	1 (14.3)	5 (26.3)	1 (33.3)	7 (24.1)
Penetration/aspiration after swallow	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)

[a]*Pooling cleared with multiple swallows among all participants (100.0%).*

CHAPTER 5: EVOLUTION OF FEEDING AND DEVELOPMENTAL OUTCOMES IN INFANTS WITH MODERATE HYPOXIC-ISCHAEMIC ENCEPHALOPATHY

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5.1 Abstract

Outcomes of infants with moderate hypoxic-ischaemic encephalopathy (HIE) are diverse and uncertain. A prospective case series explored the evolution of swallowing, feeding, and development among infants with moderate HIE from hospitalization to the ages of six- and 12-months. Four participants with moderate HIE were recruited. Early feeding and swallowing were assessed, using the Neonatal Feeding Assessment Scale and video fluoroscopic swallow studies. Developmental assessments were conducted at six- and 12-months, using the Rossetti Infant-Toddler Language Scale and Vineland-3 Scale. All participants displayed atypical outcomes throughout the study, including oropharyngeal dysphagia initially during hospitalization. All participants were discharged on oral feeds but some breastfeeding difficulties persisted. Variable but pervasive developmental delays were found among all participants at six- and 12-months. This study emphasizes the need for consistent early intervention from the neonatal period onward, for all infants with moderate HIE. Future studies should use larger cohorts, longer follow-up, and correlational designs.

Keywords: Moderate hypoxic-ischaemic encephalopathy, feeding, swallowing, developmental outcomes, infant

5.2 Introduction

Hypoxic-ischaemic encephalopathy (HIE) is a significant cause of infant mortality and adversely affects feeding, swallowing, and development among survivors, despite the recent widespread use of therapeutic hypothermia as a neuroprotective strategy (Arvedson et al., 2020; Ballot et al., 2020; Douglas-Escobar & Weiss, 2015). From the early neonatal stage, HIE often causes oropharyngeal dysphagia [OPD] (Arvedson et al., 2020; Krüger et al., 2019). OPD symptoms may include falling asleep during feeding, short sucking bursts, oral-motor difficulties, absence of frequent swallowing, coughing, nostril flaring, and presence of visible oral secretions (Krüger et al., 2019). Symptoms may be caused by muscle tone disturbances, poor movement coordination, impaired functioning of neuromuscular units, poor state regulation and/or reduced feeding endurance (Arvedson et al., 2020; Krüger et al., 2017). Although research on feeding outcomes in infants with HIE is emerging, a general lack of understanding of OPD among these infants remains, and instrumental evaluations are needed (Jadcherla et al., 2017; Krüger et al., 2019). Permanent developmental sequelae of HIE may include cerebral palsy (CP), epilepsy, cognitive impairment, communication difficulties, attention deficits, vision loss, hearing impairment, behavioural difficulties, and autism spectrum disorder (De Vries & Jongmans, 2013; Ballot et al., 2020). Developmental outcomes among individuals with HIE vary greatly, therefore neurological prognostication from an early age is essential for the development of treatment plans, parent counselling, and decision-making (Rasmussen et al., 2016). Prognostication may also contribute to early intervention during infancy for those who need it the most, when neuroplasticity is thought to be the greatest (Mizuno & Ueda, 2005).

Later outcomes of neonates with mild and severe HIE are often effectively predicted through early rating systems such as the modified Sarnat stages or Thompson score (Adhikhari & Rao, 2017; Murray et al., 2009; Shalak et al., 2003; Thompson et al., 1997). However, outcomes of neonates with moderate HIE are less certain, and significant diversity exists among this group (Adhikhari & Rao, 2017; De Vries &

Jongmans, 2013; Robertson & Perlman, 2006). It is widely accepted that neonates with severe HIE are at higher risk of mortality and major developmental impairment (Bruckmann & Velaphi, 2015; Padayachee & Ballot, 2013). There is also an increase in research about developmental outcomes associated with mild HIE as more evidence emerges that this group's outcomes are not typical (Conway et al., 2018; Finder et al., 2020). The heterogeneous moderate group continues to be under-researched and is often grouped with mild and severe counterparts in studies (Bruckmann & Velaphi, 2015; Padayachee & Ballot, 2013). The multi-disciplinary team (MDT) working with feeding, swallowing, and development among this population, therefore, requires a better understanding of the unique profiles of infants with moderate HIE, to inform early intervention strategies in this high-risk population (Adhikhari & Rao, 2017; Rasmussen et al., 2016). As infants present with rapidly changing anatomical and physiological subsystems, serial assessment of infants with HIE is proposed to understand their evolving needs (Krüger et al., 2019; Murray et al., 2009). The aim of this exploratory study was to describe the evolution of outcomes among infants with moderate HIE; from their early swallowing and feeding abilities during hospitalization, to their later developmental outcomes at six and 12 months.

5.3 Method

5.3.1 Study design

A prospective case series design was implemented from October 2018 to June 2020. Case series designs are often a useful first step when exploring complex populations (Kooistra et al., 2009). The early feeding and swallowing abilities of four neonates with moderate HIE were assessed by a speech-language therapist (SLT) while they were admitted to the 29-bed neonatal unit of an urban tertiary academic hospital in South Africa after birth. The hospital where data were collected is a Baby Friendly Hospital Initiative-accredited facility, encouraging and supporting exclusive breastfeeding for all infants (WHO & UNICEF, 2018). Exclusive breastfeeding includes direct breastfeeding or receiving breast milk via other methods such as cup or bottle (WHO, 2009). Developmental assessments were conducted at the hospital on an outpatient basis at the ages of six and 12 months. All four participants returned for developmental assessments.

5.3.2 Participants and recruitment

Ethical clearance was obtained from the University of Pretoria Faculty of Health Sciences Research Ethics Committee (protocol number 380/2018) and participants' legal guardians provided written informed consent for inclusion in the study. During the study time frame, all full-term neonates admitted to the neonatal unit who were independently diagnosed with moderate HIE by a neonatologist according to hospital protocol were consecutively recruited to participate in the study (Kooistra et al., 2009). Eligible participants were born ≥37 weeks' gestation, using the most reliable information available, including: ultrasound <22 weeks' gestation, sure dates or new Ballard score (ACOG, 2017). Neonatal encephalopathy was suspected to be secondary to an acute peri- or intrapartum event if participants presented with encephalopathy (disturbed neurological function manifested as an abnormal level of consciousness or seizures, possibly accompanied by respiratory difficulties and decreased tone and/or primitive reflexes), and had at least one of the following criteria: i) APGAR scores <5 at 5 and 10 minutes, or ii) evidence of foetal acidemia (arterial umbilical cord blood gas or radial artery blood gas done within 60 minutes of delivery with a pH <7.0 or a base deficit ≥12 mmol/L) (AAP, 2014; Shankaran et al., 2005). Encephalopathy grading was performed using the modified Sarnat stages and was confirmed by a neonatologist (Shalak et al., 2003). Serial modified Sarnat scores were performed during the first six hours of life; if there was progression of disease, the worse staging was assigned to the participant. Thompson scores were conducted daily until day 10 of life. Participants' first, highest and day seven Thompson scores were recorded where available (Thompson et al., 1997). Participants were excluded if they had genetic syndromes or major congenital abnormalities, metabolic disease, meningitis, structural brain abnormalities, intracerebral or intraventricular haemorrhage, congenital hydrocephalus or perinatal stroke.

Table 5.1 indicates participant characteristics. Everyone received whole-body therapeutic hypothermia (TH) under intensive care, where core body temperature was kept at 33.5°C - 34.5°C for 72 hours using servo-controlled methods (n=2) or frozen gel packs (n=2). Low-cost devices such as ice packs have proven to be plausible substitutes for servo-controlled methods in lower- and middle-income countries, as similar outcomes were found among neonates receiving the two modalities previously

(Kinoshita et al., 2021; Rossouw, 2015). The mean initial Thompson score for participants was 10.25 (Standard deviation [SD]=3.59) and the mean highest Thompson score was 13.50 (SD=3.11). The Day 7 Thompson score was only available for Participant 1 (it was five). Participant 2 developed seizures at six hours of life but did not require anti-epileptic medication by discharge home. All participants were born at the hospital where data were collected. Participant 1 was transferred from a nearby district hospital due to complications during labour. The mean length of hospitalization was 20.75 days (SD=9.90). Half of the participants were male (n=2). The mean gestational age was 38.75 weeks (SD=2.217) and the mean birth weight was 2869.00 grams (SD=457.49). No participants were HIV-exposed. The mean maternal age was 29.25 years (SD=2.87). All mothers attended antenatal clinics regularly. Participant 1's mother experienced fever during pregnancy and Participant 2's mother had an elevated body-mass index. All mothers had a high level of support from their families, and the mothers of Participants 1, 2, and 4 were married or in committed relationships. Participants 1, 2, and 4 lived in urban areas. Participant 3 lived in a peri-urban area

Table 5.1

Participant characteristics (n=4)

Characteristics	Participant 1	Participant 2	Participant 3	Participant 4
Gender	Female	Female	Male	Male
Gestational age (weeks)	38	38	42	37
Birth weight (grams)	2500	3530	2801	2645
Anthropometry	SGA	AGA	SGA	AGA
Mode of delivery	Caesarean section	NVD	Assisted delivery	Caesarean section
Maternal age (years)	33	27	27	30
Parity	1	1	1	2
Singleton	Yes	Yes	Yes	No
Birth complications	Failed vacuum delivery, foetal distress, antepartum haemorrhage, poor maternal effort	Breech position, meconium stained amniotic fluid	Prolonged second stage of labour	Foetal distress, retained twin more than one hour
APGAR scores (1, 5, 10 minutes)	3, 3, 8	5, 7, 8	3, 7, 5	2, 7, 10
Arterial pH and Base deficits (mmol/L)	6.99; 22.20	7.42; 14.70	7.11; 19.90	6.88; 18.40
Thompson score: Initial	11	5	13	12
Thompson score: Highest	11	18	13	12
Type of therapeutic hypothermia received	Criticool	Criticool	Gel packs	Gel packs
Length of hospital stay (days)	12	30	11	30

SGA (small for gestational age); AGA (appropriate for gestational age); NVD (normal vaginal delivery).

5.3.3 Materials, apparatus and procedures

Each participant was assessed twice using the Neonatal Feeding Assessment Scale [NFAS] (Viviers et al., 2016) during their hospital admission: once when they were deemed medically ready for introduction of oral feeds by the treating paediatrician (see Supplementary file 5.1) and once on the day of discharge home. The NFAS is a valid tool for describing neonatal feeding skills and shows acceptable inter-rater reliability (Viviers et al., 2017; Viviers et al., 2019).

A video fluoroscopic swallow study (VFSS) was conducted prior to discharge, using the CombiDiagnost R90 remote controlled fluoroscopy system (Koninklijke Philips

N.V., Netherlands) in the presence of a radiographer and in consultation with a radiologist. A checklist based upon guidelines by Arvedson and Brodsky (2002) was used in conjunction with the Penetration Aspiration Scale [PAS] (Rosenbek et al., 1996) to interpret the VFSS. Both were completed by two SLTs with experience in assessment and management of paediatric OPD. They were blinded to participants' NFAS results. All participants received daily oral sensorimotor stimulation and feeding intervention by the same SLT since initiation of oral feeds.

After discharge, participants were given dates to attend developmental assessments at the hospital on an outpatient basis at the ages of six and 12 months. Dates were coordinated with participants' check-ups at an MDT high-risk clinic to minimize the time and cost associated with travel to and from hospital. The MDT consisted of a paediatrician, nurse, SLT, audiologist, and occupational therapist (OT) who worked closely together to regard infants' health status and developmental functioning holistically. Dietitians and physiotherapists were available on a consultation basis. The goals of the clinic were to detect impairment, inform parents, promote early intervention, and discover changes in outcomes (Robertson & Perlman, 2006). Intervention included caregiver education regarding developmental stimulation and modelling of appropriate techniques. Techniques broadly included establishing sensitive, responsive interactions between caregivers and infants; establishing joint attention; providing stimulating materials; and scaffolding infants' behaviours (Guralnick, 2017). If needed, referrals were made for more frequent treatment. No participants were diagnosed with CP during the study. However, Participant 2 was referred to a paediatric neurologist for diagnosis following her 12-month assessment, as CP was suspected.

The Vineland Adaptive Behaviour Scales, Third Edition [Vineland-3] (Sparrow, 2016) assessed participants' communication development, daily living skills, socialization, and motor development in the presence of their parents/caregivers. Sub-domains included receptive and expressive language, personal, interpersonal, play, gross and fine motor development. The Vineland-3 Comprehensive Interview Form was completed through caregiver interview. The Rossetti Infant-Toddler Language Scale [RITLS] (Rossetti, 2006) further assessed participants' communication development,

including their interaction-attachment, pragmatics, gesture, play, language comprehension and language expression skills. The RITLS was completed by observing or eliciting various behaviours among participants, or by using caregivers' reports. The Vineland-3 and RITLS are both suitable for assessing developmental functioning. The Vineland-3 is a valid and reliable norm-referenced tool (Pepperdine & McCrimmon, 2017). The RITLS, although criterion-referenced, is a tool that has been used successfully in previous research, including studies conducted in South Africa (Van der Linde et al., 2016; Stevens et al., 2017; Dettman et al., 2007).

5.3.4 Data analysis

IBM Statistical Package for the Social Sciences (SPSS), Version 26.0 (IBM Corp, 2019) generated descriptive statistics. The NFAS and VFSS were both scored using a binary yes/no system. The NFAS identified symptoms of OPD across six diagnostic areas: physiological functioning; neonatal state; stress cues; motor performance; oral anatomy and primitive reflexes; and signs and symptoms of OPD (Viviers et al., 2019). Neonates could have OPD symptoms in more than one area. The VFSS identified OPD, whether penetration and/or aspiration occurred, and the reason for penetration/aspiration. Composite scores were obtained for both the NFAS and VFSS. In the NFAS, the composite score determined whether an overall diagnosis of OPD was given. In the VFSS, the composite score determined how many symptoms of OPD were evident, reflecting OPD severity. A PAS score of one to eight was additionally assigned to participants during VFSSs, based upon the level of penetration or aspiration found.

The Vineland-3 test items were scored using a three-point rating scale (0=never, 1=sometimes, 2=usually), reflecting the frequency with which participants performed behaviours (Pepperdine & McCrimmon, 2017). Participants' performance in developmental domains (communication, daily living skills, socialization, and motor skills) was expressed as standard scores (mean=100; SD=15). Participants' performance in developmental sub-domains (receptive and expressive language, personal, interpersonal, play, gross and fine motor development) was expressed as v-scale scores [mean=15; SD=3] (Sparrow et al., 2016). Scores were interpreted according to the following adaptive levels: adequate (<1 SD), moderately high (≥+1

SD), moderately low (≥-1 SD), high (≥+2 SD), or low [≥-2 SD] (Sparrow et al., 2016). Participants' strengths included areas in which their development was interpreted as moderately high or high. Participants' delays included areas in which their development was interpreted as moderately low or low. An overall standard score, the Adaptive Behaviour Composite (ABC), was calculated by adding the standard scores from the communication, daily living skills, and socialization domains. An infant was considered to have an overall developmental delay if the ABC score was one or more standard deviations below the mean [≥-1 SD] (Sparrow et al., 2016). Focal delays in specific domains or sub-domains did not necessarily add up to an overall developmental delay, as the ABC score is an average of the developmental domains.

Information obtained through observation, elicitation or caregiver report carried equal weight when scoring test items across the six developmental domains of the RITLS (Rossetti, 2006). Domains were considered delayed if a participant fell two or more three-month categories below their chronological age level (Rossetti, 2006). Assessment of the gesture domain only started at the 9-12 month level.

5.4 Results

5.4.1 Early swallowing and feeding

The mean age at initial NFAS assessment was 7.50 days (SD=3.70). Participants were assessed on direct breastfeeding or direct breastfeeding and expressed breast milk (EBM) via cup. The mean age at VFSS was 12.67 days (SD=2.08). The mean age at discharge was 20.75 days (SD=9.90). The discharge NFAS was conducted on the day participants went home. All participants were discharged on full oral feeds (n=4). Participants 2 and 3 were discharged exclusively on direct breastfeeding, Participant 1 was discharged on breastfeeding supplemented with EBM via cup, and Participant 4 was discharged bottle feeding EBM.

Table 5.2 overviews OPD among participants across NFAS diagnostic areas at initial and discharge assessments, as well as VFSS results. All participants experienced OPD in at least one NFAS diagnostic area initially (n=4). Participants 2, 3, and 4 also obtained overall diagnoses of OPD in the initial NFAS. No participants obtained an overall OPD diagnosis at discharge. However, Participants 1 and 4 experienced

persistent OPD in at least one NFAS diagnostic area sufficient to interfere with their direct breastfeeding abilities at home. The mean number of combined OPD difficulties during the VFSS was 2.25 (SD=1.17). Participant 4 displayed the highest number of combined OPD difficulties during the VFSS (number of combined difficulties=4). Participants 2 and 4 demonstrated silent aspiration during VFSSs (PAS score=8). Participant 2 demonstrated aspiration associated with reduced feeding endurance. Participant 2's endurance improved during hospitalization, and aspiration was no longer a problem at discharge. Participant 4 aspirated on thin liquids using a fast-flow teat during the VFSS, but neither penetration nor aspiration was found when liquids were presented via a slow-flow bottle. As Participant 4 was unable to tolerate the fast flow of milk during breastfeeding, he was discharged home on EBM via slow-flow bottle. All participants demonstrated slow emptying of the oesophagus and intra-oesophageal reflux during VFSSs.

Table 5.2

Oropharyngeal dysphagia (OPD) among participants: NFAS and VFSS findings (n=4)

NFAS and VFSS Findings	Participant 1	Participant 2	Participant 3	Participant 4
NFAS diagnostic areas: Initial assessment				
Physiological function			X	X
State	X			
Stress cues				
Motor performance				X
Oral anatomy and primitive reflexes				
OPD signs and symptoms		X	X	X
Overall OPD diagnosis		X	X	X
NFAS diagnostic areas: Discharge assessment				
Physiological function				X
State	X			
Stress cues				
Motor performance				X
Oral anatomy and primitive reflexes				
OPD signs and symptoms				
Overall OPD diagnosis				
VFSS findings				
Oral phase difficulties		X	X	X
Pharyngeal phase difficulties		X		X
Number of combined OPD difficulties (OPD severity)	0	2	2	4
PAS scale score	1	8	1	8

The subsections of the NFAS and VFSS that are marked with an X indicate the areas in which participants experienced OPD.

Table 5.3 details participants' early feeding and swallowing difficulties during initial and discharge NFAS assessments, as well as during VFSSs. NFAS difficulties are

described according to diagnostic areas. Participant 1 mostly experienced difficulties related to non-optimal states of alertness during feeding initially and at discharge. Participants 2, 3, and 4 had specific signs and symptoms of OPD initially. Participant 3 displayed the most signs and symptoms of OPD.

Table 5.3

Detailed feeding and swallowing difficulties of participants: NFAS and VFSS findings (n=4)

Participant 1	Participant 2	Participant 3	Participant 4
	Initial NFAS		
State Drowsy state	**Signs & Symptoms of OPD (6 signs and symptoms)** *During non-nutritive suck (NNS) and nutritive suck (NS):* - Short sucking bursts - Reduced endurance *During NS:* -Reduced lip closure -Excessive jaw thrusting -Wet respiratory sounds - Mild but clinically significant desaturation during swallowing (repeated episodes of SpO_2 85-89% for periods ≥ 1 second)	**Physiological function** Irregular breathing **Signs & Symptoms of OPD (7 signs and symptoms)** *During NNS and NS:* -Reduced endurance -Short sucking bursts *During NNS:* -Reduced lip closure -Reduced tongue cupping -Reduced anterior-posterior lingual movement -Reduced sucking strength -Gagging	**Physiological function** Stridor **Motor performance** Floppy/extended posture at rest and during feeding **Signs & symptoms of OPD (4 signs and symptoms)** *During NNS and NS:* -Reduced endurance -Reduced suck-swallow-breathe synchrony -Abnormal breathing pattern *During NS:* -Coughing when swallowing
	Discharge NFAS		
State Light sleep	No further difficulties in any diagnostic area	No further difficulties in any diagnostic area	**Physiological function** Stridor **Motor performance** Increased tone noted during feeding
	VFSS		
No oral or pharyngeal phase difficulties PAS=1	**Oral phase difficulties** -Reduced labial closure **Pharyngeal phase difficulties** -Aspiration associated with reduced endurance PAS=8	**Oral phase difficulties** -Weak lingual movements -Lingual residue PAS=1	**Oral phase difficulties** -Weak lingual movements **Pharyngeal phase difficulties** -Delayed trigger of pharyngeal swallow -Reduced epiglottic inversion -Aspiration on fast flow bottle PAS=8

5.4.2 Developmental assessments

Tables 5.4 and 5.5 indicate the developmental outcomes of participants at six- and 12-months' chronological age, using the RITLS and Vineland-3 Scale respectively. At

six months, all participants displayed typical communication development across all RITLS domains. However, Participant 3 demonstrated a communication delay according to the Vineland-3. All participants were delayed in at least one of the Vineland-3 sub-domains at six months (n=4). Participants 2, 3, and 4 had the most developmental delays in the Vineland-3 and were all considered to have delayed overall development (ABC score ≥-1 SD). Participant 4's developmental strength included moderately high gross motor skills.

At 12 months, all participants experienced delayed gross motor development (n=4), with Participant 2 demonstrating the biggest gross motor delay (v-scale score 6; ≥-2 SD). Overall, Participant 4 improved by 12-months' age and showed a similar developmental profile to Participant 1. Both participants were only delayed in one area of the Vineland-3 (gross motor skills). For Participant 1, this delay occurred because she was not yet walking at the time of the 12-months assessment. Participant 4 was not yet standing or walking unsupported at the assessment. Both participants were found to have adequate overall development (ABC score <1 SD) and typical communication development, as they demonstrated no delays in the RITLS. Participant 1 additionally demonstrated moderately high interpersonal skills. Participants 2 and 3 showed multiple focal developmental delays in the RITLS and Vineland-3 at 12 months. Participant 2 appeared the most delayed and was the only participant who demonstrated an overall developmental delay (ABC score ≥-1 SD). Strengths of both Participants 2 and 3 included their typical interaction-attachment and pragmatics skills according to the RITLS. All participants continued to receive developmental surveillance beyond 12 months. Participants 1 and 4 started walking soon after their 12-months assessments. Participants 2 and 3 were referred for regular SLT and OT services at the age of 12 months. Participant 2 was additionally referred to a paediatric neurologist at this age, due to a suspected CP diagnosis

Table 5.4

Participants' RITLS outcomes at 6- and 12-months assessments (n=4)

Developmental domains	**Participant 1**	**Participant 2**	**Participant 3**	**Participant 4**
6-months assessment				
Interaction-attachment	3-6 months	6-9 months	3-6 months	6-9 months
Pragmatics	3-6 months	3-6 months	0-3 months	6-9 months
Play	6-9 months	0-3 months	3-6 months	3-6 months
Language comprehension	3-6 months	3-6 months	0-3 months	3-6 months
Language expression	3-6 months	0-3 months	0-3 months	3-6 months
12-months assessment				
Interaction-attachment	6-9 months	6-9 months	9-12 months	9-12 months
Pragmatics	9-12 months	6-9 months	9-12 months	12-15 months
Play	6-9 months	3-6 months *(delayed)*	9-12 months	6-9 months
Language comprehension	6-9 months	3-6 months *(delayed)*	3-6 months *(delayed)*	6-9 months
Language expression	9-12 months	3-6 months *(delayed)*	6-9 months	9-12 months

Gesture is not indicated, as assessment items are only included in this domain from 9-12 months. A child can therefore only display a delay from 15 months or older.

Table 5.5

Participants' Vineland-3 Scale outcomes at 6- and 12-months assessments (n=4)

Developmental domains	Participant 1		Participant 2		Participant 3		Participant 4	
	Score	Interpretation	Score	Interpretation	Score	Interpretation	Score	Interpretation
6-months assessment								
Communication	91	Adequate	88	Adequate	85	**Moderately low**	88	Adequate
Receptive language	13	Adequate	13	Adequate	13	Adequate	11	**Moderately low**
Expressive language	14	Adequate	13	Adequate	12	**Moderately low**	15	Adequate
Daily living skills	88	Adequate	94	Adequate	100	Adequate	80	**Moderately low**
Personal	13	Adequate	14	Adequate	15	Adequate	11	**Moderately low**
Socialization	94	Adequate	79	**Moderately low**	82	**Moderately low**	97	Adequate
Interpersonal	13	Adequate	12	**Moderately low**	12	**Moderately low**	12	**Moderately low**
Play	15	Adequate	11	**Moderately low**	12	**Moderately low**	17	Adequate
Motor	86	Adequate	83	**Moderately low**	86	Adequate	110	Adequate
Gross motor	14	Adequate	13	Adequate	12	**Moderately low**	18	*Moderately high*
Fine motor	11	**Moderately low**	11	**Moderately low**	13	Adequate	15	Adequate
ABC	87	Adequate	83	**Moderately low**	85	**Moderately low**	85	**Moderately low**
12-months assessment								
Communication	103	Adequate	70	**Low**	83	**Moderately low**	103	Adequate
Receptive language	15	Adequate	10	**Moderately low**	9	**Low**	14	Adequate
Expressive language	16	Adequate	9	**Low**	15	Adequate	17	Adequate
Daily living skills	101	Adequate	87	Adequate	101	Adequate	107	Adequate
Personal	15	Adequate	12	**Moderately low**	15	Adequate	16	Adequate
Socialization	110	Adequate	94	Adequate	94	Adequate	97	Adequate
Interpersonal	18	*Moderately high*	14	Adequate	12	**Moderately low**	14	Adequate
Play	15	Adequate	13	Adequate	15	Adequate	14	Adequate
Motor	87	Adequate	62	**Low**	89	Adequate	87	Adequate
Gross motor	12	**Moderately low**	6	**Low**	12	**Moderately low**	10	**Moderately low**
Fine motor	14	Adequate	10	**Moderately low**	15	Adequate	16	Adequate
ABC	105	Adequate	80	**Moderately low**	89	Adequate	102	Adequate

5.5 Discussion

All participants displayed atypical outcomes throughout the study; from early swallowing and feeding abilities, to later developmental outcomes. Initially during hospitalization, all participants displayed some form of OPD and required SLT intervention. By discharge, participants' OPD had mostly resolved and everyone went home on oral feeds. However, two out of four participants continued to display difficulties with direct breastfeeding. By six months, focal developmental delays emerged in various areas among all participants. However, communication abilities

were relatively spared. By 12 months, focal developmental delays persisted among all participants and increased communication delays were also evident. The variable but pervasive developmental delays found among and within individual participants over time, emphasize the need for early intervention for all infants with moderate HIE.

Initially, three out of four participants obtained an overall OPD diagnosis and all participants experienced OPD in at least one NFAS diagnostic area. Participants with an overall OPD diagnosis on the NFAS were also found to have oral and/or pharyngeal dysphagia during the VFSS (n=3). This high occurrence of OPD among participants correlates with previous findings that most infants with HIE experience at least one symptom of OPD, suggesting that all infants with HIE should receive early support for swallowing and feeding (Krüger et al., 2019). Various signs and symptoms of OPD occurred among Participants 2, 3, and 4. These included short sucking bursts, reduced endurance, and poor lip closure. Short sucking bursts and oral motor difficulties were previously found among infants with HIE (Krüger et al., 2019). Reduced endurance is common among infants with neurological impairment (Arvedson et al., 2020; Krüger et al., 2019; Prasse & Kikano, 2009). Participants 2 and 4 additionally demonstrated clinical signs of aspiration during initial NFAS. Their aspiration was confirmed during VFSSs. Clinical signs of aspiration included wet respiratory sounds, coughing, and mild but clinically significant desaturation when swallowing [repeated episodes of oxygen saturation levels dropping to 85-89% for periods ≥1 second] (Thoyre & Carlson, 2003). All participants demonstrated slow oesophageal emptying and intra-oesophageal reflux during VFSSs. This concurs with knowledge that infants with neurological impairment are at significant risk for gastro-oesophageal reflux disease and that oesophageal dysmotility exists among infants with HIE (Arvedson et al., 2020; Hill & Jadcherla, 2013).

Participants' mean length of hospital stay was 20.75 days (SD=9.90). This extended hospital stay was mainly caused by an increased time taken to establish full oral feeds. OPD has previously been associated with extended length of hospitalization and places a heavy burden on parents/caregivers, families, staff, and healthcare resources (Dziewas et al., 2017; Krüger et al., 2017). Although all participants were oral feeders when they went home, Participants 1 and 4 displayed persistent OPD in at least one

NFAS diagnostic area upon discharge. This interfered with their direct breastfeeding abilities. Not being able to breastfeed directly may have several implications, including diarrhoea and infection, earlier weaning from breast milk, and reduced developmental outcomes (Pang et al., 2017; Pang et al., 2020; WHO, 2021). Participant 1 displayed non-optimal states of alertness for feeding initially and at discharge. She required supplementation of direct breastfeeding with EBM via cup. Falling asleep and drowsiness during feeds have been found among neonates with HIE previously and may be related to neurological compromise (Krüger et al., 2019). Participant 4 exhibited stridor and increased muscle tone during feeding. Upon discharge, he still required EBM via slow-flow bottle to prevent aspiration. Significant associations exist between respiratory comorbidities and OPD (Slattery et al., 2012). Atypical muscle tone is furthermore one of the most common features observed among infants with neurological disorders and is particularly important when considering oral feeding safety (Arvedson, 2008; Goo et al., 2018).

At both six and 12 months, all participants displayed delayed development in at least one area. Focal delays occurred in various areas across participants and even occurred in different areas for the same individuals over time. At six months, a common area of delay was interpersonal development, which contributes to infants' socialization. Participants' strengths at this age included fair communication development, as no participants demonstrated delays in the RITLS. In contrast, two out of four of participants displayed communication delays in the RITLS at 12 months, correlating with previous studies where delayed language became more evident with advancing age in children with HIE (Martinez et al., 2014). This finding may indicate greater communication difficulties as communication demands increase, highlighting the need for ongoing communication intervention among this population (Chin et al., 2018). Interestingly, the Vineland-3 indicated a communication delay in Participant 3 at six months which was not evident in the RITLS. The difference in outcomes between the two assessment tools may reflect differences emerging when using global tests (Vineland-3) compared to tests for specific developmental areas [RITLS] (Pin et al., 2009). At 12 months, both the Vineland-3 and RITLS found communication delays among Participants 2 and 3. No other differences between the two assessment tools were found.

At 12 months, all participants demonstrated gross motor delays. As motor testing at one year predicts motor and mental outcomes at two years, this may indicate the need for continued developmental surveillance among all participants in early childhood (Van Schie et al., 2010). For Participants 1 and 4, gross motor development was the only area of delay. In contrast, Participants 2 and 3 showed multiple focal delays, including delayed receptive and expressive language, personal, interpersonal, and fine motor development. Strengths of Participants 2 and 3 included adequate interaction-attachment and pragmatics development. These strengths may be beneficial, as they may contribute to fostering parent-child interactions, which is crucial for communication development and an important goal of early intervention (Danguecan et al., 2020). Both Participants 2 and 3 demonstrated numerous signs and symptoms of OPD during the initial NFAS and had greater highest Thompson scores than other participants (scores of 18 and 13, respectively). These findings may indicate greater severity of the condition from the neonatal period. Participant 2 displayed the lowest developmental outcomes of all participants at 12 months and was the only participant with delayed overall development at this age (Vineland-3 ABC score ≥-1 SD). Participant 2 was referred to a paediatric neurologist at 12 months, due to a suspected CP diagnosis. It is important to note that Participant 2 developed seizures at six hours of life. Approximately one-third of individuals with moderate HIE develop seizures in the neonatal period, and among those developing seizures, the risk of severe long-term outcomes such as CP is three-fold (Dixon et al., 2002; Glass et al., 2009).

The variable but pervasive focal developmental delays found among and within individual participants over time, emphasize the need for early intervention among all infants with moderate HIE. Early intervention by an MDT is essential to ensure that infants and their families are supported across all developmental domains. Regular follow-ups are required as affected infants' developmental profiles appear to change over time. Early developmental intervention may contribute to lessening the burden of HIE as it positively affects infants and young children in numerous areas, including health, language, cognition, and socio-emotional functioning (Goode et al., 2011). Due to the persistent OPD among participants and their increasing communication delays with time, the need for early SLT services for infants with moderate HIE is highlighted.

Neonatal communication intervention constitutes some of the earliest services directed at neonates and their families in neonatal intensive and high care units (SASLHA, 2017). Early initiation of oral sensorimotor therapy and personalized feeding strategies during hospitalization may improve progression of swallowing and feeding skills. Additionally, neonates who are fed orally may display better developmental outcomes due to the stimulatory effects of oral feeding (Jadcherla et al., 2017).

This study used a small cohort and case series design, limiting the generalizability of findings. However, to the authors' knowledge, it is the first study to generate data on the evolution of swallowing, feeding, and developmental outcomes among infants with moderate HIE. The fact that it prospectively and consecutively recruited participants who were independently diagnosed with moderate (stage 2) HIE by a neonatologist using stringent criteria is a strength. The study additionally used a battery of valid and reliable outcome measures, including instrumental assessments, to provide a rich description of participants. Future studies may include longer developmental follow-up, as this may detect abnormal outcomes that are not evident at an early age (Van Schie et al., 2010). Additionally, larger cohorts should be used as this may increase the generalizability of study findings. The two participants with the greatest developmental delays at 12 months demonstrated the most signs and symptoms of OPD during the initial NFAS assessment. As early sucking has previously been associated with later cognitive, motor, speech, and language development, correlational designs should be considered in future. These studies should investigate the links between early swallowing and feeding and later development among infants with HIE.

5.6 Conclusion

This study provided a necessary exploration of how outcomes of infants with moderate HIE evolve over time. All participants displayed atypical outcomes throughout the study; from early swallowing and feeding abilities during hospitalization, to later developmental outcomes at six- and 12-months. Participants' developmental profiles varied from each other and changed with time. A continuous route of early intervention from the neonatal period is therefore indicated to support infants with moderate HIE

and their families. Findings of this study may be beneficial for the MDT working with this population to target lessening the burden of the condition. Future studies should use larger cohorts of participants and implement longer developmental follow-up. Additionally, correlational designs should be considered to determine the links between early swallowing and feeding and later development among infants with HIE.

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5.8 Declaration of interest

The authors report no conflict of interest.

5.9 Funding

No external funding was received for this study.

5.10 Disclosure statement

There are no competing interests to declare.

5.11 Data availability

All data are stored securely in the University of Pretoria repository. Due to the nature of the research, data cannot be made publicly available to ensure privacy of participants.

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Supplementary file 5.1

Criteria for participants to be deemed medically ready for introduction of oral feeds

	Criteria	Definition
1.	**Therapeutic Hypothermia (TH)**	The participant should have completed TH.
2.	**Respiratory stability**	The participant should display a stable respiratory rate at 35-60 breaths per minute
		The participant should not currently be on mechanical ventilation or continuous positive airway pressure (CPAP).
3.	**Cardiac stability**	The participant should display a stable heart rate at 100-160 beats per minute

Among participants who were ventilated or on CPAP, first assessment was conducted 24 hours after it was discontinued.

CHAPTER 6: DISCUSSION, IMPLICATIONS, AND CONCLUSION

6.1 Aim of the chapter

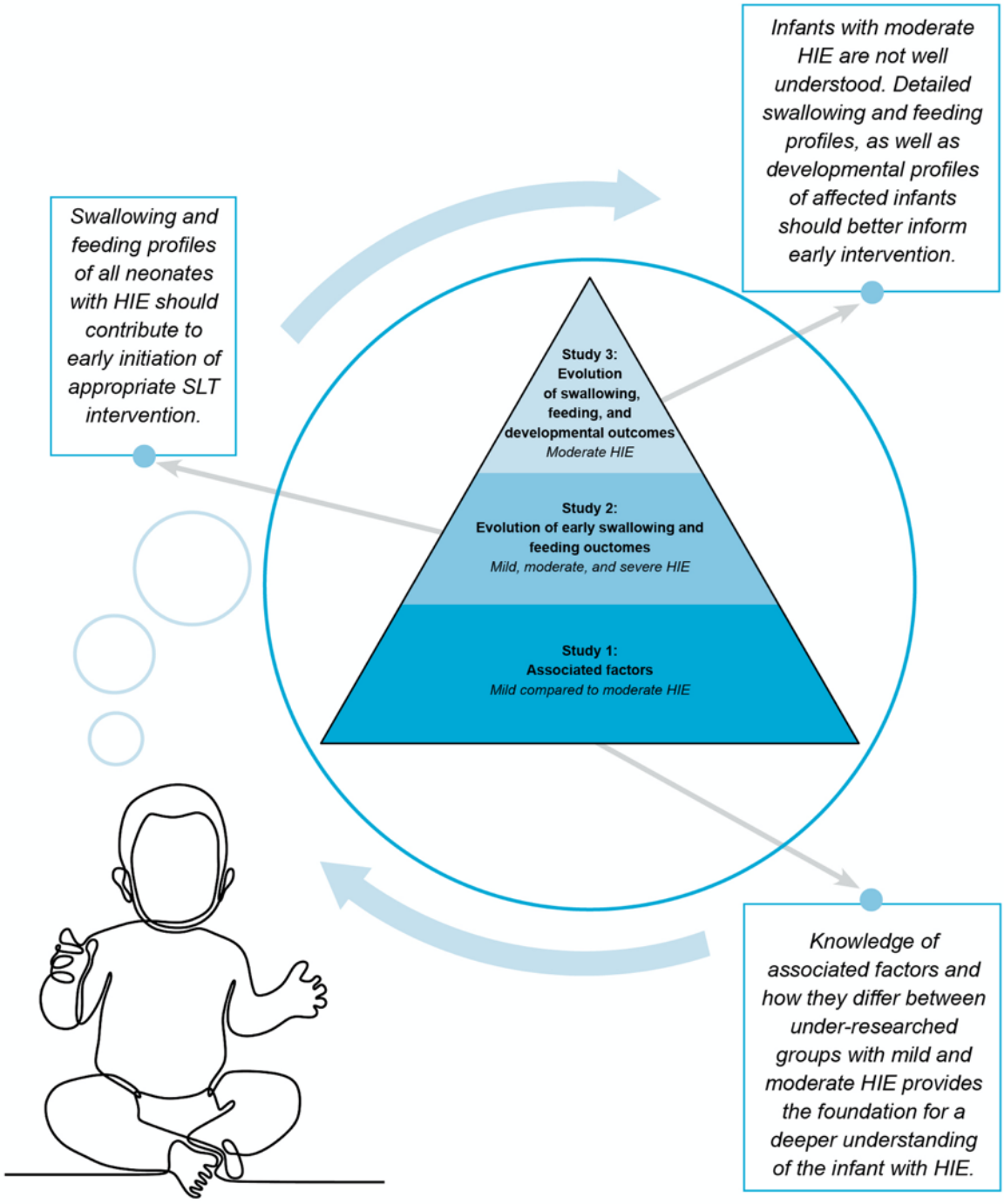
Chapter 6 presents the key findings of the research and discusses the contributions as well as clinical and theoretical implications of the three sub-studies involved. A critical evaluation of the main study is provided, and recommendations are made for future research.

6.2 Overview of research findings

Figure 6.1 gives an overview of the contributions that the three sub-studies made to answering the over-arching research question, “What are the swallowing, feeding, developmental outcomes and associated factors of infants with HIE in South Africa?” The findings of the sub-studies comprised three components associated with different aspects of infants’ functioning. The SLT who must provide effective early intervention services to infants with HIE in South Africa requires knowledge of all three parts to treat infants holistically. A key strength of the research was that it investigated different grades of HIE severity, instead of simply regarding HIE as a whole. As infants are dynamic beings with rapidly changing physiological systems, the evolution of their swallowing, feeding and developmental profiles over time was another valuable contribution of the research, considered in Studies 2 and 3.

Figure 6.1

Overview of the three sub-studies' contributions to answering the over-arching research question



Study 1 described and compared factors associated with mild and moderate HIE according to the following categories: antepartum, intrapartum, maternal, environmental, and management factors. Results of the study showed significant differences between mild and moderate groups and confirmed the value of performing various clinical measures among infants with HIE. Management factors such as

resuscitation duration, length of time to spontaneous respiration, and clinical tests such as five- and 10-minute APGAR scores differed significantly between participants with mild and moderate HIE. The admission Thompson score and highest Thompson score were significantly lower in participants with mild compared to moderate HIE, which indicates that noting the Thompson score remains important. Study findings provide the MDT with an increased understanding of the heterogeneous HIE population and indicate which infants are more likely to benefit from TH. Findings also lay the foundation for early intervention, as SLTs working in the field should be knowledgeable about factors increasing the likelihood of a disorder that affects early development or feeding, such as HIE (ASHA, 2016; SASLHA, 2017).

Study 2 described the evolution of swallowing and feeding abilities of infants with HIE during hospitalisation. The study also described the OPD associated with different grades of HIE severity and investigated the relationship between OPD severity and length of hospitalisation. Approximately two-thirds of participants presented with swallowing and feeding difficulties during the initial NFAS and VFSS. Common initial difficulties included reduced endurance, short sucking bursts, uncoordinated SSB rhythm, and abnormal breathing patterns. Significantly fewer signs and symptoms of OPD occurred at discharge NFAS compared to the initial NFAS assessment ($p=0.004$). This could be due to infants' dynamic anatomical and physiological subsystems, neurological recovery, and early intervention by the SLT during admission (Jensen et al., 2017; Lau, 2015). Nine participants (31.0%) demonstrated penetration or aspiration during VFSSs. Most aspiration events were silent (60.0%). Instrumental assessment identified pharyngeal phase dysphagia more effectively than bedside evaluation. OPD symptoms occurred most frequently for infants with severe HIE and were also the most severe for this group. Participants with mild HIE initially experienced OPD symptoms, but no further OPD symptoms were found among this group by discharge. Participants with moderate HIE displayed the most variable swallowing and feeding outcomes during the study. They had the fewest OPD symptoms during VFSSs but constituted the bulk of the participants who displayed penetration/aspiration ($n=7$; 36.8%). They also had persistent difficulties across all NFAS areas at discharge. The high proportions of participants with HIE who displayed OPD symptoms regardless of severity indicate that neonates with all grades of HIE

should be considered for early SLT intervention. Correlations between OPD severity and length of hospitalisation (p=0.052) were not significant. The early introduction of oral feeding and involvement of the SLT may have played a role in mitigating the effect of OPD severity on length of hospital stay. This should be further explored in future research using more participants.

Study 3 described the evolution of outcomes among infants with moderate HIE; from early swallowing and feeding abilities during hospitalisation, to later developmental outcomes at six and 12 months. The NFAS and VFSS were used to assess early swallowing and feeding abilities of participants. The Vineland-3 scales and RITLS were used to assess development at the ages of six and 12 months. All participants displayed atypical outcomes throughout the study. Initially during hospitalisation, all participants displayed some form of OPD and required SLT intervention. Specific signs and symptoms of OPD included short sucking bursts, reduced endurance, and poor lip closure. Two out of four participants demonstrated aspiration during VFSSs. By discharge, participants' OPD had mostly resolved, and everyone went home on oral feeds. However, two out of four participants continued to display difficulties with direct breastfeeding. By six months, focal developmental delays emerged in various areas among all participants, but communication abilities were relatively spared. By 12 months, focal developmental delays persisted among all participants, and everyone demonstrated gross motor delays. Increased communication delays were also evident. The variable but pervasive developmental delays found among and within individual participants over time emphasise the need for early intervention for all infants with moderate HIE. Regular follow-ups are required as affected infants' developmental profiles appear to change over time. The persistent OPD among participants and their communication delays that increase over time emphasise the need for early SLT services for infants with moderate HIE.

6.3 Clinical and theoretical implications

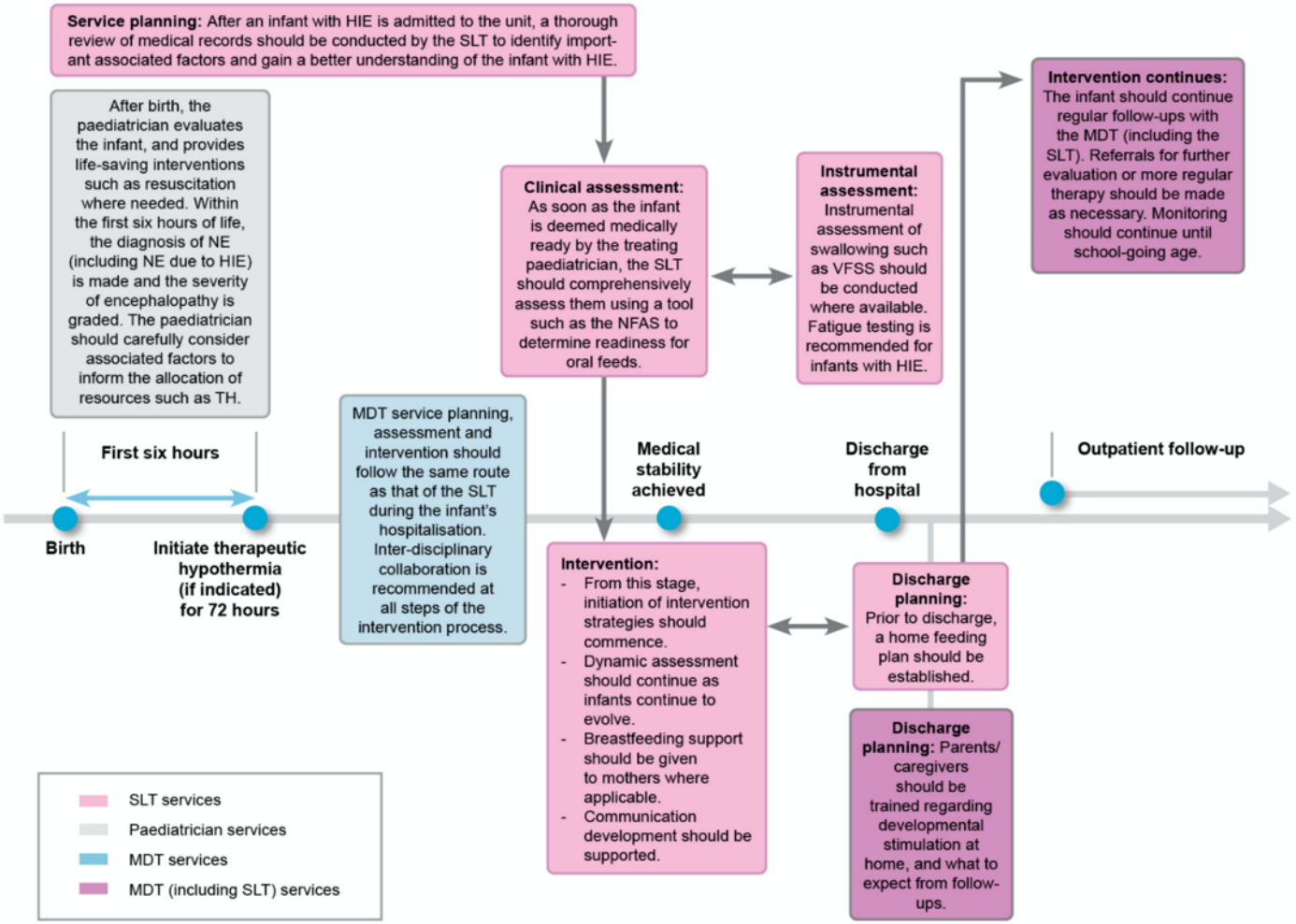
6.3.1 Clinical implications

While research regarding the efficacy of various neuro-protective strategies such as TH is ongoing, early intervention may be one of the most effective tools currently available to lessen the burden of HIE. This study proposes a continuous route of early

intervention from birth through infancy for individuals with HIE and their families (see Figure 6.2). This route is especially important in LMICs such as South Africa, where the burden of HIE is high and where resources are limited. Important clinical implications of the current research along the route of early intervention are highlighted in the discussion below and can be applied in public and private healthcare sectors. While SLT services are the focus of the discussion, services rendered by the MDT should occur in parallel with these services, as seen in Figure 6.2. Inter-disciplinary collaboration is important at all steps of the intervention process and best serves the infant and family with multiple inter-related medical and developmental issues (Arvedson et al., 2008).

Figure 6.2

The route of early intervention proposed for infants with HIE from birth to school-going age



Service planning:

Early intervention by the SLT should start soon after the infant with HIE is born, when the medical records are reviewed, and associated factors are identified. Special attention should be given to management factors and clinical test outcomes, as these differ significantly between affected infants. The findings of Study 1 may help SLTs better understand infants with HIE in their caseloads and should enable them to anticipate the severity of the infant's condition and whether they will require TH. A thorough understanding of HIE severity may assist not only with the development of treatment plans and clinical decision making, but also with parent counselling (Rasmussen et al., 2016; Pin et al., 2009). It is important to note whether TH is anticipated. Although it may be beneficial in the longer term, this treatment modality may affect the infant's early swallowing and feeding abilities due to early mother-infant separation, non-optimal states of alertness for oral feeding, and possible delayed initiation of milk feeds (Craig et al., 2020; Gale et al., 2021; Genna et al., 2013; Krüger et al., 2019).

Clinical and instrumental assessment:

- In Studies 2 and 3, oral feeds were introduced among infants with HIE when the treating paediatrician determined that they were medically ready. In Study 2, approximately two-thirds of participants presented with signs of OPD when assessed at this stage and in Study 3, all participants still had swallowing and feeding difficulties at this stage too. These findings imply that medical readiness alone is insufficient to determine oral feeding readiness among infants with HIE. Decisions regarding oral feeding readiness should follow an inter-disciplinary team approach to meet the integrated needs of the infant and their family (Arvedson, 2008; Lefton-Greif & Arvedson, 2016). The team should importantly include SLTs, who are primarily responsible for the assessment and treatment of OPD (ASHA, 2016). SLTs should assess infants with HIE as soon as medical stability is achieved to ensure safe and efficient feeding.
- Although practice regarding whether infants receive milk feeds during TH varies globally and restrictions on oral feeding during TH are common, there is compelling evidence to support the provision of milk feeds during TH in both

HICs and LMICs (Alburaki et al., 2022; Craig et al., 2020; Gale et al., 2021; Kulkarni et al., 2021). The breastfeeding abilities of neonates with HIE during TH were previously described and it appears feasible to hold stable, non-ventilated infants for 30 minutes during TH (Craig et al., 2019; Krüger et al. 2019). This implies that the SLT may become involved in the neonate's care during TH if they are medically stable. Early assessment and involvement of the SLT may mitigate some of the negative consequences associated with OPD, including malnutrition, aspiration, difficulties administering medication, reduced health status, and increased length of hospitalisation (Arvedson et al., 2020; Attrill et al., 2018; Martinez-Biarge et al., 2012). Earlier contact between mother and infant should also have a positive impact on breastfeeding, bonding, and attachment (Craig et al., 2019; WHO & UNICEF, 2018). Despite these indications, the ideal early feeding regime for infants with HIE on TH has not yet been described; hence, further research in this area is needed (Chandrasekaran et al., 2021).

- High proportions of infants with HIE experienced OPD in Study 2. Common initial difficulties included non-optimal states of alertness for oral feeds, SSB incoordination, reduced endurance, short sucking bursts, and abnormal breathing patterns. All grades of HIE severity experienced OPD. This includes infants with mild HIE who were previously thought to have similar outcomes to their typically developing peers (Goswami et al., 2020). Findings imply that all infants with HIE should receive early SLT assessment for swallowing and feeding.
- Studies 2 and 3 utilised the NFAS to describe swallowing and feeding skills among infants with HIE. The tool was developed in South Africa and has proven to be valid and reliable for OPD assessment (Viviers et al., 2017; Viviers et al., 2019). The NFAS comprehensively assesses a variety of areas that impact an infant's swallowing and feeding abilities. Although clinical assessment cannot replace gold-standard instrumental evaluations, the comprehensive NFAS may enable early and accurate diagnosis of OPD when there is a lack of instrumental evaluation available– as is often the case in resource-constrained settings (Ostrofsky & Seedat, 2016; Viviers et al., 2017).

- Limited concordance currently exists between clinical assessment findings and aspiration events during instrumental evaluation (Lefton-Greif & Arvedson, 2016). In contexts where instrumental assessments are not available, findings from Studies 2 and 3 may be useful, as they identified risk factors that contribute to penetration and aspiration in this population. Risk factors include disorganisation of the infant initially during the feed, non-optimal states of alertness, and reduced feeding endurance. As these factors may often be overlooked in the neonatal unit, findings again underscore the importance of SLT involvement in decision making regarding oral feeding readiness. The risk factors may be identified during a comprehensive clinical SLT assessment and treated to reduce the risk of penetration and aspiration.
- Where there are systems in place for a VFSS, infants should be screened intermittently during continued drinking to conduct "fatigue testing" (Weir et al., 2011). Study 2 found that numerous oral and pharyngeal phase difficulties as well as aspiration emerged during this assessment strategy.

In-patient intervention:

- Infants present with rapidly evolving anatomical and physiological subsystems that continue to mature throughout hospitalisation (Jensen et al., 2017; Krüger et al., 2019; Lau, 2015). This evolution was evident in Study 2, as infants with HIE improved in various areas related to oral feeding. For this reason, dynamic assessment of infants' swallowing and feeding is recommended during hospitalisation. This may assist with decision making about the management of infants and increase the efficacy of SLT services by ensuring that feeding recommendations are in line with the infant's current level of functioning.
- Study 2 indicated that early introduction of oral feeding and SLT intervention may have played a role in mitigating the effect of OPD severity on participants' length of hospitalisation. The following intervention strategies may be relevant for infants with HIE:
    - Cue-based feeding is an individualised feeding strategy that relies on infant-exhibited behaviour to control the timing and number of oral feeds (Lane et al., 2021; Osman et al., 2021). This may assist infants who have

non-optimal states of alertness, SSB incoordination and abnormal breathing patterns (Lefton-Greif & Arvedson, 2016).

- Oral sensorimotor therapy was provided daily to participants in Studies 2 and 3, from the day that oral feeds were introduced. Oral sensorimotor therapy consists of various active and passive oral-motor exercises, sensory stimulation techniques, and non-nutritive sucking opportunities that are commonly provided to infants to optimise their oral feeding skills (Arvedson et al., 2010a; Arvedson et al., 2010b; Rhooms et al., 2019).
- Appropriate positioning of the infant allows for sufficient head, trunk, and neck support during oral feeds (Lefton-Greif & Arvedson, 2016). Positioning is fundamental for oral feeding safety among infants with HIE, as atypical muscle tone and strength are commonly observed in infants with neurological disorders (Arvedson, 2008; Goo et al., 2018).
- Adjusted flow rates and slower pacing of feeds may assist with SSB coordination (Lefton-Greif & Arvedson, 2016; Lubbe, 2017; Settle & Francis, 2019). These compensatory strategies were found to eliminate aspiration in Studies 2 and 3.

- The above intervention techniques show promise (Gonzalez et al., 2021; Osman et al., 2020; Samane et al., 2022). However, they have not yet been studied among infants with HIE. Future research should investigate the efficacy of various OPD interventions for these infants.
- Although generally improved swallowing and feeding abilities were evident and all participants were discharged home on oral feeds, some signs of OPD persisted at this stage. These difficulties limited some participants' ability to feed directly on the breast as found in Study 3. Not being able to breastfeed directly may have various implications for infants, including increased risk of diarrhoea and infection, earlier weaning from breast milk and reduced developmental outcomes (Pang, 2017; Pang, 2020; WHO & UNICEF, 2018). The presence of breastfeeding difficulties among infants with HIE reinforces the need for breastfeeding support to be offered to affected infants and their mothers (WHO & UNICEF, 2018). Although SLTs are considered main role-players in the management of OPD that contributes to breastfeeding difficulties,

all team members working in the neonatal unit may facilitate breastfeeding among infants with HIE. This can be done by counselling mothers and families on the importance of breastfeeding, promoting skin-to-skin contact, encouraging mothers to room-in with their infant 24 hours per day, and teaching mothers to recognise and respond to infant cues (WHO & UNICEF, 2018).

- Due to the presence of persistent OPD symptoms at discharge, some participants went home with compensatory feeding strategies such as breastfeeding supplemented with cup feeding or the adjustment of flow rates. Proper identification of infants likely to experience persistent OPD should allow for home feeding plans to be developed earlier during their hospital stay; this may have significant benefits for affected infants and their families by decreasing their length of hospitalisation (Gupta et al., 2018).
- Due to the communication delays observed among infants with HIE, the need for early communication intervention in this population was highlighted in Study 3. The hospitalisation of high-risk infants may present the ideal opportunity for SLTs to intervene and ameliorate threats to typical communication development (Kritzinger & Van Rooyen, 2014). Parents/caregivers of infants with HIE should be trained to establish responsive interactions with their infants (Kritzinger & Van Rooyen, 2014; Guralnick, 2017). Due to the strong benefits of kangaroo mother care for mother-infant interaction, bonding and attachment, this type of care should also be included in early communication intervention programmes (Kostandy & Ludington-Hoe, 2019; Kritzinger & Van Rooyen, 2014). It may be especially important for infants with HIE who are treated with TH, which involves the early separation of mother and infant (Craig et al., 2020).
- Study 3 found focal delays in various developmental domains among all participants with moderate HIE at the ages of six and 12 months. It is also widely accepted that surviving infants with severe HIE are at high risk of developmental impairment and that the outcomes of infants with mild HIE are not typical (Bruckmann & Velaphi, 2015; Conway et al., 2018; Finder et al., 2020; Padayachee & Ballot, 2013). Due to the pervasive developmental delays, it is important that families of all infants with HIE be counselled regarding the importance of early intervention and what to expect from developmental follow-

ups before they go home. Discussion of early intervention programmes prior to hospital discharge should help parents and families learn how to use the resources closest to them effectively (Roberston & Perlman, 2006). This is important in South Africa, where infants may be discharged to a wide variety of geographical areas.

Outpatient intervention:

- The timing and type of follow-up provided to infants with HIE is often based on the detectability of impairments (De Vries & Jongmans, 2013; Robertson & Perlman, 2006). It is proposed that early intervention following discharge take the form of a follow-up clinic. Infants with HIE should attend the clinic at regular intervals to detect impairment, inform parents, promote early intervention, and discover changes in outcomes (Robertson & Perlman, 2006). Intervention should include caregiver coaching regarding developmental stimulation and the modelling of appropriate techniques. Relevant early intervention techniques may include establishing sensitive caregiver-infant interactions, establishing joint attention, providing stimulating materials, and scaffolding infants' behaviours (Guralnick, 2017).
- Study 3 found that focal delays occurred among infants in a variety of developmental domains and that affected developmental domains appeared to change over time. It is therefore important that various disciplines be represented at the follow-up clinic to address the current needs of infants and their families holistically, and to meet their changing needs over time. Professionals from relevant disciplines may include paediatricians, nurses, OTs, physiotherapists, audiologists, dietitians, and SLTs. Transdisciplinary teamwork is widely regarded as best practice in early intervention settings as it follows an integrative approach (Sheppard & Moran, 2022). Professionals may work outside their discipline boundaries and collaborate with each other and families to work towards common goals (Sheppard & Moran, 2022). This approach may be especially important in resource-constrained hospitals where not all professional disciplines are available. Referrals to relevant disciplines for further evaluation or more regular therapy should be made where necessary.

As infants with moderate HIE appeared to have increasing communication delays as they grew older, Study 3 highlighted the role of the SLT in early intervention teams for infants with HIE.

- Even in the absence of severe disability such as CP, childhood survivors of HIE may still be at risk of cognitive, behavioural, and memory deficits that may affect school readiness and school placement (De Vries & Jongmans, 2013). Intermittent transdisciplinary monitoring of HIE survivors is therefore recommended to continue beyond infancy until school-going age.

6.3.2 Theoretical implications

The study provides a rich description of how HIE affects multiple aspects of survivors' functioning in infancy. Specifically, it adds the following novel contributions to the current body of literature on this population:

Outcomes of specific HIE severity grades:

- The study adds to the literature on swallowing, feeding, developmental outcomes and associated factors among infants with HIE. Where previous research mostly regarded HIE in total, this study distinguished between different HIE severity grades in its investigations. This enables a better understanding of how to distinguish between different HIE groups to plan the allocation of resources such as TH and early intervention services in resource-constrained settings like South Africa.
- Study 2 added to the growing body of evidence that the outcomes of infants with mild HIE are not typical and that all grades of HIE warrant early intervention (Conway et al., 2018; Finder et al., 2020).
- Due to the high prevalence of HIE locally and the study's holistic approach to affected infants, research findings have implications for the future under-graduate training of all professionals working with infants with HIE. Shared decision making has proven to be important in the neonatal unit and early intervention requires a transdisciplinary model of teamwork. Therefore, inter-professional communication and collaboration, as well as communication with families should be taught already from an undergraduate level.

HIE distribution in South Africa:

The current research indicated how HIE severity grades are distributed in a South African setting. In contrast to global contexts, where it is estimated that 50.0% of HIE cases are mild, Studies 1 and 2 suggested that moderate categories account for greater proportions of the HIE population, which correlates with previous South African research (Bruckmann & Velaphi, 2015, Conway et al., 2018). These findings should inform service planning, as infants with moderate HIE require TH and present with variable and persistent swallowing, feeding and developmental outcomes throughout infancy. Research findings also emphasise the need for more in-depth investigations into infants with moderate HIE due to the condition's high prevalence locally.

Evolving outcomes:

Studies 2 and 3 recognised that infants are not static by incorporating the concept of evolving outcomes into their research designs. The value of this approach was confirmed when firstly, significant differences were found in the swallowing and feeding abilities of infants with HIE at discharge compared to initial assessments, and secondly, when various focal delays were found in and among participants with moderate HIE over time. This supports the use of serial assessments in research among infants with HIE to obtain a more holistic view of their functioning over time.

Instrumental assessment:

Whereas previous research on the swallowing and feeding abilities of infants with HIE relied heavily on clinical evaluation, the current research supplemented clinical findings with instrumental evaluations. Instrumental assessments such as VFSSs are the gold standard of OPD evaluation and provide dynamic assessment of the oral, pharyngeal, and oesophageal phases of swallowing (Arvedson, 2008; Audag et al., 2016). The use of instrumental assessments yielded novel information about the swallowing and feeding of infants with HIE, as well as about the unseen pharyngeal and oesophageal phases of swallowing. It also contributed to a greater understanding of penetration and aspiration among this population. Hence, these findings can greatly impact the health status of affected infants (Arvedson et al., 2020).

Thompson score:

Although this was not a specific research aim, Study 1 added to the body of evidence advocating for the use of the Thompson score among infants with HIE. This study indicated that admission and highest Thompson scores differed significantly for mild and moderate groups. Findings also corresponded with a recent study suggesting that mild modified Sarnat stages align with a Thompson score of 5-6 and that the moderate modified Sarnat stages align with a Thompson score of 7-13 rather than aligning with their original classifications (Chansarn et al., 2021; Thompson et al., 1997). This is an important theoretical contribution as the Thompson score was originally studied in a small group of participants (n=45) before the use of TH; yet it enjoys widespread popularity globally today (Mendler et al., 2018). The current findings may have implications for future studies that use the Thompson score to grade encephalopathy.

6.4 Study strengths and weaknesses

The strengths and weaknesses of the study are discussed next and provide a critical evaluation of the research.

6.4.1 Study strengths

The study generated new data regarding multiple facets of HIE in infancy. This included studying distinct HIE severity grades and adding the concept of evolving outcomes to the current body of knowledge. Investigating distinct severity grades allowed for a deeper understanding of the HIE population and highlighted the heterogeneity of infants with moderate HIE. Thus, a rich description of this group could be provided in Study 3. In noting the evolution of outcomes for participants in Studies 2 and 3, clinicians and researchers are encouraged to meet infants' needs at their current level of functioning, rather than to regard them as static entities. Research on OPD in high-risk infants such as those with HIE is scant, and few studies use instrumental assessments such as VFSSs, despite instrumental assessments being the criterion standards in the field. A strength of Studies 2 and 3, therefore, included the use of VFSSs to collect data from participants. Additional strengths of the study included the prospective nature of the research, the consecutive inclusion of participants, and a multi-disciplinary perspective incorporated in the research design.

A qualified neonatologist confirmed the gestation of all participants, established their HIE diagnoses according to stringent inclusion criteria, and confirmed their encephalopathy grading according to the modified Sarnat stages. The neonatologist also corroborated participants' Thompson scores and determined whether other diagnoses were present to exclude potential participants from the sample. Furthermore, all VFSSs were independently reviewed by two radiologists who were blinded to the NFAS results and participant characteristics.

Consistent data collection procedures were followed as all three studies were conducted at a single site with a strict management protocol for infants with HIE (including the availability of medical criteria for the introduction of oral feeds). A single researcher collected the data for all three studies and all participants for Studies 2 and 3 received daily oral sensorimotor intervention by the same SLT during hospitalisation. After discharge, all Study 3 participants continued to attend the same follow-up high-risk clinic where similar intervention techniques were followed. The researcher used a battery of valid and reliable outcome measures to describe the swallowing, feeding and development of infants with HIE holistically. These measures included the NFAS, VFSS, Vineland-3 and RITLS, all of which had been used successfully in South African studies previously.

6.4.2 Study weaknesses

The study was based on a small sample. This is a common feature of similar studies and was probably exacerbated by the stringent inclusion criteria and prospective nature of the current study. Additionally, more equally distributed HIE severity grades may have allowed for more effective comparisons between groups. Limitations of Study 1 included the fact that it did not incorporate any participants from rural areas, and incomplete information was presented on participants' environmental factors, antenatal care, and Day 7 Thompson scores. To counter the latter problem, health care professionals such as paediatricians and nurses who are often responsible for completing clinical records should be encouraged to do so thoroughly so that infants can be treated holistically.

Common resource limitations in LMICs were highlighted in the study. These included a lack of availability of early ultrasound, a lack of trained medical personnel, and poor maternal access to healthcare, which sometimes necessitated the use of sure dates or the new Ballard score to determine gestational age (Lee et al., 2017). Although a qualified neonatologist oversaw the administration of the new Ballard score, which may improve its validity, this scoring system may over- or underestimate gestational age and may therefore affect interpretations of swallowing and feeding (Lee et al., 2017). Similarly, VFSSs could not be conducted on the same day as NFAS assessments in Studies 2 and 3 due to challenges surrounding the availability of screening equipment, staff shortages, and high patient loads which are commonly found in the South African context (Ostrofsky & Seedat, 2016). Neuroimaging tools such as MRI are costly and were not available for all participants. The relationship between patterns of brain injury and OPD could therefore not be determined.

Although this was outside the researcher's control, it is important to note that the way in which infants with different grades of HIE are managed medically may independently impact swallowing and feeding. This may include intubation and ventilation which are associated with increased risk for OPD (Tutor, 2022). Additionally, infants with mild HIE do not usually receive TH. As restrictions on oral feeding are often implemented during TH, this group may subsequently be introduced to oral feeds sooner than their moderate and severe counterparts, possibly having positive effects on their swallowing and feeding abilities (Craig et al., 2020; Goswami et al., 2020).

6.5 Future perspectives

It is recommended that more research be conducted to determine which populations will benefit most from TH (Ballot et al., 2021). Additionally, it is well-known that the ideal feeding regime for infants on TH should still be established (Chandrasekaran et al., 2021). The early introduction of oral feeds for medically stable infants with HIE on TH should be investigated through stringent experimental research. Such research should include an inter-disciplinary perspective (importantly including SLT input) to determine the safety and efficiency of participants' oral feeding. Early introduction of oral feeds may improve the swallowing and feeding ability of affected infants, reduce

the length of their hospitalisation, and improve their developmental outcomes due to the stimulatory effects of oral feeding (Jadcherla et al., 2017). Intervention techniques such as cue-based feeding and oral sensorimotor therapy for OPD among infants with HIE should also be investigated. Studies should focus on the potential for SLT intervention to mitigate the effect of OPD severity and reduce the length of hospitalisation.

Longitudinal studies investigating the swallowing, feeding, and developmental outcomes of infants with HIE are also still required. Future research should aim to use larger sample sizes and a more equal distribution of HIE severity grades to improve comparisons between groups and increase the generalisability of study findings. Studies should follow up on individuals with HIE into childhood to detect outcomes that are not present at an earlier age (Van Schie et al., 2010). Early sucking has hitherto been associated with later cognitive, motor, speech, and language development (Mizuno & Ueda, 2005; Poore & Barlow, 2012). Correlational designs to investigate the link between early swallowing and feeding abilities and later development among infants with HIE should therefore also be considered. Where neuroimaging is available, the link between the distinct patterns of brain injury associated with HIE and the presence of OPD among affected infants should also still be investigated.

6.6 Conclusion

This study provided the first known description of the evolution of swallowing, feeding, developmental outcomes and associated factors among infants with HIE. This is particularly relevant in South Africa, where the prevalence of HIE is high. A battery of valid and reliable outcome measures, including instrumental evaluation of OPD, was used to provide rich descriptions of infants with HIE according to different severity grades. The study focused on the under-researched moderate HIE group whose outcomes are often difficult to predict. A major contribution of the study includes a proposed route of early intervention for infants with HIE, from birth to school-going age. In South Africa, where uncertainty exists about available neuro-protective strategies such as TH, early intervention may be the most effective tool to ease the burden of the condition. Although SLT services are highlighted in the study, research findings may be of interest to all members of the multi-disciplinary team.

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APPENDICES

APPENDIX A – Checklist of biological and environmental factors

APPENDIX B – Neonatal Feeding Assessment Scale (NFAS)

APPENDIX C – Video fluoroscopic swallow study data collection sheet

APPENDIX D – Vineland-3 Comprehensive Interview Form

APPENDIX E – The Rossetti Infant Toddler Language Scale (RITLS) test form

APPENDIX F – Informed consent forms

APPENDIX G – Approval to conduct research at the hospital

APPENDIX H – Approval from the Research Ethics Committee

APPENDIX I – Proof of acceptance: South African Journal of Child Health

APPENDIX J – Proof of acceptance: International Journal of Speech-Language Pathology

APPENDIX K – Proof of submission: Early Child Development and Care

APPENDIX A

Checklist of biological and environmental factors

For office use

Participant number:	
Date of birth: (dd/mm/yy)	
Chronological age: (days)	

Factors:	**Specification:**	
Biological information		
Gender	Male	1
	Female	2
Gestational age (weeks)		
Birth weight (grams)		
Growth*	SGA	1
	AGA	2
	LGA	3
Apgar scores (/10)	1 min	
	5 mins	
	10 mins	
Parity		
Antenatal visits	Yes	1
	No	2
Mode of delivery	NVD**	1
	Assisted	2
	Caesarean section	3
Family history of disability (including seizures or neurological disorders)	No	1
	Yes	2
	Specify:	
Birth complications	PROM***	1
	Meconium stained amniotic fluid	2
	Nuchal cord	4
	Failed vacuum delivery	5
	Foetal distress	6
	Prolonged 2nd stage	7
	Sentinel events**** Specify:	8
	Other complications Specify:	9

V1 [ ][ ][ ] 1-3

V2 [ ][ ][ ] 4-9
[ ][ ][ ]

V3 [ ][ ] 10-11

V4 [ ] 12

V5 [ ][ ] 13-14

V6 [ ][ ] 15-18
[ ][ ]

V7 [ ] 19

V8 [ ][ ][ ] 20-22

V9 [ ] 23

V10 [ ] 24

V11 [ ] 25

V12 [ ] 26

V13 [ ][ ][ ] 27-35
[ ][ ][ ]
[ ][ ][ ]

Cardiotocography (CTG) records of foetal heart rate tracings *(ACOG, 2009)*	Category I (Normal)	1	V14		36
	Category II (Indeterminate)	2			
	Category III (Abnormal)	3			
Arterial blood gas/ arterial cord gas 1-hour post birth	pH		V15		37
	Base deficit (mmol/L)		V16		38
Resuscitation type required *(Wyckoff et al., 2015)*	None	1	V17		39-42
	Initial stabilization	2			
	Ventilation/ oxygenation	3			
	Chest compressions	4			
	Administration of adrenaline	5			
Resuscitation time required (minutes)			V18		43-44
Time to spontaneous respiration (minutes)			V19		45-46
Severity of hypoxic ischaemic encephalopathy (HIE) based on modified Sarnat stages	Mild	1	V20		47
	Moderate	2			
	Severe	3			
Thompson score	On admission		V21		48
	Highest score		V22		49
	Score on day seven of life		V23		50
Maternal factors					
Age (years)			V24		51-52
HIV status	Negative	1	V25		53
	Positive	2			
	Unknown	3			
Use of ARVs	No	1	V26		54
	Yes	2			
	Specify type:				
Use of other medication	No	1	V27		55
	Yes	2			
	Specify type:				
Maternal disease*****	Absent	1	V28		56
	Present	2			
	Specify type:				
Maternal infection******	Absent	1	V29		57
	Present	2			
	Specify type:				
Maternal fever > 38°C	No	1	V30		58
	Yes	2			

Short stature	No		1	V31	59
	Yes		2		
Cephalopelvic disproportion	No		1	V32	60
	Yes		2		
Smoking/alcohol consumption	None		1	V33	61-62
	Smoking		2		
	Alcohol		3		
Environmental information					
Parental marital status	Mother	Single	1	V34	63
		Married	2		
	Father	Single	1	V35	64
		Married	2		
Parental employment status	Mother	Employed	1	V36	65
		Unemployed	2		
	Father	Employed	1	V37	66
		Unemployed	2		
Place of labour	Inborn		1	V38	67
	Outborn (including born before arrival)		2		
Time of delivery (hh/mm)				V39	68-71
Lives in (area)	Urban		1	V40	72
	Peri-urban		2		
	Rural		3		
Other housing information:	Specify:				
Additional information:					

* Growth: SGA (Small for Gestational Age), AGA (Appropriate for Gestational Age), LGA (Large for Gestational Age)
** NVD (Normal Vaginal Delivery)
*** PROM (Premature Rupture of Membranes)
****Sentinel events may include uterine rupture, placental abruption, cord prolapse, foetal exsanguination or maternal collapse
*****Maternal disease may include but is not limited to eclampsia, pre-eclampsia, thyroid disease, HELLP syndrome, diabetes, chronic hypertension or cardiac disease
******Maternal infection may include but is not limited to chorioamnionitis, vaginitis or urinary tract infection

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APPENDIX B

NEONATAL FEEDING ASSESSMENT SCALE: 32 WEEKS – 4 MONTHS POST TERM (IFAS)

(Compiled by Mari Viviers, 2016)

Patient name:	Date of birth:
Gestational age at birth:	Current adjusted age:
Birth weight:	Current weight:
Diagnosis:	
Date of assessment:	
Examiner:	

SECTION A: FUNCTIONING OF PHYSIOLOGICAL SUBSYSTEMS (Dieckman, Brownstein & Gausche-Hill, 2000; Henning, 2002; Hodgman, Hoppenbrouwers, & Cabal, 1993)		
A.1. Observation of heart rate		
Instructions: Observe the infant's heart rate if the infant is attached to a cardiac monitor during feeding, if not proceed to A.2. Complete the relevant items for the infant's current adjusted age.		
A.1a Infant attached to cardiac monitor	YES	NO
32 – 39 weeks		
A.1.1 Normal heart rate (120 – 170 beats per minute)	YES	NO
A.1.1.1 Tachycardia (>170 beats per minute)	YES	NO
A.1.1.2 Bradycardia (<20 beats per minute)	YES	NO
40 weeks – 2 months 3 weeks post term		
A.1.2.1 Normal heart rate (100 – 150 beats per minute)	YES	NO
A.1.2.2 Tachycardia (>150 beats per minute)	YES	NO
A.1.2.3 Bradycardia (<100 beats per minute)	YES	NO
3 – 4 months post term		
A.1.3.1 Normal heart rate (90 – 120 beats per minute)	YES	NO
A.1.3.2 Tachycardia (>120 beats per minute)	YES	NO
A.1.3.3 Bradycardia (<90 beats per minute)	YES	NO
SCORE SECTION A.1: If bradycardia/tachycardia present indicate YES for the likelihood of dysphagia to be present		
OUTCOME SECTION A.1: Dysphagia likely to be present	YES	NO

A.2. Observation of Respiratory function			
Instructions: If the infant is attached to a respiratory monitor ***during feeding*** complete the items relevant to current (adjusted) age, as well as subsection A.2c. If the infant is *not attached to a monitor*, complete only subsection A.2c.			
A.2a Infant attached to respiratory monitor	YES	NO	
32 – 39 weeks			
A.2.1 Normal breathing rate (40 – 70 breaths per minute)	YES	NO	
A.2.1.1 Tachyapnoea (>70 breaths per minute)	YES	NO	
A.2.1.2 Apnoea (absent breathing efforts for > 15 seconds)	YES	NO	
40 weeks – 2 months 3 weeks post term			
A.2.2 Normal breathing rate (35 – 55 breaths per minute)	YES	NO	
A.2.2.1 Tachyapnoea (>45 breaths per minute)	YES	NO	
A.2.2.2 Apnoea (absent breathing efforts for > 15 seconds)	YES	NO	
3 – 4 months post term			
A.2.3 Normal breathing rate (35 – 45 breaths per minute)	YES	NO	
A.2.3.1 Tachyapnoea (>45 breaths per minute)	YES	NO	
A.2.3.2 Apnoea (absent breathing efforts for > 15 seconds)	YES	NO	
A.2c Signs of abnormal respiratory patterns during feeding			
A.2.4.1 Laboured/noisy breathing	YES	NO	
A.2.4.2 Obligatory mouth breather	YES	NO	
A.2.4.3 Non-obligatory mouth breather	YES	NO	
A.2.4.4 Stridor	YES	NO	
A.2.4.5 Rib cage flaring	YES	NO	
A.2.4.6 Sternum depression/retraction	YES	NO	
A.2.4.7 Irregular/shallow breathing	YES	NO	
A.2.4.8 Intercostal retractions (related to Respiratory Distress Syndrome)	YES	NO	
SCORE SECTION A.2: If tachyapnoea/apnoea present in items A.2.1-A.2.3.2, select YES for the likelihood of dysphagia being present. If items A.2.1-A.2.3.2 not scored, select NOT APPLICABLE (N/A). If YES was selected for any item/s in subsection A.2c, indicate YES for the likelihood of dysphagia being present.			
OUTCOME SECTION A.2.1-A.2.3.2: Dysphagia likely to be present	YES	NO	N/A
OUTCOME SECTION A.2c: Dysphagia likely to be present	YES	NO	
COMBINED OUTCOME SECTION A : If one YES obtained in a sub-section, select YES for likelihood of dysphagia being present.			
OUTCOME SECTION A: Dysphagia likely to be present	YES	NO	

SECTION B: STATE OF ALERTNESS DURING FEEDING

(Als, 1982; Brazelton, 1973; Nugent, Keefer, Minear, Jonhson & Blanchard, 2007; Prechtl & Beintema, 1964; Wolff, 1959)		
Instructions: Observe the infant's state of alertness during feeding. Select YES only once in this section, and score the remaining items NO.		
B.1.1 Stage 1 – Deep sleep	YES	NO
B.1.2 Stage 2 – Light sleep	YES	NO
B.1.3 Stage 3 - Drowsy	YES	NO
B.1.4. Stage 4 – Quiet alert	YES	NO
B.1.5 Stage 5 – Active alert	YES	NO
B.1.6 Stage 6 – Alert agitated	YES	NO
B.1.7 Stage 7 - Crying	YES	NO
SCORE SECTION B: Optimal state of alertness for feeding is indicated by a YES for either item B.1.4 or B.1.5. Items B.1.1-B.1.3 and B.1.6-B.1.7 reflects non-optimal states of alertness for feeding. A non-optimal state of alertness could likely contribute to a feeding problem.		
OUTCOME SECTION B: Non-optimal state of alertness during feeding	YES	NO
COMBINED SCORE FOR SECTION A & B:		
Section A	YES	NO
Section B	YES	NO
SCORE OBTAINED SECTION A & B OVERALL: If both sections obtained YES responses, indicate YES for the likelihood of dysphagia being present.		
OVERALL OUTCOME SECTION A & B: Dysphagia likely to be present	YES	NO

SECTION C: STRESS CUES DURING FEEDING (Als, 1982; Brazelton & Nugent, 1995; Hall, 2002; Karl, 2004)		
Instructions: Observe the infant during feeding and note down the stress cues the infant displays. Circle either YES or NO for all items in Section C.		
State related stress cues		
C.1.1 Staring	YES	NO
C.1.2 Panicked, worried or dull look	YES	NO
C.1.3 Silent/weak cry	YES	NO
C.1.4 Dozing	YES	NO
C.1.5 Startle	YES	NO
Motor related stress cues		
C.1.6 Twitching limbs	YES	NO
C.1.7 Hypextension of limbs	YES	NO
C.1.8 Fluctuating tone	YES	NO
C.1.9 Increased stiffness (arching/finger splays/fisting)	YES	NO
C.1.10 Excessive diffuse movements	YES	NO
Mild autonomic stress cues		

C.1.11 Gasping	YES	NO
C.1.12 Sighing	YES	NO
C.1.13 Sneeze	YES	NO
C.1.14 Sweating	YES	NO
C.1.15 Hiccup	YES	NO
C.1.16 Trembling jaw/limbs	YES	NO
Moderate autonomic stress cues		
C.1.17 Startling	YES	NO
C.1.18 Straining/Squirming	YES	NO
C.1.19 Averting gaze	YES	NO
C.1.20 Facial grimacing	YES	NO
C.1.21 Increased floppiness	YES	NO
C.1.22 Increased stiffness	YES	NO
C.1.23 Falling asleep during feeding	YES	NO
C.1.24 Crying during feeding	YES	NO
Severe autonomic stress cues		
C.1.25 Coughing	YES	NO
C.1.26 Gagging	YES	NO
C.1.27 Skin colour changes	YES	NO
C.1.28 Apnoea	YES	NO
C.1.29 Irregular respiration	YES	NO
C.1.30 Spitting up	YES	NO
C.1.31 Arching back	YES	NO
C.1.32 Breath holding	YES	NO
C.1.33 Bradycardia	YES	NO
C.1.34 Continued excessive crying	YES	NO
C.1.35 Choking	YES	NO
SCORE SECTION C: If YES selected for 3 or more items, then indicate YES for the likelihood of dysphagia being present.		
OUTCOME SECTION C: Dysphagia likely to be present	YES	NO

SECTION D: GENERAL MOVEMENT & MUSCLE TONE SCREENING (Clark, 2009; Van Haastert et al., 2006)		
Instructions: Observe the infant's muscle tone at rest and during handling for feeding. Complete all items in the section relevant to the infant's current (adjusted) age.		
32 – 39 weeks AT REST		
D.1.1 Normal resting posture (full flexion of all limbs not yet present, relatively adequate muscle tone/flexion in lower limbs; partial flexion in upper limbs)	YES	NO

D.1.2 Extremely floppy/extended resting posture (all limbs)	YES	NO
D.1.3 Extremely stiff resting posture (arched head & neck/arched back)	YES	NO
32 – 39 weeks DURING FEEDING		
D.1.4 Normal resting posture (full flexion of all limbs not yet present, relatively adequate muscle tone/flexion in lower limbs; partial flexion in upper limbs)	YES	NO
D.1.5 Extremely floppy/extended resting posture (all limbs / froggy position)	YES	NO
D.1.6 Extremely stiff resting posture (arched head & neck/arched back)	YES	NO
40 weeks term – 4 months post term AT REST		
D.2.1 Normal fully flexed resting posture of all limbs	YES	NO
D.2.2 Extended resting posture of all limbs (froggy position)	YES	NO
D.2.3 Stiff resting posture (arched head & neck/arched back)	YES	NO
40 weeks term – 4 months post term DURING FEEDING		
D.2.4 Normal fully flexed posture of all limbs maintained at midline	YES	NO
D.2.5 Floppy/extension of limbs/difficult to maintain midline flexion	YES	NO
D.2.6 Extremely stiff (arched head & neck – hyperextension pattern/arched back – shoulder retraction or elevation pattern)	YES	NO
SCORE SECTION D: If normal posture is indicated at rest and during feeding, then dysphagia is not likely to be present. Then select NO. If abnormal posture is noted at rest and during feeding or only during feeding, then dysphagia is likely to be present. Then select YES.		
OUTCOME SECTION D: Dysphagia likely to be present	YES	NO

SECTION E: ORAL PERIPHERAL EVALUATION (Arvedson & Brodsky, 2002; Chapman Barr, 2001; Hall, 2001; Swigert, 2010)			
E.1 Oral reactions			
Instructions: The oral reactions should preferably be elicited BEFORE feeding if the infant presents with relatively adequate state regulation and appears alert.			
Permanent reactions	**Stimulus & Appropriate expected response**	**Present**	**Absent**
E.1.1 Transverse tongue reaction	Stroke sides of tongue. Response: Tongue moves to the side that has been stimulated.	YES	NO
E.1.2.Sucking	Stroke tongue or touch hard palate. Response: Tongue should push little finger up against hard palate with good strength.	YES	NO
Temporary reactions	**Stimulus & Appropriate expected response**	**Present**	**Absent**
E.1.3 Phasic bite	Stimulate the gums by stroking the upper/lower gums. Response: Rapid rhythmical up and down movement of the jaw.	YES	NO
E.1.4 Tongue protrusion	Touch tongue tip. Response: Anterior tongue protrusion beyond the border of the lips.	YES	NO

E.1.5 Rooting reaction	Stroke cheek or corner of mouth. Response: Head move toward side of stimulus and mouth opens. {Rooting reaction starts to integrate (diminish) by 3 0 6 months of age.}	YES	NO
E.1.6 Santmyer reflex	Administer a puff of air to the perioral area in the face of an alert non-crying infant. Response: Infant should swallow	YES	NO
E.1.7 Palmomental (Babkin) reflex	Bilateral pressure to the palms. Response: Mandibular depression & suckling movements of the tongue.	YES	NO
SCORES SECTION E.1: If the sucking reflex is absent dysphagia is likely to be present. Select YES.			
SECTION E.1: Dysphagia likely to be present		YES	NO

E.2 – E.5 Oral structure & function		
Instructions: Observe oral structure and function AT REST or where indicated DURING FEEDING.		
E.2 LIPS		
E.2.1 Symmetrical appearance	YES	NO
E.2.2 Lips touch when gums are together	YES	NO
E.2.3 Closure maintained *at rest*	YES	NO
E.2.4 Closure maintained around nipple *during feeding*	YES	NO
E.2.5 Upper lip tone at rest		
E.2.5.1 Normal appearance	YES	NO
E.2.5.2 Stiff / retracted	YES	NO
E.2.5.3 Floppy / inactive	YES	NO
E.2.6 Upper lip tone during feeding		
E.2.6.1 Normal appearance	YES	NO
E.2.6.2 Stiff / retracted	YES	NO
E.2.6.3 Floppy / inactive	YES	NO
E.2.7 Lower lip tone at rest		
E.2.7.1 Normal appearance	YES	NO
E.2.7.2 Stiff / curled in towards lower gum	YES	NO
E.2.7.3 Sagging	YES	NO
E.2.8 Lower lip tone during feeding		
E.2.8.1 Normal supportive appearance	YES	NO
E.2.8.2 Stiff / curled in towards lower gum	YES	NO
E.2.8.3 Sagging	YES	NO
E.2.9 Structural deviations of the lips		
E.2.9.1 Bilateral cleft lip	YES	NO

E.2.9.2 Unilateral cleft lip	YES	NO
E.2.9.3 Other (i.e lip pits etc.)	YES	NO
E.3 CHEEKS		
E.3.1 Age appropriately absent fat pads (32 – 39 weeks old infant) OR Fat pads present (40 weeks – 4 month old infant)	YES	NO
E.3.2 Stiffness during feeding	YES	NO
E.3.3 Inactivity / sagging during feeding	YES	NO
E.4 PALATE		
E.4.1 Intact hard palate	YES	NO
E.4.2 Cleft of the hard palate	YES	NO
E.4.3 Intact soft palate	YES	NO
E.4.4 Cleft of the soft palate (incl submucous cleft)	YES	NO
E.4.5 Intact uvula	YES	NO
E.4.6 Bifid uvula	YES	NO
E.5 TONGUE		
E.5.1 Normal size *at rest*	YES	NO
E.5.2 Macroglossia	YES	NO
E.5.3 Microglossia	YES	NO
E.5.4 Ankyloglossia	YES	NO
E.5.5 Normal muscle tone *at rest*	YES	NO
E.5.6. Protruded / thick appearance *at rest*	YES	NO
E.5.7 Retracted / bunched appearance *at rest*	YES	NO
E.5.8 Normal muscle tone / movement *during feeding*	YES	NO
E.5.9 Inactive / protruded tongue during feeding	YES	NO
E.5.10 Stiff / retracted tongue during feeding	YES	NO
E.5.11 Structural deviations of the tongue	YES	NO
E.5.12 Abnormal movement patterns		
E.5.12.1 Tongue thrust	YES	NO
E.5.12.2 Limited movement	YES	NO
E.6 JAW		
E.6.1 Normal appearance of the jaw	YES	NO
E.6.2 Micrognathia	YES	NO
E.6.3 Maxillary hypoplasia	YES	NO
E.6.4 Prognathism (protruded)	YES	NO
E.6.5 Retrognathism (retracted)	YES	NO
E.6.6 Abnormal movement patterns		
E.6.6.1 Jaw clenching	YES	NO
E.6.6.2 Jaw thrusting	YES	NO

SCORE SECTION E.2-E.6: If YES was selected to indicate any structural or physiological abnormality likely to impact on any of the stages of swallowing, select YES for the likelihood of dysphagia being present.		
OUTCOME SECTION E.2-E.6: Dysphagia likely to be present	YES	NO

E.7 Observation of cranial nerve function to indicate symptoms of possible dysfunction (Chapman Barr, 2001; Hall, 2001; Henning, 2002)		
Instructions: This section is to be completed based on the observation of oral structure and function "at rest" or "during feeding"(*). Item E.7.1.4 should be scored based on the elicitation of the rooting response in item E.1.5.		
E.7.1 CN V Trigeminal nerve dysfunction		
E.7.1.1 Reduced mandibular movements*	YES	NO
E.7.1.2 Failure to initiate sucking*	YES	NO
E.7.1.3 Weak lip seal*	YES	NO
E.7.1.4 Asymmetric reaction during rooting response	YES	NO
E.7.2 CN VII Facial nerve dysfunction		
E.7.2.1 Facial asymmetry	YES	NO
E.7.2.2 Reduced facial movements (at rest/when crying)	YES	NO
E.7.2.3 Weak lip seal*	YES	NO
E.7.3 CN IX Glossopharyngeal nerve dysfunction		
E.7.3.1 Failure to initiate sucking*	YES	NO
E.7.3.2 Suspected delayed swallow response*	YES	NO
E.7.3.3 Nasopharyngeal penetration (unrelated to structural deficit of hard/soft palate)*	YES	NO
E.7.4 CN X Vagus nerve dysfunction		
E.7.4.1 Absent voicing when crying (suspected vocal fold paralysis)	YES	NO
E.7.4.2 Weak cry (suspected vocal fold paresis)	YES	NO
E.7.4.3 Hypernasal cry	YES	NO
E.7.4.5 Suspected delayed swallow response*	YES	NO
E.7.4.6 Weak/poor sucking*	YES	NO
E.7.5 CN XII Hypoglossal nerve dysfunction		
E.7.5.1 Reduced tongue movements*	YES	NO
E.7.5.2 Weak/poor sucking*	YES	NO
SCORE SECTION E.7: If YES selected for any item in this section, indicate YES for the likelihood of dysphagia being present.		
OUTCOME SECTION E.7: Dysphagia likely to be present	YES	NO
OVERALL OUTCOME SECTION E:		
E.1	YES	NO
E.2 – E.6	YES	NO

E.7	YES	NO
SCORE OBTAINED SECTION E OVERALL: If a score of 2 OR more YES responses are obtained indicate YES for the likelihood of dysphagia being present.		
OUTCOME SECTION E OVERALL: Dysphagia likely to be present	YES	NO

SECTION F: CLINICAL FEEDING & SWALLOWING EVALUATION (Arvedson & Brodsky, 2002; Darrow & Harley, 1998; Rudolph & Thompson Link, 2002; Swigert, 2010)		
Instructions: Only complete the sections relevant to the infant's current (adjusted) age for section F.1.1 – F.1.4.		
F.1.1 – F.1.2 Non-nutritive sucking (NNS) skills		
F.1.1 NNS characteristics of the preterm infant (32 – 39 weeks)		
Instructions: Use a pacifier/your little finger to stimulate a suckling response. For item F.1.1.1 the approximate number of suckles before a pause occurs, should be counted.		
F.1.1.1 Burst cycles of approximately < 10 sucks before pausing	YES(0)	NO (1)
F.1.1.2 Adequate endurance throughout the feeding session	YES(0)	NO (1)
F.1.1.3 Adequate lip closure around finger/pacifier	YES(0)	NO (1)
F.1.1.4 Attempted tongue cupping/grooving against finger/pacifier	YES(0)	NO (1)
F.1.1.5 Anterior-posterior tongue movement present during suckling	YES(0)	NO (1)
F.1.1.6 Adequate sucking strength	YES(0)	NO (1)
F.1.1.7 Coordinated suck-swallow-breathe rhythm	YES(0)	NO (1)
F.1.1.8 Normal breathing pattern with no catch-up breathing	YES(0)	NO (1)
SCORE OBTAINED SECTION F.1.1.: If a score of 2 or more is obtained, indicate YES for the likelihood of dysphagia being present.		
OUTCOME SECTION F.1.1: Dysphagia likely to be present	YES	NO
F.1.2 NNS characteristic of the term (40 weeks) to four month post term infant		
Instructions: Use a pacifier/your little finger to stimulate a suckling response. For item F.1.2.1 the approximate number of sucks before a pause occurs, should be counted.		
F.1.2.1 Burst cycles of approximately 10 - 20 sucks before pausing	YES(0)	NO (1)
F.1.2.2 Adequate endurance throughout the feeding session	YES(0)	NO (1)
F.1.2.3 Adequate lip closure around finger/pacifier	YES(0)	NO (1)
F.1.2.4 Attempted tongue cupping/grooving against finger/pacifier	YES(0)	NO (1)
F.1.2.5 Anterior-posterior tongue movement present during suckling	YES(0)	NO (1)
F.1.2.6 Adequate sucking strength	YES(0)	NO (1)
F.1.2.7 Coordinate suck-swallow-breathe rhythm	YES(0)	NO (1)
F.1.2.8 Normal breathing pattern with no catch-up breathing	YES(0)	NO (1)
SCORE OBTAINED SECTION F.1.2: If a score of 2 or more is obtained, indicate YES for the likelihood of dysphagia being present.		
OUTCOME SECTION F.1.2: Dysphagia likely to be present	YES	NO
F.1.3 – F.1.4 Nutritive sucking (NS) skills		

F.1.3 NS characteristics of the preterm infant (32 – 39 weeks)		
Instructions: Ask the mother/caregiver/nurse to feed the infant. Observe the infant for the duration of the feeding session.		
F.1.3.1 Burst cycle of approximately < 10 sucks before pausing	YES(0)	NO (1)
F.1.3.2 Adequate endurance throughout the feeding session	YES(0)	NO (1)
F.1.3.3 Adequate lip closure/seal on nipple/bottle teat	YES(0)	NO (1)
F.1.3.4 Timely initiation of sucking	YES(0)	NO (1)
F.1.3.5 Adequate sucking strength	YES(0)	NO (1)
F.1.3.6 Coordinated suck-swallow-breathe rhythm	YES(0)	NO (1)
F.1.3.7 Clinical signs of possible aspiration during feeding:		
F.1.3.7.1 Gurgling	YES(1)	NO (0)
F.1.3.7.2 Coughing	YES(1)	NO (0)
F.1.3.7.3 Choking	YES(1)	NO (0)
F.1.3.7.4 Teary/watery eyes	YES(1)	NO (0)
F.1.3.8 Avoidance behaviour during feeding:		
F.1.3.8.1 Tongue thrust	YES(1)	NO (0)
F.1.3.8.2 Jaw clenching	YES(1)	NO (0)
F.1.3.8.3 Jaw thrusting	YES(1)	NO (0)
F.1.3.8.4 Lip retraction on presentation of nipple/bottle teat/small cup/syringe	YES(1)	NO (0)
F.1.3.8.5 Arching of the back & neck (extension pattern)	YES(1)	NO (0)
F.1.3.8.6 Turning the head away from the breast/bottle/cup/syringe	YES(1)	NO (0)
SCORE OBTAINED SECTION F.1.3: If a score of 2 or more is obtained, indicate YES for the likelihood of dysphagia being present.		
OUTCOME SECTION F.1.3: Dysphagia likely to be present	YES	NO
F.1.4 NS characteristics of the term (40 weeks) to 4 month post term infant		
Instructions: Ask the mother/caregiver/nurse to feed the infant. Observe the infant for the duration of the feeding session		
F.1.4.1 Burst cycle of approximately 10 - 20 sucks before pausing	YES(0)	NO (1)
F.1.4.2 Adequate endurance throughout the feeding session	YES(0)	NO (1)
F.1.4.3 Adequate lip closure/seal on nipple/bottle teat	YES(0)	NO (1)
F.1.4.4 Timely initiation of sucking	YES(0)	NO (1)
F.1.4.5 Adequate sucking strength	YES(0)	NO (1)
F.1.4.6 Coordinated suck-swallow-breathe rhythm	YES(0)	NO (1)
F.1.4.7 Clinical signs of possible aspiration during feeding:		
F.1.4.7.1 Gurgling	YES(1)	NO (0)
F.1.4.7.2 Coughing	YES(1)	NO (0)
F.1.4.7.3 Choking	YES(1)	NO (0)
F.1.4.7.4 Teary/watery eyes	YES(1)	NO (0)

F.1.4.8 Avoidance behaviour during feeding:		
F.1.4.8.1 Tongue thrust	YES(1)	NO (0)
F.1.4.8.2 Jaw clenching	YES(1)	NO (0)
F.1.4.8.3 Jaw thrusting	YES(1)	NO (0)
F.1.4.8.4 Lip retraction on presentation of nipple/bottle teat/small cup/syringe	YES(1)	NO (0)
F.1.4.8.5 Arching of the back & neck (extension pattern)	YES(1)	NO (0)
F.1.4.8.6 Turning the head away from the breast/bottle/cup/syringe	YES(1)	NO (0)
SCORE OBTAINED SECTION F.1.4: If a score of 2 or more is obtained, indicate YES for the likelihood of dysphagia being present.		
OUTCOME SECTION F.1.4: Dysphagia likely to be present	YES	NO
F.2 Behavioural response to feeding method & NNS stimulation		
Instructions: Observe the infant's acceptance of pacifier/little finger during NNS stimulation as well as during feeding.		
F.2.1 Infant accepts nipple/bottle teat/syringe/small medicine cup	YES(0)	NO (1)
F.2.2 Infant accepts pacifier/finger	YES(0)	NO (1)
F.2.3 Negative behavioural responses during feeding or NNS stimulation		
F.2.3.1Refusal by turning the head away from source of feeding or pacifier/finger	YES(1)	NO (0)
F.2.3.2 Arching or the back and neck (extension pattern) to avoid feeding	YES(1)	NO (0)
F.2.3.3 Emesis after feeding	YES(1)	NO (0)
SCORE OBTAINED SECTION F.2: If a score of more than 0 is obtained, indicate YES for the likelihood of dysphagia being present.		
OUTCOME SECTION F.2: Dysphagia likely to be present	YES	NO
F.3 – F.4 Symptoms of Oropharyngeal dysphagia		
Instructions: Completing this section is based on the clinician's interpretation of the observation of respiration during feeding, oral function, cranial nerve function, NNS stimulation and feeding.		
F.3 Oral symptoms		
F.3.1 Delayed initiation of sucking	YES(1)	NO (0)
F.3.2 Poor/weak sucking response	YES(1)	NO (0)
F.3.3 Absent sucking response	YES(1)	NO (0)
F.3.4 Uncoordinated tongue movement during NNS and NS	YES(1)	NO (0)
F.3.5 Inadequate lip closure with excessive anterior spillage during feeding	YES(1)	NO (0)
F.3.6 Multiple swallow attempts to initiate pharyngeal swallow response	YES(1)	NO (0)
F.4 Pharyngeal symptoms		
F.4.1 Gurgling during/after swallowing	YES(1)	NO (0)
F.4.2 Coughing during/after swallowing	YES(1)	NO (0)
F.4.3 Choking during/after swallowing	YES(1)	NO (0)
F.4.4 Teary eyes during/immediately after swallowing	YES(1)	NO (0)
F.4.5 "Wet" respiratory sounds	YES(1)	NO (0)

F.4.6 "Wet" vocal sounds	YES(1)	NO (0)
F.4.7 Suspected delayed pharyngeal swallowing response	YES(1)	NO (0)
F.4.8 Absent pharyngeal swallowing response	YES(1)	NO (0)
SCORE OBTAINED SECTION F.3-F.4: If a score of more than 0 is obtained, indicate YES for the likelihood of oropharyngeal dysphagia being present.		
OUTCOME SECTION F.3-F.4: Dysphagia likely to be present	YES	NO
OVERALL OUTCOME SECTION F:		
F.1.1 – F.1.2	YES	NO
F.1.3 – F.1.4	YES	NO
F.2	YES	NO
F.3 – F.4	YES	NO
SCORE OBTAINED SECTION F OVERALL: If a score of 2 OR more YES responses are obtained indicate YES for the likelihood of oropharyngeal dysphagia being present.		
OUTCOME SECTION F OVERALL: Dysphagia likely to be present	YES	NO

CALCULATING DIAGNOSTIC OUTCOME			
SECTION A & B	Dysphagia likely to be present	YES	NO
SECTION C	Dysphagia likely to be present	YES	NO
SECTION D	Dysphagia likely to be present	YES	NO
SECTION E	Dysphagia likely to be present	YES	NO
SECTION F	Dysphagia likely to be present	YES	NO
SCORING INSTRUCTION: If a score of 3 or more YES responses obtained in the section outcomes above, indicate YES for the final diagnosis of oropharyngeal dysphagia likely to be present. However, at least one of the 3 YES responses required for reaching the final diagnosis of oropharyngeal dysphagia being present, must either be obtained in SECTION E or F.			
Diagnostic outcome	Oropharyngeal dysphagia likely to be present	YES	NO

APPENDIX C

Video fluoroscopic swallow study data collection sheet

(Arvedson & Brodsky, 2002)

For office use:

Participant number:			V1 [ ][ ][ ] 1-3
Date of birth: (dd/mm/yy)			V2 [ ][ ][ ] [ ][ ][ ] 4-9
Study results:	**Present (+) / Absent (-):**	**Comments**	
Lateral View			
Reduced labial closure (Anterior loss)			V3 [ ] 10
Disorganised/weak lingual movements			V4 [ ] 11
Premature loss of bolus			V5 [ ] 12
Reduced velopharyngeal closure			V6 [ ] 13
Delayed triggering of the swallow reflex			V7 [ ] 14
Reduced epiglottic closure			V8 [ ] 15
Limited hyolaryngeal (El)evation / (Ex)cursion			V9 [ ] 16
Residue: (T)ongue / (P)alate / (Ph)aryngeal wall			V10 [ ] 17
Pooling: (V)alleculae / (P)yriform sinuses			V11 [ ] 18
Residue/Pooling cleared with: (M)ultiple swallows / (C)ough / (P)ostural changes / (O)ther (Specify)			V12 [ ] 19
Penetration / Aspiration: (B)efore / (D)uring / (A)fter swallow			V13 [ ] 20
Penetration-Aspiration Score (see PAS key below)			V14 [ ] 21
Participant response to penetration/ aspiration: (C)ough / (N)o response			V15 [ ] 22
Anterior-Posterior View			
Symmetric bolus in the oral cavity			V16 [ ] 23
Symmetric bolus in the pharynx			V17 [ ] 24
Pooling: (V)alleculae / (P)yriform sinuses			V18 [ ] 25

Compensatory techniques used and outcome	
Summary and Recommendations	

Penetration Aspiration Scale (PAS)

(Rosenbek et al., 1996)

	Score	Description
Neither penetration nor aspiration	1	Material does not enter airway
Penetration	2	Material enters airway but remains above vocal folds; and is ejected from airway, no stasis
	3	Material remains above vocal folds, visible stasis
	4	Material contacts vocal folds but is ejected, no stasis
	5	Material contacts vocal folds and is not ejected, visible stasis remains
Aspiration	6	Material passes below vocal folds but is ejected into the larynx or out of airway; no visible subglottic stasis
	7	Material passes below vocal folds and is not ejected from airway; visible subglottic stasis despite effort/participant response
	8	Material passes below vocal folds and no effort is made to eject it from airway (no participant response)

APPENDIX D

Vineland-3

Vineland Adaptive Behavior Scales™–Third Edition

Comprehensive Interview Form

WITHOUT ITEM-LEVEL PROBES

Examinee's Name: _____ Today's Date: _____ Examinee's Birth Date: _____
(first, middle, last) (month, day, year) (month, day, year)

Examinee's Age: _____ Examinee's Sex: ☐ Female ☐ Male Respondent's Name: _____

Respondent's Relationship to the Examinee: ☐ Mother ☐ Father ☐ Other _____ Interviewer's Name: _____

DIRECTIONS

Complete instructions for administering this form are provided in Chapter 2 of the Vineland–3 Manual. The Manual also includes a list of suggested interview questions and scoring criteria for the items in Appendix G, which you may wish to have available when conducting the interview.

Keep in mind that the Coping Skills subdomain does not begin until age 2; the Written, Domestic, and Community subdomains do not begin until age 3; and the optional Maladaptive Behavior domain does not begin until age 3.

SCORING THE ITEMS

Score each item 2, 1, or 0 as follows:

Circle 2 if, when the behavior is needed or appropriate, the individual ***usually*** performs it without help or prompting (or if he/she performed the behavior when younger, but has now outgrown it).

Circle 1 if, when the behavior is needed or appropriate, the individual ***sometimes*** performs it without help or prompting.

Circle 0 if the individual ***never*** performs the behavior, or never performs it without help or prompting. Whether he/she hasn't learned the behavior, is not physically able to perform it, is not expected or allowed to perform it, or chooses not to perform it, circle 0.

Some items use a different scoring system: 2 = Yes, 0 = No. This is indicated in the booklet.

If the respondent has not had the opportunity to observe a behavior, ask him/her to estimate a score for that item. In addition to marking the item score, also check the box to the right of the item score, in the column labeled **Check if Est**.

If the individual performed a behavior when he/she was younger, but has now outgrown it, circle 2. Do not check the Estimated box.

Some items include a Scoring Tip, indicated with the symbol ☑. Use the tips to help you score those items.

BASAL AND CEILING RULES

A basal is established when there are ***four consecutive items*** with scores of 2. A ceiling is established when there are ***four consecutive items*** with scores of 0. Continue administering Interview Topics until you have established a basal and a ceiling, and all items between the basal and ceiling have been scored. If there is no basal, you must score all items from the first item in the subdomain up to the ceiling. If there is no ceiling, you must score all items from the last item in the subdomain back to the basal.

PEARSON

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PsychCorp

RECEPTIVE — COMMUNICATION DOMAIN

INTERVIEW TOPICS

A Responding
B Understanding Words
C Understanding Nonverbal Communication
D Identifying Things
E Following Basic Instructions
F Understanding Questions
G Understanding Implied Messages
H Attending to Entertaining Material
I Following Complex Instructions
J Attending to Informational Material

			Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*	Check if Est
0	A	1. Looks toward parent or caregiver when hearing parent's or caregiver's voice.	2 1 0	☐
	A	2. Looks toward parent or caregiver who is gesturing to get his/her attention.	2 1 0	☐
	A	3. Responds upon hearing his/her name called (for example, turns toward speaker, smiles).	2 1 0	☐
	C	4. When parent or caregiver looks or points at something, looks in that direction.	2 1 0	☐
	B	5. Understands at least 10 words. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	C	6. Responds appropriately to at least three basic gestures (for example, head nod for *yes*, head shake for *no*, hand out for *give me*, reaching, waving, clapping).	2 1 0	☐
	B	7. Understands the meaning of *no*.	2 1 0	☐
	C	8. Responds appropriately to at least three facial expressions being made by others (for example, frown, smile, surprised look, angry face).	2 1 0	☐
	B	9. Understands the meaning of *yes*.	2 1 0	☐
	E	10. Follows instructions requiring only one action (for example, "Sit down"; "Come here").	2 1 0	☐
	D	11. Identifies at least three *actual* objects when asked (for example, points to a dog, car, cup, key, etc.).	2 1 0	☐
	B	12. Understands at least 50 words. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	G	13. Responds to the tone of spoken words (for example, approaches eagerly when "Come here" is spoken lovingly, but hesitantly when "Come here" is spoken sharply).	2 1 0	☐
	D	14. Identifies at least three body parts on self when asked (for example, points to own nose, mouth, hands, feet, etc.).	2 1 0	☐
	E	15. Follows instructions with one action and one object (for example, "Bring me the book"; "Close the door").	2 1 0	☐
	C	16. Responds appropriately to at least three more advanced gestures (for example, motioning *come here*, finger over lips meaning *be quiet*, hands apart to show *this big*).	2 1 0	☐
	D	17. Identifies at least three objects pictured in a book, magazine, or electronic screen when asked (for example, points to a dog, car, cup, key, etc.).	2 1 0	☐
1	D	18. Identifies at least three body parts pictured in a book, magazine, or electronic screen when asked (for example, points to a nose, a mouth, hands, feet, etc.).	2 1 0	☐
	F	19. Responds to questions that use *what* (for example, when asked "What is this?" replies "A ball").	2 1 0	☐
	F	20. Responds to questions that use *who* (for example, when asked "Who is that?" replies "Auntie Kesha").	2 1 0	☐
	D	21. Identifies at least three basic actions pictured in a book, magazine, or electronic screen when asked (for example, points to someone eating, sitting, jumping, etc.).	2 1 0	☐
	F	22. Responds to questions that use *where* (for example, when asked "Where did Felipe go?" points where Felipe went).	2 1 0	☐
	E	23. Follows instructions with two related actions (for example, "Pick up those toys and put them away"; "Get your coat and put it on").	2 1 0	☐
	E	24. Follows instructions with one action and two objects (for example, "Bring me the crayons and the ball"; "Put on your shirt and your shoes").	2 1 0	☐
	E	25. Follows instructions in "if–then" form (for example, "If you're thirsty, then get a drink"; "If you are cold, then get a sweatshirt").	2 1 0	☐

RECEPTIVE — COMMUNICATION DOMAIN

Response Options: 2 = Usually, 1 = Sometimes, 0 = Never

			Check if Est
H	26. Pays attention to a story for at least 15 minutes. ☑ Score 2 if the individual did this when younger, but has now outgrown listening to stories.	2 1 0	☐
2 → F	27. Responds to questions that use *why* (for example, when asked "Why are you crying?" replies "My toy broke").	2 1 0	☐
E	28. Follows instructions with two unrelated actions (for example, "Turn off the TV and get my keys").	2 1 0	☐
F	29. Responds to questions that use *when* (for example, when asked "When do you eat breakfast?" replies "In the morning").	2 1 0	☐
H	30. Pays attention to a show for at least 30 minutes and understands what is happening.	2 1 0	☐
I	31. Identifies left and right on own body (for example, hands, feet, arms).	2 1 0	☐
I	32. Follows instructions requiring three actions (for example, "Get dressed, eat breakfast, and brush your teeth").	2 1 0	☐
3+ → H	33. Pays attention to a show for at least 60 minutes and understands what is happening.	2 1 0	☐
G	34. Understands sarcasm (for example, understands when a comment such as "That's just great!" really means "That's awful!").	2 1 0	☐
J	35. Pays attention to a 15-minute informational presentation and understands what is being said.	2 1 0	☐
I	36. Follows instructions involving left and right (for example, "Go to the left"; "Look to the right").	2 1 0	☐
I	37. When instructed to do something up to an hour later, remembers to do it (for example, "When your show is over, put your dishes in the sink").	2 1 0	☐
I	38. When instructed to do something several hours later, remembers to do it (for example, "When you get home from school, let the dog out").	2 1 0	☐
J	39. Pays attention to a 30-minute informational presentation and understands what is being said.	2 1 0	☐

Comments or Observations: _____

Office Use Only

Calculation of % Est *(see Manual)*

No. of Est ____ A

No. of Items Answered ____ B

(A ÷ B) × 100 = ____ % Est

Raw Score Calculation

Highest-Numbered Basal Item ____ × 2 = ____ C

Points Between Basal and Ceiling ____ D

rec Raw Score ____ C + D

EXPRESSIVE

COMMUNICATION DOMAIN

INTERVIEW TOPICS

A Beginning Sounds & Gestures
B Beginning Speech
C Vocabulary
D Using Gestures
E Communicating Names & Age
F Using Simple Grammatical Forms
G Using Intermediate Grammatical Forms
H Using Pronouns
I Asking Questions
J Using Complex Grammatical Forms
K Expressing Ideas & Experiences
L Stating Age, Birthday, & Address
M Giving Directions

		Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*	Check if Est
0	A 1. Makes sounds of pleasure (for example, coos, laughs).	2 1 0	☐
	A 2. Cries or fusses when uncomfortable (thirsty, hungry, wet, etc.). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	A 3. Vocalizes or gestures (for example, cries or waves arms) to get parent's or caregiver's attention.	2 1 0	☐
	A 4. Makes at least three one-syllable speech sounds (for example, "Mah," "Bah," "Ee," "Oh"). ☑ Score 2 if the individual did this when younger, but now says words.	2 1 0	☐
	A 5. Babbles in strings of sounds (for example, "Ba-ba-ba-ba," "Ma-ma-ma-ma," "Da-da-da-da"). ☑ Score 2 if the individual did this when younger, but now says words.	2 1 0	☐
	A 6. Vocalizes or gestures if he/she wants an activity to keep going or stop (for example, says "Again," shakes head *no*).	2 1 0	☐
	B 7. Says "Dada," "Mama," or another name for parent or caregiver (including parent's or caregiver's first name or nickname).	2 1 0	☐
	D 8. Uses at least three basic gestures (for example, head nod for *yes*, head shake for *no*, reaching or pointing toward something desired, waving, clapping).	2 1 0	☐
	B 9. Repeats or tries to repeat common words immediately upon hearing them (for example, *ball*, *car*, *more*). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	B 10. Says "No"; must actually mean *no*, not just repeat the word.	2 1 0	☐
	C 11. Names at least three objects (for example, ball, dog, favorite toy).	2 1 0	☐
1	B 12. Says one-word requests (for example, "Want," "More," "Open"). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	C 13. Names at least 10 objects. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	B 14. Says "Yes"; must actually mean *yes*, not just repeat the word.	2 1 0	☐
	C 15. Names at least three actions (for example, drink/drinking, eat/eating, play/playing).	2 1 0	☐
	E 16. Calls brothers, sisters, or friends by their name or nickname.	2 1 0	☐
	C 17. Says at least 50 words. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	F 18. Uses phrases with a noun and a verb (for example, "Mommy stay," "Give ball").	2 1 0	☐
	E 19. Says own first name or nickname.	2 1 0	☐
	H 20. Uses pronouns to refer to self; grammar need not be correct (for example, "Give me," "Me want," "Mine toy").	2 1 0	☐
	F 21. Uses simple adjectives to describe things (for example, *dirty*, *pretty*, *big*, *loud*).	2 1 0	☐
	F 22. Says what he/she is doing using simple sentences; grammar need not be correct (for example, "Ginger and me play," "Dan read me a book").	2 1 0	☐
	D 23. Uses at least three more advanced gestures (for example, motioning *come here*, finger over lips meaning *be quiet*, hands apart to show *this big*).	2 1 0	☐
	F 24. Uses negatives in sentences; grammar need not be correct (for example, "I won't drink it," "Me no go").	2 1 0	☐
	E 25. Says correct age when asked; holding up correct number of fingers counts.	2 1 0	☐
	G 26. Uses possessives in phrases or sentences; grammar need not be correct (for example, "This is mine," "Your book," "This is Carol's desk").	2 1 0	☐
	G 27. Uses *and* in phrases or sentences (for example, "Mom and Dad," "I want ice cream and cake").	2 1 0	☐

EXPRESSIVE — COMMUNICATION DOMAIN

Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*

				Check if Est
	I	28. Asks questions beginning with *who* (for example, "Who's that?"; "Who went to the store?"); just asking "Who?" (one word) doesn't count.	2 1 0	☐
2	G	29. Uses plural nouns (for example, "Two cats," "More crackers," "Those flowers").	2 1 0	☐
	H	30. Uses pronouns to refer to others; pronoun gender and grammar need not be correct (for example, "You want?"; "Her happy"; "Him ball").	2 1 0	☐
	G	31. Uses *in*, *on*, and *under* correctly in phrases or sentences (for example, "In the box," "Ball go under table").	2 1 0	☐
	I	32. Asks questions beginning with *why* (for example, "Why do I have to go?"; "Why did you put my stuff away?"); just asking "Why?" (one word) doesn't count.	2 1 0	☐
	E	33. Says first and last name when asked; saying first name only doesn't count.	2 1 0	☐
	H	34. Uses pronouns correctly; pronoun gender and grammar must be correct (for example, "I want," "Their ball," "Call her").	2 1 0	☐
	I	35. Asks questions beginning with *when* (for example, "When is dinner?"; "When can we go home?"); just asking "When?" (one word) doesn't count.	2 1 0	☐
	J	36. Uses *because* in phrases or sentences (for example, "Because I want to," "Kathy went home because she was sick").	2 1 0	☐
	L	37. Says his/her age at next birthday correctly when asked; holding up correct number of fingers counts.	2 1 0	☐
	J	38. Uses past tense verbs (for example, *walked*, *baked*).	2 1 0	☐
	K	39. Tells the basic parts of a familiar story or book or movie plot (the characters, what happens, how it ends, etc.).	2 1 0	☐
	J	40. Uses *behind*, *in front of*, and *between* correctly in phrases or sentences (for example, "Terrell is behind you," "I walked in front of her," "The ball went between the cars").	2 1 0	☐
	M	41. Gives simple directions involving one or two steps (for example, how to make, find, or do something).	2 1 0	☐
	J	42. Uses compound sentences joined by *and* or *but* (for example, "She asked me, and I told her no"; "Jerome wanted to go, but I didn't").	2 1 0	☐
3+	K	43. Uses own knowledge or opinions to comment on things, situations, and emotions (for example, "I think he's mad at her because she said mean things about him").	2 1 0	☐
	K	44. Tells about everyday (i.e., routine) experiences in detail (for example, when asked what he/she did with a friend today, tells who was involved, where the activity took place, etc.).	2 1 0	☐
	K	45. Tells about one-time (i.e., non-routine) experiences in detail (for example, when asked to describe a trip, tells who was involved, where the activity took place, etc.).	2 1 0	☐
	L	46. Says both the month and day of his/her birthday when asked.	2 1 0	☐
	K	47. Clarifies by restating with different words when he/she is not fully understood at first.	2 1 0	☐
	L	48. Says complete home address correctly when asked (that is, street or rural route, apartment number, city, and state, with or without zip code).	2 1 0	☐
	M	49. Gives complex directions involving three or more steps in logical order (for example, to a distant location, for a recipe requiring many steps).	2 1 0	☐

Comments or Observations: _____

Office Use Only

Calculation of % Est *(see Manual)*		Raw Score Calculation	
No. of Est	A	Highest-Numbered Basal Item × 2 =	C
No. of Items Answered	B	Points Between Basal and Ceiling	D
(A ÷ B) × 100 =	% Est	**exp** Raw Score	C + D

WRITTEN — COMMUNICATION DOMAIN

INTERVIEW TOPICS

A Identifying Signs & Letters
B Understanding How Writing Works
C Copying
D Beginning Reading
E Beginning Writing
F Working With Written Information
G Personal Writing
H Reading Level
I Advanced Writing
J Forms & Business Letters

			Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*	Check if Est
0–2	B	1. Holds a book correctly for reading and turns the pages from front to back.	2 1 0	☐
	A	2. Recognizes one or more simple signs and icons/symbols (for example, STOP signs, bathroom door signs, arrows, smiley face).	2 1 0	☐
	A	3. Identifies one or more alphabet letters.	2 1 0	☐
	A	4. Recognizes own name in printed form.	2 1 0	☐
	A	5. Identifies at least 10 alphabet letters. ☑ Score 2 for Yes or 0 for No.	2 0	☐
3	B	6. Understands what direction his/her language is written in (for example, from left to right in English; in other languages from right to left or top to bottom).	2 1 0	☐
	B	7. Writes in the correct direction (for example, from left to right in English; in other languages from right to left or top to bottom).	2 1 0	☐
	C	8. Copies own first name without mistakes. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
4	C	9. Copies simple words from an example without mistakes (for example, *cat, see, go*); copying name doesn't count. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	D	10. Identifies all alphabet letters, both uppercase and lowercase. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	E	11. Writes alphabet letters using the correct orientation (that is, not reversed or upside down).	2 1 0	☐
	D	12. Reads at least 10 words. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	E	13. Writes own first and last name from memory; writing first name only doesn't count.	2 1 0	☐
5	D	14. Reads simple sentences of three or more words out loud.	2 1 0	☐
	C	15. Copies phrases or sentences of four or more words without mistakes. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	E	16. Writes at least 10 simple words from memory (for example, *hat, ball, the*); may make small spelling errors. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	D	17. Reads simple stories out loud. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	E	18. Writes simple sentences of three or more words; may make small errors in spelling or grammar.	2 1 0	☐
	E	19. Writes at least 20 words from memory; may make small spelling errors. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	H	20. Reads and understands material of a second-grade level or higher. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	G	21. Writes simple notes, letters, emails, or texts that include at least three sentences (for example, thank you notes, postcards, invitations); may use abbreviated words and make small errors in spelling or grammar. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	F	22. Finds or sorts things in alphabetical order (for example, finds a name in an alphabetized address book or list of phone numbers, finds a word in a dictionary, alphabetizes a list of words or movie titles).	2 1 0	☐
	F	23. Accurately interprets information presented in simple tables, graphs, or charts.	2 1 0	☐
	I	24. Writes short reports or summaries (for example, a summary of something read) at least three sentences long; must use own words rather than simply borrowing or copying from other sources. ☑ Score 2 if the individual did this when younger, but now no longer needs to write reports or summaries.	2 1 0	☐

WRITTEN — COMMUNICATION DOMAIN

Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*

				Check if Est
6–7	F	25. Accurately interprets visual instructions (for example, assembly instructions, directions shown on a map).	2 1 0	☐
	F	26. Uses a table of contents or index to find information within a book or electronic resource.	2 1 0	☐
	H	27. Reads and understands material of a fourth-grade level or higher. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	G	28. Writes emails, stories, letters, journal entries, etc. at least 10 sentences long; may use abbreviated words and make small errors in spelling or grammar. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	F	29. Uses the Internet or a library to find information for writing a paper or completing a job assignment.	2 1 0	☐
8+	I	30. Writes reports, papers, or essays at least one page long; must use own words rather than simply borrowing or copying from other sources. ☑ Score 2 if the individual did this when younger, but now no longer needs to write reports, papers, or essays.	2 1 0	☐
	G	31. Writes or draws instructions for others (for example, how to do something, how to get somewhere).	2 1 0	☐
	I	32. Edits or corrects own written work before handing it in (for example, checks punctuation, spelling, grammar, etc.); use of computer spell-checker is okay.	2 1 0	☐
	J	33. Accurately completes paper or electronic forms of one page or less (for example, forms for school or work).	2 1 0	☐
	H	34. Reads and understands material of a sixth-grade level or higher. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	I	35. Writes reports or compositions at least three pages long; must use own words rather than simply borrowing or copying from other sources. ☑ Score 2 if the individual did this when younger, but now no longer needs to write reports or compositions.	2 1 0	☐
	H	36. Reads and understands material of a ninth-grade level or higher. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	J	37. Accurately completes paper or electronic forms of two pages or more (for example, a job, college, or credit application).	2 1 0	☐
	J	38. Writes business or application letters (for example, requests information, makes a complaint, applies for a job or to a school).	2 1 0	☐

Comments or Observations: _____

Office Use Only

Calculation of % Est (*see Manual*)		Raw Score Calculation	
No. of Est	A	Highest-Numbered Basal Item	× 2 = C
No. of Items Answered	B	Points Between Basal and Ceiling	D
(A ÷ B) × 100 =	% Est	**wrn** Raw Score	C + D

PERSONAL — DAILY LIVING SKILLS DOMAIN

INTERVIEW TOPICS

A Beginning to Eat
B Cooperating in Dressing & Washing
C Beginning to Drink
D Using Spoon & Fork
E Removing Clothing
F Toilet Training
G Cleaning Hands & Face
H Putting on Clothes & Shoes
I Hygiene
J Fastening Fasteners
K Bathing
L Using the Bathroom
M Using Knives When Eating
N Eating & Exercise Choices
O Preparing for Weather
P Health Care

		Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*	Check if Est
0	A 1. Opens mouth when food is offered. ☑ Score 2 if the individual did this when younger, but has now outgrown being fed.	2 1 0	☐
	C 2. Drinks from a bottle or spill-proof drinking cup (often called a "sippy cup"); must hold the bottle or cup himself/herself. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	A 3. Sucks or chews on finger foods (for example, crackers, cookies, toast).	2 1 0	☐
	A 4. Eats solid foods (for example, cooked vegetables, chopped meats).	2 1 0	☐
	B 5. Cooperates actively in undressing and dressing (raises arms for removing top, holds out feet for putting on pants or shoes, etc.). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	B 6. Cooperates actively in washing of hands and face (holds out hands, turns face toward parent or caregiver, etc.). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	D 7. Feeds self with a spoon; may spill.	2 1 0	☐
	E 8. Removes shoes and socks.	2 1 0	☐
1	C 9. Drinks from a regular cup or glass (sippy cups don't count); some spilling may occur.	2 1 0	☐
	D 10. Feeds self with a fork; may spill.	2 1 0	☐
	E 11. Removes clothing that opens in the front (for example, a coat or jacket); does not have to unbutton or unzip the clothing.	2 1 0	☐
	F 12. Lets someone know when he/she has a wet or soiled diaper or pants (for example, points, vocalizes, pulls at diaper). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	H 13. Pulls up clothing with elastic waistbands (for example, underwear, sweatpants).	2 1 0	☐
	C 14. Drinks from a regular cup or glass without spilling (sippy cups don't count).	2 1 0	☐
	F 15. Urinates in a toilet or potty chair; parent or caregiver may initiate.	2 1 0	☐
	G 16. Washes hands using soap and water and dries them; does not need to turn the water on and off or adjust the temperature.	2 1 0	☐
	D 17. Feeds self with a spoon without spilling.	2 1 0	☐
	E 18. Removes pullover garments (for example, T-shirt, sweatshirt, dress).	2 1 0	☐
	H 19. Puts on shoes; may be on the wrong feet and does not need to tie or fasten.	2 1 0	☐
	H 20. Puts on clothing that opens in the front (for example, a coat or jacket); does not need to zip or button.	2 1 0	☐
	F 21. Defecates in a toilet or potty chair; parent or caregiver may initiate.	2 1 0	☐
	F 22. Is toilet-trained during the day; may require help with undressing, flushing, wiping, or washing hands, *but must initiate using the toilet.*	2 1 0	☐
	H 23. Puts on pullover garments (for example, T-shirt, sweatshirt, dress).	2 1 0	☐
	I 24. Wipes or blows nose using tissue, napkin, toilet paper, or other appropriate material.	2 1 0	☐
2	G 25. Washes and dries face; does not need to turn the water on and off or adjust the temperature.	2 1 0	☐
	G 26. Wipes or cleans face and hands as needed during or after meals.	2 1 0	☐
	H 27. Puts clothing on with the right side forward and correct side out.	2 1 0	☐
	F 28. Is toilet-trained during the night; may require help with undressing, flushing, wiping, or washing hands, *but must initiate using the toilet.*	2 1 0	☐
	I 29. Covers mouth and nose when coughing or sneezing.	2 1 0	☐

Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*

			Check if Est
	F	30. Uses the toilet during the day and at night without help; must wipe, flush, and wash hands by himself/herself.	2 1 0 ☐
	J	31. Fastens snaps.	2 1 0 ☐
	I	32. Brushes teeth; must put toothpaste on toothbrush, brush adequately, and rinse.	2 1 0 ☐
3	J	33. Buttons large buttons, in the correct buttonholes (for example, coat buttons).	2 1 0 ☐
	I	34. Changes clothing that has become dirty, wet, muddy, or smelly.	2 1 0 ☐
	J	35. Connects and zips zippers that are not already fastened at the bottom (for example, on a coat or jacket).	2 1 0 ☐
	K	36. Bathes or showers and dries self; does not need to turn the water on and off or adjust the temperature.	2 1 0 ☐
	H	37. Puts shoes on the correct feet and securely ties or fastens them.	2 1 0 ☐
	M	38. Spreads food with a table knife (for example, butter, jam, mustard).	2 1 0 ☐
	J	39. Buttons small buttons, in the correct buttonholes (for example, shirt buttons).	2 1 0 ☐
	N	40. Shows awareness that some foods are healthier than others (for example, states that fruits and vegetables are healthier than foods high in sugar or fat).	2 1 0 ☐
	L	41. Finds and uses an appropriate restroom when away from home.	2 1 0 ☐
	K	42. Turns faucets on and adjusts the water temperature.	2 1 0 ☐
	O	43. Selects appropriate clothing during wet or cold weather (for example, raincoat, boots, sweater).	2 1 0 ☐
	M	44. Cuts easy-to-cut food with a table knife (for example, fish, pancakes, butter).	2 1 0 ☐
4+	N	45. Shows awareness that physical exercise is good for people (for example, states that exercise is healthy, that people should exercise, etc.).	2 1 0 ☐
	K	46. Washes and rinses hair; does not need to turn the water on and off or adjust the temperature.	2 1 0 ☐
	N	47. Chooses to exercise for health and/or enjoyment.	2 1 0 ☐
	L	48. Uses the toilet before going out if uncertain about the availability of a restroom.	2 1 0 ☐
	N	49. Makes healthy eating choices (eats a balanced diet, eats unhealthy foods in moderation, etc.).	2 1 0 ☐
	M	50. Cuts harder-to-cut food with a sharp knife (for example, meat, raw vegetables).	2 1 0 ☐
	O	51. Plans for changes in weather by taking along an umbrella, a sweater, etc.	2 1 0 ☐
	P	52. Takes own temperature when needed.	2 1 0 ☐
	P	53. Takes medicine as directed on his/her own.	2 1 0 ☐
	P	54. Goes to the doctor when needed (that is, when illness or injury requires professional care).	2 1 0 ☐
	P	55. Monitors supply of medications (nonprescription and prescription) and replaces them as needed. ☑ If the respondent has not had the opportunity to observe this, estimate a score and check the Estimated box.	2 1 0 ☐

Comments or Observations: _____

Office Use Only

Calculation of % Est *(see Manual)*		Raw Score Calculation	
No. of Est	A	Highest-Numbered Basal Item	× 2 = C
No. of Items Answered	B	Points Between Basal and Ceiling	D
(A ÷ B) × 100 =	% Est	**per** Raw Score	C + D

DOMESTIC

DAILY LIVING SKILLS DOMAIN

INTERVIEW TOPICS

A Beginning Home Safety
B Cleaning Up After Self
C Putting Clothes, etc. Where They Belong
D Food Preparation Basics
E Advanced Home Safety
F Basic Household Chores
G Cleaning Up After Meals
H More Complex Food Preparation
I Advanced Household Chores

		Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*	Check if Est
0–2	A 1. Is careful around hot objects (for example, the stove or oven, an open fire).	2 1 0	☐
	A 2. Is careful when using sharp objects (for example, scissors, knives).	2 1 0	☐
	B 3. Wipes up own spills; must get wiping material and clean the spill adequately.	2 1 0	☐
	C 4. Puts dirty clothes in the proper place to be washed (for example, a laundry basket or chute).	2 1 0	☐
3–4	B 5. Removes dirty shoes or wipes them on a doormat before entering a residence.	2 1 0	☐
	B 6. Puts away his/her books, toys, etc. when done using them.	2 1 0	☐
	D 7. Washes hands before preparing food.	2 1 0	☐
	B 8. Fully clears own dishes, utensils, napkins, cups, etc. after eating.	2 1 0	☐
	F 9. Does at least two simple household chores (for example, dusts, empties trash cans, feeds pet).	2 1 0	☐
5–6	D 10. Prepares a simple snack or meal (for example, a sandwich, cheese and crackers, microwave foods).	2 1 0	☐
	E 11. Understands what to do in dangerous situations (for example, when to get help, when to call 911, how to distance self from danger).	2 1 0	☐
	C 12. Hangs wet towel on a towel rack or hook, or puts in the proper place to be washed.	2 1 0	☐
	C 13. Puts clean clothes away where they belong (for example, in drawers or closet, on hooks).	2 1 0	☐
	D 14. Uses at least two simple kitchen appliances (for example, toaster, microwave, electric can opener).	2 1 0	☐
	D 15. Washes fruits and vegetables before eating or cooking them.	2 1 0	☐
	E 16. Secures home against intruders when home (keeps doors locked, finds out who is at the door before opening it, etc.).	2 1 0	☐
	D 17. Uses at least three kitchen utensils to prepare food (for example, knives, tongs, spatula, vegetable peeler).	2 1 0	☐
7–8	E 18. Is careful when operating household appliances or equipment (for example, vacuum cleaner, lawnmower, iron, power tools).	2 1 0	☐
	D 19. Prepares and eats leftovers.	2 1 0	☐
	F 20. Uses household products correctly (for example, laundry detergent, furniture polish, glass cleaner).	2 1 0	☐
	G 21. Puts dishes away when clean and dry.	2 1 0	☐
	E 22. Secures home against intruders when leaving home (locks doors, closes windows, turns on alarm, etc.).	2 1 0	☐
	G 23. Washes dishes (either by hand, or by loading and running the dishwasher when needed).	2 1 0	☐
	F 24. Cleans floors thoroughly (sweeps, vacuums, mops, etc.).	2 1 0	☐
9+	G 25. Puts leftover food away (for example, in plastic bags or wrap, in containers).	2 1 0	☐
	H 26. Uses the stove or oven for cooking or baking (turns burners on and off, sets oven temperature, etc.).	2 1 0	☐

DOMESTIC — DAILY LIVING SKILLS DOMAIN

Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*

			Check if Est
I	27. Recognizes when simple maintenance tasks need to be done and does them (for example, replaces light bulbs, batteries, filters, or vacuum cleaner bag).	2 1 0	☐
I	28. Cleans bathroom (toilet, sink, tub or shower, etc.).	2 1 0	☐
I	29. Does laundry; must wash, dry, and fold/hang.	2 1 0	☐
H	30. Prepares a full meal consisting of three or more food items.	2 1 0	☐

Comments or Observations: _____

Office Use Only	Calculation of % Est *(see Manual)*		Raw Score Calculation		
	No. of Est	A	Highest-Numbered Basal Item	× 2 =	C
	No. of Items Answered	B	Points Between Basal and Ceiling		D
	(A ÷ B) × 100 =	% Est	**dom** Raw Score		C + D

COMMUNITY — DAILY LIVING SKILLS DOMAIN

INTERVIEW TOPICS

A Basic Money Skills
B Basic Safety Outside the Home
C Telling Time
D Basic Rights & Responsibilities
E Calendar Basics
F Telephone Use
G Using Money
H Using Technology
I Eating Out
J Advanced Safety Outside the Home
K Being On Time
L Shopping Skills
M Achieving Goals
N Understanding Rights
O Traveling
P Earning Money
Q Managing Money

Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*

				Check if Est
	F	1. Talks to a familiar person using a phone, computer, or other electronic device; does not need to place the call.	2 1 0	☐
0–2	A	2. Understands that money is used to buy things.	2 1 0	☐
	A	3. Counts at least 10 objects, one by one.	2 1 0	☐
	B	4. Remains within safe distance of caregiver when in public places; being carried, pushed in a stroller, etc. doesn't count. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	B	5. Understands and follows safety precautions while riding in a car (for example, keeps seat belt on, refrains from unnecessarily distracting the driver).	2 1 0	☐
	C	6. Understands that a clock is used to tell time.	2 1 0	☐
	H	7. Operates at least two technology devices for entertainment (for example, a television, DVD player, music player, handheld game, computer used for entertainment).	2 1 0	☐
	I	8. Uses appropriate manners when eating in public (for example, uses utensils, sits properly, doesn't disrupt others).	2 1 0	☐
	E	9. Says all seven days of the week in order when asked.	2 1 0	☐
3–4	B	10. Looks both ways when crossing streets or roads.	2 1 0	☐
	D	11. Respects the right to personal privacy for self and others (for example, while using the restroom or changing clothes; not opening others' mail).	2 1 0	☐
	A	12. Names a penny, nickel, dime, and quarter when asked; does not need to know the value of the coins.	2 1 0	☐
5	E	13. Says the current day of the week when asked.	2 1 0	☐
	A	14. Understands that some items cost more than others (for example, might say "I have enough money to buy stickers but not a book" or "Which pens cost less?").	2 1 0	☐
	F	15. Knows what phone number to call in an emergency and how to make the call (for example, knows how to call 911 or an emergency contact).	2 1 0	☐
	B	16. Obeys traffic lights and *Walk/Don't Walk* signs when crossing streets or roads.	2 1 0	☐
	C	17. Tells time using a digital clock or watch.	2 1 0	☐
	D	18. Understands and follows community rules and laws (for example, rules and laws regarding littering, pet control, respecting others' property, etc.).	2 1 0	☐
	F	19. Makes calls to others using a phone, computer, or other electronic device.	2 1 0	☐
	G	20. Knows the difference between bills of different values ($1, $5, $10 bills, etc.).	2 1 0	☐
	B	21. Understands signs or symbols used to indicate danger (for example, skull and crossbones for poison, circle with slash for "don't do").	2 1 0	☐
	E	22. Identifies a specific date (either the current date or another) on a calendar when asked.	2 1 0	☐
	G	23. Says the value of a penny (1 cent), nickel (5 cents), dime (10 cents), and quarter (25 cents) when asked.	2 1 0	☐
	J	24. Chooses to avoid dangerous or risky activities or situations (for example, walking in an unsafe area, jumping off high places, picking up a hitchhiker).	2 1 0	☐
6–7	G	25. Makes small purchases at a store (for example, candy, stickers).	2 1 0	☐
	G	26. Combines coins to equal a specific amount (for example, 87 cents).	2 1 0	☐
	J	27. Follows safety precautions in work and/or leisure activities (for example, wears safety equipment, uses caution when operating tools and machinery).	2 1 0	☐
	H	28. Watches or listens to TV or radio or uses the Internet to obtain current information (for example, news, weather report, traffic conditions).	2 1 0	☐
	K	29. Uses a clock to keep track of when to do something (for example, watch a TV show, meet a friend).	2 1 0	☐
	M	30. Sets a short-term goal and achieves it (for example, completes all homework by Thursday night in order to have the weekend free).	2 1 0	☐
	F	31. Finds a needed phone number (for example, uses a contact list, the Internet, a phone book, 411).	2 1 0	☐

COMMUNITY — DAILY LIVING SKILLS DOMAIN

			Response Options: 2 = Usually, 1 = Sometimes, 0 = Never	Check if Est
	J	32. Keeps personal belongings secure (wallet, purse, phone, etc.) when away from home (for example, when shopping, eating out, or traveling).	2 1 0	☐
8–9	K	33. Gets up on time when needed (for example, sets alarm, arranges to be awakened).	2 1 0	☐
	L	34. Carries or stores money/debit card/credit cards safely, without losing (for example, in a wallet, purse, or money belt).	2 1 0	☐
	H	35. Operates technology to accomplish at least two kinds of tasks (for example, writing documents, school-related email, organizing information, finding information on the Internet).	2 1 0	☐
	N	36. Understands the right to vote.	2 1 0	☐
	H	37. Uses at least two social interaction technologies (for example, personal email, texting, social media, Skype™; telephone calls don't count).	2 1 0	☐
10–11	L	38. Checks change to make sure it is correct after buying something.	2 1 0	☐
	L	39. Evaluates quality and price when deciding what to buy.	2 1 0	☐
	N	40. Understands the right to begin or discontinue services (for example, telephone or Internet service).	2 1 0	☐
	N	41. Understands the right to report legitimate problems with products, services, living situation, etc.	2 1 0	☐
	K	42. Notifies an appropriate person when he/she will be late or absent for school, work, an appointment, etc.	2 1 0	☐
	M	43. Sets a goal that can be done in six months or more and achieves it (for example, works and saves money to buy something expensive, gets in better physical shape).	2 1 0	☐
12+	O	44. Travels at least one mile to a familiar destination when needed (using public transportation, walking, biking, driving, etc.).	2 1 0	☐
	P	45. Has worked to earn money outside the home (for example, babysitting or yard work for a neighbor, having a job). ☑ Score 2 for Yes or 0 for No.	2 0	☐
	I	46. At a restaurant, gets seating, chooses what to order, places order, and pays for meal.	2 1 0	☐
	N	47. Understands the right to access records and information (for example, school or medical records, credit history).	2 1 0	☐
	O	48. Travels at least one mile to an unfamiliar destination when needed (using public transportation, walking, biking, driving, etc.).	2 1 0	☐
	M	49. Sets a long-range goal requiring two years or more and achieves it (for example, makes a sports or academic team, gets into college).	2 1 0	☐
	O	50. Uses a city, highway, bus, or electronic map (or GPS) to figure out how to reach a destination when needed.	2 1 0	☐
	L	51. Buys groceries and household supplies when needed.	2 1 0	☐
	Q	52. Manages daily expenses responsibly (for example, meals, bus fare).	2 1 0	☐
	Q	53. Uses a bank account responsibly (keeps money in the account, keeps tracks of the balance, doesn't overdraw, etc.).	2 1 0	☐
	P	54. Has held a job (10 hours or more a week) for at least one month. ☑ Score 2 for Yes or 0 for No.	2 0	☐
	Q	55. Uses a credit or debit card in his/her name responsibly (for example, does not exceed credit limit, pays on time).	2 1 0	☐
	Q	56. Manages monthly expenses responsibly (for example, rent, utilities).	2 1 0	☐
	Q	57. Pays bills on time.	2 1 0	☐
	P	58. Has held the same job (10 hours or more a week) for at least one year. ☑ Score 2 for Yes or 0 for No.	2 0	☐

Comments or Observations: _____

Office Use Only	Calculation of % Est (see Manual)		Raw Score Calculation	
	No. of Est	A	Highest-Numbered Basal Item × 2 =	C
	No. of Items Answered	B	Points Between Basal and Ceiling	D
	(A ÷ B) × 100 =	% Est	cmm Raw Score	C + D

INTERPERSONAL RELATIONSHIPS — SOCIALIZATION DOMAIN

INTERVIEW TOPICS

A Beginning Social Behavior	D Identifying Self & Others	G Friendships	J Taking Others' Perspective
B Responding to Familiar People	E Imitating Others	H Demonstrating Caring	K Interpersonal Flexibility
C Expressing & Recognizing Emotions	F Interpersonal Appropriateness	I Conversational Skills	

			Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*	Check if Est
0	A	1. Looks at the face of parent or caregiver.	2 1 0	☐
	A	2. Smiles in response to a smile or a friendly voice.	2 1 0	☐
	B	3. Recognizes family members or other significant people.	2 1 0	☐
	B	4. Smiles or makes sounds when approached by a familiar person.	2 1 0	☐
	C	5. Shows at least three different emotions (for example, happiness, sadness, surprise, fear).	2 1 0	☐
	A	6. Tries to interact with others (for examples, smiles or makes noises at someone, reaches for someone).	2 1 0	☐
	B	7. Reaches for familiar person when that person holds out arms to him/her. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	B	8. Shows affection to familiar people (for example, touches, hugs, kisses, cuddles).	2 1 0	☐
	A	9. Shows interest in children the same age, other than brothers or sisters (for example, watches them, smiles at them).	2 1 0	☐
	B	10. Looks around from time to time to check that parent, caregiver, or other familiar person is nearby. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	D	11. Identifies self while looking at own image in mirror or photo.	2 1 0	☐
	C	12. Smiles in response to praise or compliments (for example, "Good job," "That's a nice shirt").	2 1 0	☐
	E	13. Imitates or tries to imitate parent's or caregiver's facial expressions (for example, when parent or caregiver makes a happy, sad, or surprised face). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
1	C	14. Recognizes emotions in others (for example, might say "You look sad" or "Rachel is happy").	2 1 0	☐
	E	15. Imitates relatively complex actions as they are being performed by another person (for example, shaving, putting on makeup, vacuuming, hammering nails). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	H	16. Uses actions or words to show happiness, sympathy, or concern for others on own initiative (for example, hugs, holds hands, asks "Are you okay?").	2 1 0	☐
	G	17. Tries to make friends with others his/her age (that is, shows particular interest in interacting with certain other children).	2 1 0	☐
	D	18. Says the relationship of family members to self (for example, "That's my mom," "He's my brother"); simply calling parents Mom, Dad, or equivalent doesn't count.	2 1 0	☐
	C	19. Uses words to express own emotions (for example, "I'm happy," "I'm scared," "I don't like him").	2 1 0	☐
	F	20. Maintains culturally appropriate eye contact during social interactions.	2 1 0	☐
	F	21. Answers politely when familiar adults make small talk (for example, if asked "How are you?" says "I'm fine"; if told "You look nice," says "Thank you").	2 1 0	☐
	E	22. Imitates relatively complex actions several hours after watching someone else perform them (for example, shaving, putting on makeup, vacuuming, hammering nails). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
2	F	23. Speaks using a loudness, speed, and level of excitement that is appropriate for the conversation.	2 1 0	☐
	H	24. Does things to try to please others on own initiative (for example, makes someone a card or gift, helps without being asked).	2 1 0	☐

INTERPERSONAL RELATIONSHIPS — SOCIALIZATION DOMAIN

Response Options: 2 = Usually, 1 = Sometimes, 0 = Never

			Check if Est
G	25. Has a best friend or a few good friends. ☑ Score 2 for Yes or 0 for No.	2 0	☐
F	26. Maintains an acceptable distance between self and others in social situations (for example, does not get too close to another person when talking).	2 1 0	☐
G	27. Is a good friend: Treats his/her friends fairly and with respect, is supportive, etc.	2 1 0	☐
I	28. Talks with others about shared interests (for example, sports, TV shows, summer plans).	2 1 0	☐
G	29. Maintains friendships over time (for example, has had the same good friend for over a year).	2 1 0	☐
J	30. Recognizes that the likes and dislikes of others can differ from his/her own (for example, might say "Kelly likes pizza, but I don't"; "I liked that movie, but Gretchen hated it").	2 1 0	☐
3 I	31. Starts small talk when he/she meets people he/she knows (for example, says "How are you?"; "What's up?").	2 1 0	☐
G	32. Chooses friends with good qualities: Friends who treat him/her with respect, are supportive, stay out of trouble, etc.	2 1 0	☐
I	33. Moves easily from one topic to another in conversation when needed; does not "get stuck" on one topic.	2 1 0	☐
I	34. Talks with others without interrupting or being rude.	2 1 0	☐
J	35. Tells others what he/she is thinking and feeling instead of assuming that they know.	2 1 0	☐
4 I	36. Stays on topic in conversations when needed; does not digress.	2 1 0	☐
H	37. Responds positively to the good fortune of others on own initiative (for example, congratulates a friend who receives an award).	2 1 0	☐
H	38. Gives cards and/or gifts to immediate family members on "special days" on own initiative.	2 1 0	☐
K	39. Will engage in activities suggested by friends, even if not preferred. ☑ If the respondent has not had the opportunity to observe this, estimate a score and check the Estimated box.	2 1 0	☐
5+ J	40. Starts conversations with others by talking about things that interest them (for example, "Tyrone tells me you like cars").	2 1 0	☐
K	41. Participates in conversations on a topic not of interest to him/her.	2 1 0	☐
J	42. Responds to hints or indirect cues in conversation (for example, knows that a yawn may mean "I'm bored," an abrupt change of subject may mean "I don't want to talk about that," looking at the time may mean "I need to end this conversation").	2 1 0	☐
J	43. Provides additional explanation when needed in order for someone to follow what he/she is saying (for example, "In case you missed what I said…," "What we were talking about was…").	2 1 0	☐

Comments or Observations: _____

Office Use Only	Calculation of % Est (see Manual)		Raw Score Calculation		
	No. of Est	A	Highest-Numbered Basal Item	× 2 =	C
	No. of Items Answered	B	Points Between Basal and Ceiling		D
	(A ÷ B) × 100 =	% Est	ipr Raw Score		C + D

PLAY AND LEISURE — SOCIALIZATION DOMAIN

INTERVIEW TOPICS

A Beginning to Play	D Sharing	G Playing Games
B Playing With Others	E Responding to Social Cues	H Doing Things With Peers
C Make-Believe	F Following Rules in Games & Sports	I Planning Activities

			Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*	Check if Est
0	A	1. Responds when parent or caregiver is playful (for example, smiles, laughs, claps hands).	2 1 0	☐
	A	2. Shows interest in surroundings (for example, looks or moves around, touches objects or people).	2 1 0	☐
	A	3. Plays simple interaction games with others (for example, peek-a-boo, patty-cake). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	A	4. Plays near another child, each doing different things. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	A	5. Copies the play of a child playing nearby with little or no interaction between the two. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	B	6. Plays interactively with one or more children for at least 5 minutes with someone older supervising. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
1	B	7. Chooses to join other children who are playing rather than watching them or playing alone.	2 1 0	☐
	C	8. Uses common household objects or other objects for make-believe activities (for example, pretends a block is a car or a box is a house). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	D	9. Shares toys or possessions when told to do so.	2 1 0	☐
	E	10. Joins in with a group when verbal cues indicate that he/she is welcome.	2 1 0	☐
	B	11. Plays interactively with one or more children for at least 30 minutes with someone older supervising. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	B	12. Protects self by moving away from those who try to hurt others or destroy things (those who bite, hit, throw things, smash things, etc.).	2 1 0	☐
	C	13. Plays simple make-believe activities with other children (for example, plays "dress-up," pretends to be superheroes). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	G	14. Plays with others at simple outdoor group games with no score (for example, tag, jump rope, catch). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	B	15. Seeks out others for play or companionship (for example, asks others to play or spend time together).	2 1 0	☐
	B	16. Plays with other children with minimal supervision.	2 1 0	☐
	F	17. Takes turns when asked while playing games or sports.	2 1 0	☐
	C	18. Engages with other children in elaborate make-believe activities involving more than one role (for example, plays "school" or "restaurant," enacts a TV show or movie). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
2	D	19. Shares toys or possessions without having to be told to do so.	2 1 0	☐
	E	20. Joins in with a group when nonverbal cues indicate that he/she is welcome.	2 1 0	☐
	F	21. Takes turns without having to be asked while playing games or sports.	2 1 0	☐
3	G	22. Plays with others at simple indoor or outdoor games where the players keep score (for example, tic-tac-toe, kickball, card games). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	F	23. Follows rules in games or sports without being told to do so.	2 1 0	☐

PLAY AND LEISURE — SOCIALIZATION DOMAIN

Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*

			Check if Est
G	24. Plays with others at simple card or board games based only on chance (for example, Candyland®, the card game "war"). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
E	25. Refrains from entering a group when verbal cues indicate that he/she is not welcome.	2 1 0	☐
D	26. Asks permission before using things that belong to or are being used by another.	2 1 0	☐
F	27. Shows good sportsmanship in games or sports: Plays fair, is not overly aggressive, congratulates winning players, does not act mean when he/she loses, etc.	2 1 0	☐
4+ H	28. Gets together with two or more peers at someone's home.	2 1 0	☐
E	29. Refrains from entering a group when nonverbal cues indicate that he/she is not welcome. ☑ If the respondent has not had the opportunity to observe this, estimate a score and check the Estimated box.	2 1 0	☐
H	30. Goes places with peers during the day or evening with someone supervising (for example, shopping, a movie, a sports event). ☑ Score 2 if the individual did this when younger, but has now outgrown the need to be supervised.	2 1 0	☐
G	31. Plays with others at two or more board, card, or electronic games requiring skill and decision making (for example, Monopoly™, poker, Scrabble®, interactive video games).	2 1 0	☐
I	32. Plans ahead to do things with peers on his/her own.	2 1 0	☐
I	33. Obtains schedule information for movies, sports events, concerts, etc. (for example, looks at a newspaper or on the Internet, phones a movie theater).	2 1 0	☐
H	34. Goes places with peers during the day without someone supervising (for example, a shopping mall, park, community center).	2 1 0	☐
I	35. Plans fun activities with more than two things to be arranged (for example, birthday party, group outing).	2 1 0	☐
H	36. Goes places with peers in the evening without someone supervising (for example, a concert, lecture, sports event, movie).	2 1 0	☐

Comments or Observations: _____

Office Use Only

Calculation of % Est *(see Manual)*		Raw Score Calculation	
No. of Est	A	Highest-Numbered Basal Item	× 2 = C
No. of Items Answered	B	Points Between Basal and Ceiling	D
(A ÷ B) × 100 =	% Est	**pla** Raw Score	C + D

COPING SKILLS — SOCIALIZATION DOMAIN

INTERVIEW TOPICS

A Handling Transitions
B Beginning Emotional Control
C Good Manners
D Asking For & Accepting Help
E Adapting Behavior to the Situation
F Respecting Others
G Controlling Anger
H Obeying Time Limits
I Managing Social Risks
J Making Decisions

Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*

				Check if Est
0	B	1. Seeks comfort from parent, caregiver, or other when hurt or upset.	2 1 0	☐
	A	2. Looks or moves toward parent or caregiver when approached by an unfamiliar person. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	A	3. Separates easily from parent or caregiver when left with another person (that is, does not have a temper tantrum, sulk, etc. when parent or caregiver leaves or attempts to leave).	2 1 0	☐
	A	4. Transitions easily from one activity to another.	2 1 0	☐
	C	5. Responds politely when given something (that is, expresses thanks either verbally or nonverbally).	2 1 0	☐
1	C	6. Is polite when asking for something (that is, uses *please* or an appropriate nonverbal gesture).	2 1 0	☐
	A	7. Handles changes in routine without becoming overly distressed.	2 1 0	☐
	B	8. Recovers quickly from a minor setback or disappointment (for example, doesn't pout for long after losing a game or not getting something that he/she wants).	2 1 0	☐
	B	9. Uses words or gestures to express distress rather than screaming, hitting, throwing something, etc.	2 1 0	☐
	F	10. Apologizes for small, unintentional mistakes (for example, burping, bumping into someone).	2 1 0	☐
	C	11. Acts appropriately when introduced to new people (for example, smiles, shakes hands, says "Happy to meet you").	2 1 0	☐
	D	12. Requests help when encountering a problem beyond own capability to solve (for example, a computer problem, fixing something).	2 1 0	☐
	E	13. Changes behavior intentionally depending on how well he/she knows another person (for example, acts more formally with someone new than with a friend or family member).	2 1 0	☐
2	D	14. Accepts helpful suggestions or solutions from others.	2 1 0	☐
	F	15. Apologizes with sincerity after hurting another's feelings.	2 1 0	☐
	E	16. Copies appropriate behavior of others when in a new situation and unsure how to act.	2 1 0	☐
3	F	17. Is willing to compromise in order to get along with peers.	2 1 0	☐
	G	18. Controls anger or hurt feelings when plans change for reasons that can't be helped (for example, an event cancelled due to bad weather, a trip postponed due to car trouble).	2 1 0	☐
	H	19. Follows time limits imposed by parent or caregiver (for example, amount of time allowed to watch TV, play a game, use the Internet, or play outside). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	G	20. Understands that when someone does or says something that hurts, it may be accidental rather than intentional.	2 1 0	☐
	E	21. Adjusts behavior to keep from disrupting others nearby (for example, is quiet near others who are working, listening to a show, etc.).	2 1 0	☐
4–5	G	22. Controls anger or hurt feelings when he/she does not get his/her way (for example, when not allowed to watch television or attend a party, when a suggestion is rejected by a friend or supervisor).	2 1 0	☐
	F	23. Keeps promises.	2 1 0	☐
	G	24. Controls anger or hurt feelings when given constructive criticism (for example, correction of misbehavior, discussion of a test score or grade, a performance review).	2 1 0	☐

COPING SKILLS — SOCIALIZATION DOMAIN

Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*

			Check if Est
I	25. Understands that a friendly appearing person may actually intend harm.	2 1 0	☐
F	26. Respects others' time (for example, doesn't keep others waiting or interrupt others who are busy).	2 1 0	☐
I	27. When possible, avoids or leaves harmful relationships or situations (for example, being bullied, coerced into breaking the law, taken advantage of sexually or financially). ☑ If the respondent has not had the opportunity to observe this, estimate a score and check the Estimated box.	2 1 0	☐
I	28. Avoids being manipulated, dominated, or taken advantage of by others.	2 1 0	☐
J	29. Thinks through the consequences of his/her actions before acting (for example, refrains from acting impulsively, considers relevant information).	2 1 0	☐
H	30. Obeys curfews (that is, comes home when he/she is told to, during the day or at night). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
I	31. Is aware of and uses caution when encountering risky social situations (for example, Internet solicitations, a stranger's offer of a ride or money, "binge" drinking parties, social media, personal ads). ☑ If the respondent has not had the opportunity to observe this, estimate a score and check the Estimated box.	2 1 0	☐
H	32. Informs parent or caregiver about his/her plans when he/she goes out (for example, what time he/she is leaving and returning, where he/she is going). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
J	33. Recognizes that advertising messages may not be accurate.	2 1 0	☐

Comments or Observations: _____

Office Use Only	Calculation of % Est *(see Manual)*		Raw Score Calculation	
	No. of Est	A	Highest-Numbered Basal Item × 2 =	C
	No. of Items Answered	B	Points Between Basal and Ceiling	D
	(A ÷ B) × 100 =	% Est	**cop** Raw Score	C + D

GROSS MOTOR — MOTOR SKILLS DOMAIN

INTERVIEW TOPICS

A Sitting
B Pre-Walking Mobility
C Standing
D Walking
E Ball Activities
F Climbing
G Running
H Using Stairs
I Jumping & Hopping
J Catching a Ball
K Riding a Tricycle or Bicycle

			Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*	Check if Est
0	A	1. Sits supported (for example, in a chair, with pillows, etc.) for at least 1 minute.	2 1 0	☐
	B	2. Rolls over from back onto stomach.	2 1 0	☐
	A	3. Sits unsupported for at least 1 minute.	2 1 0	☐
	B	4. Moves, scoots, or crawls across the floor. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	A	5. Sits unsupported for at least 10 minutes.	2 1 0	☐
	C	6. Stands holding on to a stable object for at least 5 seconds. ☑ Score 2 if the individual did this when younger, but now stands without holding on to anything.	2 1 0	☐
	C	7. Pulls self up to standing position.	2 1 0	☐
	C	8. Stands supported with one hand and reaches for an object with the other hand without falling. ☑ Score 2 if the individual did this when younger, but now stands without holding on to anything.	2 1 0	☐
	D	9. Takes steps while supporting self using furniture or another stable object. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	B	10. Crawls up stairs. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	C	11. Stands unsupported for at least 1 minute.	2 1 0	☐
	D	12. Takes at least two steps without support.	2 1 0	☐
	C	13. Stands unsupported and reaches for an object without falling.	2 1 0	☐
	D	14. Walks to get around; does not need to hold on to anything.	2 1 0	☐
	F	15. Safely climbs on and off low objects (for example, child's chair, step stool, low bench). ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	B	16. Goes down stairs by crawling backwards or scooting on bottom. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	C	17. Squats or bends down to pick up objects without falling.	2 1 0	☐
	E	18. Throws a ball with one hand; accuracy not important.	2 1 0	☐
	F	19. Safely gets on and off an adult-sized chair.	2 1 0	☐
1	G	20. Runs without falling; may be awkward and uncoordinated.	2 1 0	☐
	H	21. Walks up stairs, putting both feet on each step; may use railing. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	E	22. Kicks a ball while standing; accuracy not important.	2 1 0	☐
	D	23. Walks two or more blocks without having to rest or needing physical support.	2 1 0	☐
	H	24. Walks down stairs, facing forward, putting both feet on each step; may use railing. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	I	25. Jumps off the ground with both feet without falling.	2 1 0	☐
	G	26. Runs smoothly without falling.	2 1 0	☐
	F	27. Safely climbs up and down high objects (for example, jungle gym, ladder, tree).	2 1 0	☐
	D	28. Walks carefully on a sidewalk or road that is slippery or uneven.	2 1 0	☐
	I	29. Jumps forward at least three times with both feet without falling.	2 1 0	☐
	G	30. Runs smoothly, changing speed and direction (for example, when playing tag or sports, or chasing a pet).	2 1 0	☐

GROSS MOTOR — MOTOR SKILLS DOMAIN

Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*

				Check if Est
	J	31. Catches a beach ball-sized ball from a distance of 2 or 3 feet.	2 1 0	☐
	H	32. Walks up stairs, alternating feet; may use railing.	2 1 0	☐
2	H	33. Walks down stairs, alternating feet; may use railing.	2 1 0	☐
	H	34. Climbs a flight of eight or more stairs at a normal pace; may use railing.	2 1 0	☐
	K	35. Pedals a tricycle or other three-wheeled vehicle for at least 6 feet. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	I	36. Hops on one foot at least once without falling; may hold on to something for balance.	2 1 0	☐
	K	37. Pedals a tricycle or other three-wheeled vehicle around corners. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
3+	J	38. Catches a beach ball-sized ball from at least 6 feet away.	2 1 0	☐
	I	39. Hops forward on one foot with ease without holding on (for example, during hopscotch).	2 1 0	☐
	J	40. Catches a tennis- or baseball-sized ball from a distance of 2 or 3 feet, using one or both hands extended away from body.	2 1 0	☐
	K	41. Rides a balance bike or bicycle with training wheels for at least 10 feet. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	J	42. Catches a tennis- or baseball-sized ball from a distance of at least 10 feet, moving to catch it if necessary.	2 1 0	☐
	K	43. Rides a regular bicycle without training wheels without falling.	2 1 0	☐

Comments or Observations: _____

Office Use Only	Calculation of % Est *(see Manual)*		Raw Score Calculation		
	No. of Est	A	Highest-Numbered Basal Item	× 2 =	C
	No. of Items Answered	B	Points Between Basal and Ceiling		D
	(A ÷ B) × 100 =	% Est	**gmo** Raw Score		C + D

FINE MOTOR — MOTOR SKILLS DOMAIN

INTERVIEW TOPICS

A Beginning to Handle Objects
B Manipulating Things
C Opening Doors
D Beginning Crayon/Pen Use
E Hand Coordination
F Drawing
G Coloring
H Using Scissors
I Tying
J Precise Movements

			Response Options: 2 = Usually, 1 = Sometimes, 0 = Never	Check if Est
0	A	1. Reaches for a toy or object.	2 1 0	☐
	A	2. Picks up objects; may use both hands.	2 1 0	☐
	A	3. Moves an object from one hand to the other.	2 1 0	☐
	B	4. Removes an object (for example, a block or small toy) from a box or other container with no lid.	2 1 0	☐
	A	5. Picks up small objects (no larger than 2 inches on any side) with thumb and fingers (for example, raisins, beads, small blocks).	2 1 0	☐
	A	6. Picks up a small toy or object with one hand and hands it to someone without dropping it.	2 1 0	☐
	B	7. Puts an object (for example, a block or small toy) into a box or other container with no lid.	2 1 0	☐
	D	8. Marks on paper with a crayon, pen, or pencil; method of grasping the crayon, pen, or pencil is not important.	2 1 0	☐
	C	9. Opens doors that require only pushing or pulling (for example, cabinet, refrigerator, sliding, or swinging doors).	2 1 0	☐
1	B	10. Stacks at least four small blocks or other small objects; alignment need not be perfect, but the stack must remain upright. ☑ Score 2 if the individual did this when younger, but has now outgrown it.	2 1 0	☐
	B	11. Turns book or magazine pages one by one; books with cardboard pages don't count.	2 1 0	☐
	E	12. Unwraps small objects (for example, gum or candy).	2 1 0	☐
	C	13. Opens doors by turning a doorknob or handle.	2 1 0	☐
2	E	14. Uses a twisting hand–wrist motion (for example, winds up a toy or music box, screws/unscrews the lid of a jar).	2 1 0	☐
	D	15. Holds a crayon, pen, or pencil in proper position (that is, using a tripod grasp, not with fist) for writing or drawing.	2 1 0	☐
	E	16. Presses buttons accurately on a small keyboard or touch screen (for example, on a calculator, cell phone, or other handheld device).	2 1 0	☐
	H	17. Opens and closes scissors with one hand; does not have to cut with them.	2 1 0	☐
	F	18. Draws a circle freehand while looking at an example.	2 1 0	☐
	G	19. Colors simple shapes or animals; more coloring is inside the lines than outside. ☑ Score 2 if the individual did this when younger, but has now outgrown coloring.	2 1 0	☐
3	F	20. Draws more than one recognizable form (for example, a person, house, tree).	2 1 0	☐
	E	21. Pours liquid from one container to another with little or no spilling (for example, pouring milk or juice into a glass).	2 1 0	☐
	F	22. Draws a square freehand while looking at an example.	2 1 0	☐
	H	23. Uses scissors to cut along a straight line across a standard sheet of paper.	2 1 0	☐
	F	24. Draws a triangle freehand while looking at an example.	2 1 0	☐
	F	25. Uses an eraser without tearing the paper.	2 1 0	☐
4	H	26. Cuts out simple shapes (circles, squares, rectangles, etc.).	2 1 0	☐
	G	27. Colors simple pictures with all coloring inside the lines. ☑ Score 2 if the individual did this when younger, but has now outgrown coloring.	2 1 0	☐
	G	28. Colors a full-page drawing or scene using two or more colors; all coloring is inside the lines. ☑ Score 2 if the individual did this when younger, but has now outgrown coloring.	2 1 0	☐
	F	29. Draws a straight line using a ruler or straightedge.	2 1 0	☐
5+	I	30. Ties a knot.	2 1 0	☐

FINE MOTOR — MOTOR SKILLS DOMAIN

Response Options: 2 = *Usually*, 1 = *Sometimes*, 0 = *Never*

			Check if Est
H	31. Cuts out complex shapes (for example, stars, animals, alphabet letters).	2 1 0	☐
I	32. Ties a secure bow (for example, shoe laces, gift wrapping).	2 1 0	☐
J	33. Manipulates very small objects (for example, sets hands on a watch, threads a sewing needle, glues miniature model parts).	2 1 0	☐
J	34. Assembles, builds, or creates complex building toy structures, model sets, homemade jewelry, arts and crafts, etc.	2 1 0	☐

Comments or Observations: _____

Office Use Only	Calculation of % Est *(see Manual)*		Raw Score Calculation		
	No. of Est	A	Highest-Numbered Basal Item	× 2 =	C
	No. of Items Answered	B	Points Between Basal and Ceiling		D
	(A ÷ B) × 100 =	% Est	**fmo** Raw Score		C + D

MALADAPTIVE BEHAVIOR DOMAIN

Unlike the adaptive behavior items that you have just completed, the maladaptive behavior items are read directly to the respondent. Read (or paraphrase) each item as it is written, clarify if needed, and ask the respondent to tell you how often the behavior happens:

2 = *Often*, **1** = *Sometimes*, **0** = *Never*

SUGGESTED INTRODUCTION

Say to the respondent, "We're going to finish by talking about problem behaviors that [name] may or may not be exhibiting. This time I'm going to read you a description of each behavior and ask you to tell me if it happens often, happens sometimes, or never happens."

INTERNALIZING — MALADAPTIVE BEHAVIOR DOMAIN

	Response Options: 2 = Often, 1 = Sometimes, 0 = Never				Check if Est
1.	Is overly needy or dependent (for example, insists on help even when he/she does not need it, clings to parent or teacher).	2	1	0	☐
2.	Has eating problems (for example, overeats, refuses to eat, will only eat one or two things, hoards food).	2	1	0	☐
3.	Has sleep problems (for example, walks in his/her sleep, has a lot of nightmares, sleeps way more or less than others his/her age).	2	1	0	☐
4.	Refuses to go to school or work, or has to come home, because of worrying, sadness, nervousness, etc.	2	1	0	☐
5.	Is extremely anxious or nervous.	2	1	0	☐
6.	Cries or is sad for no clear reason.	2	1	0	☐
7.	Avoids interacting with others (withdraws, prefers to be alone, etc.).	2	1	0	☐
8.	Lacks interest in doing things that he/she enjoys or used to enjoy.	2	1	0	☐
9.	Is extremely fearful of one or more common objects or situations (for example, heights, snakes, elevators).	2	1	0	☐
10.	Worries for no clear reason.	2	1	0	☐
11.	Is very irritable or moody.	2	1	0	☐
12.	Feels helpless or hopeless (for example, says that things are bad and will never get better).	2	1	0	☐
13.	Complains of feeling sick, exhausted, or in pain, even though there is no medical reason.	2	1	0	☐

Office Use Only — **Internalizing** Raw Score ☐

EXTERNALIZING — MALADAPTIVE BEHAVIOR DOMAIN

	Response Options: 2 = Often, 1 = Sometimes, 0 = Never				Check if Est
1.	Has temper tantrums: Screams, cries, kicks, etc.	2	1	0	☐
2.	Disobeys those in authority.	2	1	0	☐
3.	Bullies others physically or with words.	2	1	0	☐
4.	Lies, cheats, or steals.	2	1	0	☐
5.	Is physically aggressive (for example, hits, kicks, bites).	2	1	0	☐
6.	Is stubborn or argues.	2	1	0	☐
7.	Is verbally abusive (that is, hurts others on purpose with insults, put-downs, etc.).	2	1	0	☐
8.	Breaks rules or laws because of peer pressure.	2	1	0	☐
9.	Is much more active or restless than others his/her age (for example, moves all the time, cannot sit still, fidgets).	2	1	0	☐
10.	Takes or uses school or work property when not allowed (for example, books, office supplies).	2	1	0	☐
11.	Destroys his/her own or someone else's possessions on purpose.	2	1	0	☐

Office Use Only — **Externalizing** Raw Score ☐

CRITICAL ITEMS — MALADAPTIVE BEHAVIOR DOMAIN

Response Options: 2 = *Often*, 1 = *Sometimes*, 0 = *Never*

		Check if Est
1. Gets fixated on objects or parts of objects (for example, stares at spinning wheels or fan blades, lines up objects, flips light switches over and over).	2 1 0	☐
2. Talks about hearing voices that others do not hear, or seeing things that others do not see.	2 1 0	☐
3. Harms himself/herself (for example, bangs his/her head, hits or bites self, cuts self, tears at skin, pulls out his/her hair).	2 1 0	☐
4. Uses strange or repetitive speech (for example, has conversations with himself/herself in public, says things that make no sense, repeats the same thing over and over).	2 1 0	☐
5. Loses awareness of what is happening around him/her (for example, seems to be "in a fog," "zones out").	2 1 0	☐
6. Repeats physical movements over and over (for example, rocks back and forth, spins, flaps hands).	2 1 0	☐
7. Has toileting accidents (that is, wets or soils self when not in diapers).	2 1 0	☐
8. Eats non-food items such as dirt, paste, or soap.	2 1 0	☐
9. Engages in compulsive behavior (for example, repeated hand washing, repeatedly checking and rechecking something, other compulsive rituals).	2 1 0	☐
10. Shows far more interest in weapons or extreme violence than others his/her age.	2 1 0	☐
11. Harms animals (for example, tortures or kills pets or wild animals).	2 1 0	☐
12. Has beliefs that are not true (for example, believes he/she has a "true" identity or "special" powers, believes that others secretly want to cause harm).	2 1 0	☐
13. Gets so fixated on a particular topic that it annoys others (for example, trains, reptiles, maps, subway systems).	2 1 0	☐
14. Talks about killing himself/herself or has tried to kill self.	2 1 0	☐
15. Has no response to pain (for example, does not cry or seek help when cut, bruised, or badly hurt).	2 1 0	☐
16. Wanders, darts away, or takes off from home, school, or someone watching him/her without regard for safety.	2 1 0	☐
17. Threatens to hurt or kill someone.	2 1 0	☐
18. Is tricked by others into doing something that could seriously harm him or her, or someone else.	2 1 0	☐
19. Gets fixated on a person in a way that is annoying or intrusive to that person.	2 1 0	☐
20. Engages in unwanted sexual behavior (for example, unwanted comments, unwanted physical contact, exposing himself/herself, masturbating in public, having sex at school or work).	2 1 0	☐

GENERAL COMMENTS

Use this space to record any general comments about the interview that you want included in the test record.

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Vineland-3

Comprehensive Interview Form
Score Report

Examinee's Name:

Examiner's Name:

Interview Respondent's Name:

Calculation of Examinee's Age	Year	Month	Day
Test Date			
Birth Date			
Test Age			

Score Summary

	Subdomains				
	Raw Score	v-Scale Score	Age Equivalent (AE)	Growth Scale Value (GSV)	% Est
Receptive (rec)					
Expressive (exp)					
Written (wrn)					
COMMUNICATION (COM) Sum of v-Scale Scores:		1			
Personal (per)					
Domestic (dom)					
Community (cmm)					
DAILY LIVING SKILLS (DLS) Sum of v-Scale Scores:		2			
Interpersonal Relationships (ipr)					
Play and Leisure (pla)					
Coping Skills (cop)					
SOCIALIZATION (SOC) Sum of v-Scale Scores:		3			
Gross Motor (gmo)					
Fine Motor (fmo)					
MOTOR SKILLS (MOT) Sum of v-Scale Scores:		4			

	Domains and Adaptive Behavior Composite			
	Sum of v-Scale Scores	Standard Score	85% 90% 95% Confidence Interval	Percentile Rank
Communication (COM)	1		—	
Daily Living Skills (DLS)	2		—	
Socialization (SOC)	3		—	
Sum of Domain Standard Scores				
See Table B.3 to convert to ABC		▼		
Adaptive Behavior Composite (ABC)			—	
Motor Skills (MOT)	4		—	

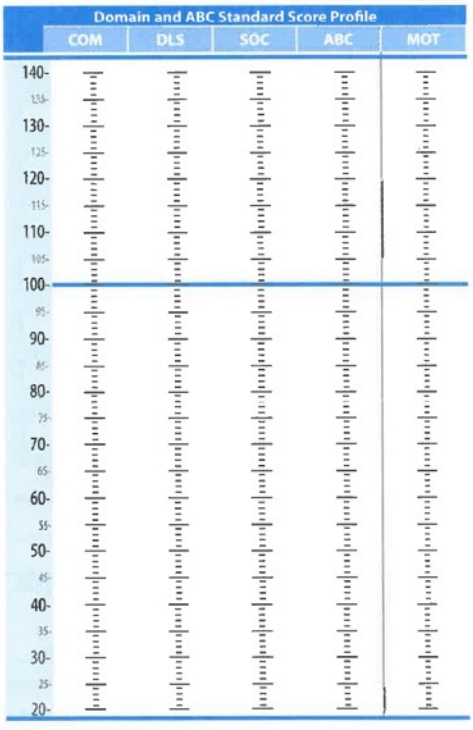
PEARSON

PsychCorp

Subdomain v-Scale Score Profile

	COMMUNICATION			DAILY LIVING SKILLS			SOCIALIZATION			MOTOR SKILLS		
	rec	exp	wrn	per	dom	cmm	ipr	pla	cop	gmo	fmo	
24	•	•	•	•	•	•	•	•	•	•	•	24
23	•	•	•	•	•	•	•	•	•	•	•	23
22	•	•	•	•	•	•	•	•	•	•	•	22
21	•	•	•	•	•	•	•	•	•	•	•	21
20	•	•	•	•	•	•	•	•	•	•	•	20
19	•	•	•	•	•	•	•	•	•	•	•	19
18	•	•	•	•	•	•	•	•	•	•	•	18
17	•	•	•	•	•	•	•	•	•	•	•	17
16	•	•	•	•	•	•	•	•	•	•	•	16
15	•	•	•	•	•	•	•	•	•	•	•	15
14	•	•	•	•	•	•	•	•	•	•	•	14
13	•	•	•	•	•	•	•	•	•	•	•	13
12	•	•	•	•	•	•	•	•	•	•	•	12
11	•	•	•	•	•	•	•	•	•	•	•	11
10	•	•	•	•	•	•	•	•	•	•	•	10
9	•	•	•	•	•	•	•	•	•	•	•	9
8	•	•	•	•	•	•	•	•	•	•	•	8
7	•	•	•	•	•	•	•	•	•	•	•	7
6	•	•	•	•	•	•	•	•	•	•	•	6
5	•	•	•	•	•	•	•	•	•	•	•	5
4	•	•	•	•	•	•	•	•	•	•	•	4
3	•	•	•	•	•	•	•	•	•	•	•	3
2	•	•	•	•	•	•	•	•	•	•	•	2
1	•	•	•	•	•	•	•	•	•	•	•	1

Domain and ABC Standard Score Profile



MALADAPTIVE BEHAVIOR

	Raw Score	v-Scale Score	Critical Items (Circle all item scores of 2 or 1)
Internalizing			1. 2 1 2. 2 1 3. 2 1 4. 2 1 5. 2 1 6. 2 1 7. 2 1 8. 2 1 9. 2 1 10. 2 1
Externalizing			11. 2 1 12. 2 1 13. 2 1 14. 2 1 15. 2 1 16. 2 1 17. 2 1 18. 2 1 19. 2 1 20. 2 1

STRENGTH/WEAKNESS ANALYSIS

Domains

	Standard Score (SS)	SS Minus Mean SS	.10 or .05 Critical Value	Strength or Weakness	Base Rate
COM				S or W	
DLS				S or W	
SOC				S or W	
MOT				S or W	

Calculation of Mean Domain Standard Score: Sum of SS ÷ No. of domains (3 or 4) = Mean SS (one decimal)

Subdomains

	v-Scale Score (vS)	vS Minus Mean vS	.10 or .05 Critical Value	Strength or Weakness	Base Rate
rec				S or W	
exp				S or W	
wrn				S or W	
per				S or W	
dom				S or W	
cmm				S or W	
ipr				S or W	
pla				S or W	
cop				S or W	
gmo				S or W	
fmo				S or W	

Calculation of Mean Subdomain v-Scale Score: Sum of vS ÷ No. of subdomains = Mean vS (one decimal)

PAIRWISE DIFFERENCE COMPARISONS

Domain Comparisons

	Standard Score	<, >, or =	Standard Score	Standard Score Difference	.10 or .05 Critical Value	Statistically Significant	Base Rate
COM		_	DLS			Y or N	
COM		_	SOC			Y or N	
DLS		_	SOC			Y or N	
COM		_	MOT			Y or N	
DLS		_	MOT			Y or N	
SOC		_	MOT			Y or N	

Subdomain Comparisons

	v-Scale Score	<, >, or =	v-Scale Score	v-Scale Score Difference	.10 or .05 Critical Value	Statistically Significant	Base Rate
Communication							
rec		_	exp			Y or N	
rec		_	wrn			Y or N	
exp		_	wrn			Y or N	
Daily Living Skills							
per		_	dom			Y or N	
per		_	cmm			Y or N	
dom		_	cmm			Y or N	
Socialization							
ipr			pla			Y or N	
ipr		_	cop			Y or N	
pla		_	cop			Y or N	
Motor Skills							
gmo		_	fmo			Y or N	
Across-Domain Comparisons							
		_				Y or N	
		_				Y or N	
		_				Y or N	

Abbreviations

COM	Communication	DLS	Daily Living Skills	SOC	Socialization	MOT	Motor Skills
rec	Receptive	per	Personal	ipr	Interpersonal Relationships	gmo	Gross Motor
exp	Expressive	dom	Domestic	pla	Play and Leisure	fmo	Fine Motor
wrn	Written	cmm	Community	cop	Coping Skills		

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APPENDIX E

The Rossetti INFANT-TODDLER LANGUAGE SCALE

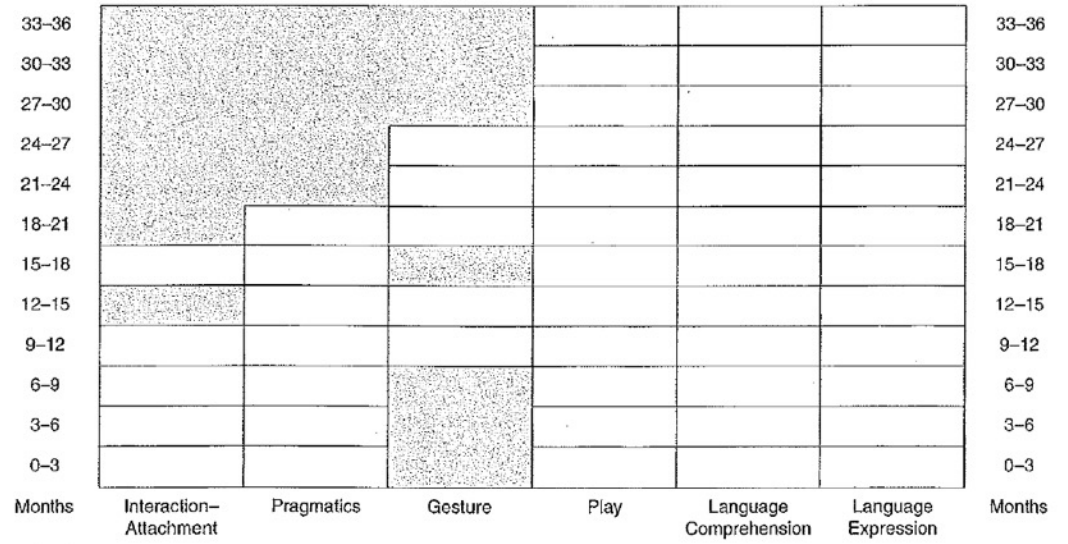
A Measure of Communication and Interaction

Louis Rossetti, Ph.D.

		First Administration	Second Administration	Third Administration
Name _____	Test Date	Yr / Mo / Day	Yr / Mo / Day	Yr / Mo / Day
Evaluation Setting _____	Birthdate	Yr / Mo / Day	Yr / Mo / Day	Yr / Mo / Day
Examiner _____	Chronological Age	Yr / Mo	Yr / Mo	Yr / Mo
Informant _____	Adjusted Age	Yr / Mo	Yr / Mo	Yr / Mo

Administration	Interaction–Attachment	Pragmatics	Gesture	Play	Language Comprehension	Language Expression
First						
Second						
Third						

Age Performance Profile



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page 25 Interaction–Attachment

O E R



1. Maintains brief eye contact during feeding
2. Shows differing responses to caregiver's vocalization
3. Crying diminishes with adult eye contact
4. Smiles purposefully in response to caregiver's face or voice
5. Caregiver appears relaxed and comfortable in handling the child
6. Caregiver smiles frequently while interacting with the child

page 37 Pragmatics

O E R



1. Responds to adult interaction
2. Seeks to make eye contact with an adult
3. Laughs at amusing activities
4. Shows interest in people, not objects
5. Cries to get attention

page 51 Gesture

No items at this age level

page 63 Play

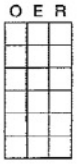
O E R



1. Plays with rattle
2. Momentarily looks at objects
3. Attempts to imitate facial expressions

page 85 Language Comprehension

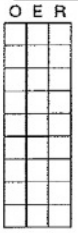
O E R



1. Quiets to a familiar voice
2. Moves in response to a voice
3. Shows awareness of a speaker
4. Attends to other voices
5. Attends to a speaker's mouth or eyes
6. Discriminates between harsh and soothing voices

page 123 Language Expression

O E R



1. Vocalizes to caregiver's smile and voice
2. Vocalizes two different sounds
3. Coos
4. Vocalizes sounds other than crying or cooing
5. Produces a hunger cry
6. Repeats a syllable while crying
7. Vocalizes to express pleasure
8. Cries to get attention
9. Makes sounds in the back of the throat

Notes

3–6 Months

page 28 **Interaction–Attachment**

O E R

7. Smiles spontaneously to human contact
8. Smiles when playing alone
9. Smiles at faces of several family members
10. Stops crying when spoken to
11. Shows different responses to family members

page 39 **Pragmatics**

O E R

6. Produces different cries for different reasons
7. Maintains eye contact
8. Vocalizes in response to vocalization
9. Imitates facial expressions

page 51 **Gesture**

No items at this age level

page 64 **Play**

O E R

4. Enjoys frolic play
5. Smiles at self in a mirror
6. Reaches for objects
7. Bangs objects in play

page 88 **Language Comprehension**

O E R

7. Turns head toward a voice
8. Searches for the speaker
9. Responds to sounds other than voices
10. Recognizes own name
11. Stops crying when spoken to
12. Responds to "no" half of the time
13. Discriminates between threatening and friendly voices
14. Anticipates feeding
15. Cries at an angry tone of voice

page 126 **Language Expression**

O E R

10. Vocalizes in response to singing
11. Vocalizes feelings through intonation
12. Takes turns vocalizing
13. Laughs
14. Babbles
15. Vocalizes to express displeasure
16. Stops babbling when another person vocalizes
17. Initiates "talking"
18. Demonstrates sound play when alone or with others
19. Whines with a manipulative purpose
20. Attempts to interact with an adult
21. Interrupts another person's vocalizations

Notes

6–9 Months

Notes

page 30 Interaction–Attachment

O E R



12. Responds to a request to "come here"
13. Becomes more lively with familiar people
14. Shows some initial separation fear
15. Shows a desire to be with people

page 41 Pragmatics

O E R



10. Exchanges gestures with an adult
11. Uses gesture and vocalization to protest
12. Shouts or vocalizes to gain attention

page 51 Gesture

No items at this age level

page 66 Play

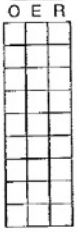
O E R



8. Smiles and laughs during games
9. Participates in games with adults
10. Demonstrates anticipation of play activities
11. Searches for hidden objects
12. Reaches for self in a mirror
13. Interacts with objects without mouthing or banging

page 91 Language Comprehension

O E R



16. Recognizes family members' names
17. Responds with gesture to "come up" or "want up?"
18. Attends to music or singing
19. Responds to "no" most of the time
20. Maintains attention to a speaker
21. Responds to sounds when the source is not visible
22. Stops when name is called
23. Attends to pictures
24. Waves in response to "bye-bye"

page 132 Language Expression

O E R

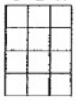


22. Vocalizes four different syllables
23. Vocalizes a two-syllable combination
24. Vocalizes in response to objects that move
25. Imitates duplicated syllables
26. Vocalizes during games
27. Sings along with a familiar song
28. Shouts or vocalizes to gain attention

9–12 Months

page 32 **Interaction–Attachment**

O E R



16. Shows sensitivity to others' moods
17. Displays fear of strangers
18. Allows release of contact in new situations
19. Performs for social attention

page 42 **Pragmatics**

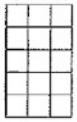
O E R



13. Vocalizes to call others
14. Indicates a desire for a change in activities
15. Vocalizes when another person calls

page 51 **Gesture**

O E R



1. Covers and uncovers face during "Peek-a-boo"
2. Reaches upward as a request to be picked up
3. Waves "hi" and "bye"
4. Extends arm to show an object
5. Points to objects to indicate awareness

page 69 **Play**

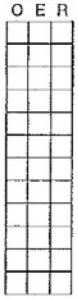
O E R



14. Participates in speech-routine games
15. Covers face with towel during "Peek-a-boo"
16. Resists removal of a toy
17. Tries to secure an object out of reach
18. Imitates stirring with a spoon
19. Pushes a toy car

page 95 **Language Comprehension**

O E R



25. Attends to new words
26. Gives objects upon verbal request
27. Looks at person saying child's name
28. Performs a routine activity upon verbal request
29. Looks at familiar objects and people when named
30. Attends to objects mentioned during conversation
31. Follows simple commands occasionally
32. Understands simple questions
33. Gestures in response to verbal requests
34. Verbalizes or vocalizes in response to verbal requests
35. Participates in speech-routine games
36. Identifies two body parts on self

page 135 **Language Expression**

O E R



29. Says "mama" or "dada" meaningfully
30. Imitates consonant and vowel combinations
31. Imitates non-speech sounds
32. Vocalizes with intent frequently
33. Uses a word to call a person
34. Says one to two words spontaneously
35. Vocalizes a desire for a change in activities
36. Imitates the names of familiar objects

Notes

page 33 Interaction–Attachment

Notes

Items resume at the 15–18 month level

page 44 Pragmatics

O E R



16. Imitates other children
17. Responds to other children's vocalizations
18. Initiates turn-taking routines
19. Uses vocalizations more frequently during interactions
20. Uses more words during turn taking

page 53 Gesture

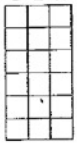
O E R



6. Feeds others
7. Combs or brushes hair
8. Brushes teeth
9. Hugs dolls, animals, or people
10. Shakes head "no"

page 72 Play

O E R



20. Plays fetching game with caregiver
21. Imitates patting a doll
22. Shows shoes or clothing during play
23. Demonstrates functional use of objects
24. Shows symbolic use of objects
25. Explores toys

page 101 Language Comprehension

O E R



37. Follows one-step commands during play
38. Responds to requests to say words
39. Maintains attention to pictures
40. Enjoys rhymes and finger plays
41. Responds to "give me" command
42. Points to two action words in pictures
43. Understands some prepositions
44. Understands new words
45. Identifies three body parts on self or a doll

page 139 Language Expression

O E R



37. Shakes head "no"
38. Says or imitates eight to ten words spontaneously
39. Names one object frequently
40. Varies pitch when vocalizing
41. Imitates new words spontaneously
42. Combines vocalization and gesture to obtain a desired object
43. Uses true words within jargon-like utterances
44. Produces three animal sounds
45. Wakes with a communicative call
46. Sings independently
47. Takes turns vocalizing with children
48. Expresses early developing modifiers
49. Asks to have needs met

15–18 Months

page 34 **Interaction–Attachment**

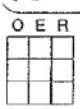
O E R



20. Plays away from familiar people
21. Requests assistance from an adult
22. Retreats to caregiver when an unfamiliar adult approaches

page 46 **Pragmatics**

O E R



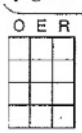
21. Points to, shows, or gives objects
22. Controls the behavior of self and others
23. Uses words to protest

page 55 **Gesture**

Items resume at the 18–21 month level

page 75 **Play**

O E R



26. Plays with a toy in different ways
27. Plays ball with adults
28. Places one object inside another
29. Hands a toy to an adult for assistance

page 106 **Language Comprehension**

O E R



46. Identifies six body parts or clothing items on a doll
47. Finds familiar objects not in sight
48. Completes two requests with one object
49. Chooses two familiar objects upon request
50. Identifies objects by category
51. Understands 50 words

page 146 **Language Expression**

O E R



50. Says 15 meaningful words
51. Uses consonant sounds, such as */t, d, n/* and */h/*
52. Talks rather than uses gestures
53. Imitates words overheard in conversation
54. Asks "What's that?"
55. Asks for "more"
56. Names five to seven familiar objects upon request

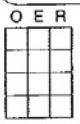
Notes

page 35 Interaction–Attachment

Notes

No items at this age level

page 47 Pragmatics



24. Engages in adult-like dialogue
25. Uses vocalizations and words during pretend play
26. Uses words to interact with others
27. Takes turns talking during conversation

page 56 Gesture



11. Leads caregiver to a desired object
12. Indicates that pants are wet
13. Pretends to play a musical instrument
14. Puts on or takes off clothing
15. Pretends to dance to music

page 77 Play



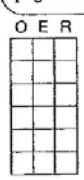
30. Imitates housework activities
31. Groups objects in play
32. Uses two toys together in pretend play

page 109 Language Comprehension



52. Identifies four body parts and clothing items on self
53. Understands the commands "sit down" and "come here"
54. Chooses five familiar objects upon request
55. Understands the meaning of action words
56. Identifies pictures when named

page 149 Language Expression



57. Uses single words frequently
58. Uses sentence-like intonational patterns
59. Imitates two- and three-word phrases
60. Imitates environmental noises
61. Verbalizes two different needs
62. Uses two-word phrases occasionally

21–24 Months

page 35 **Interaction–Attachment**

Notes

No items at this age level

page 49 **Pragmatics**

No items at this age level

page 58 **Gesture**

O E R



16. Gestures to request action
17. Gestures to indicate toileting needs
18. Pretends to pour from a container
19. Pushes a stroller or shopping cart
20. Flies a toy airplane

page 78 **Play**

O E R



33. Puts away toys on request
34. Attempts to repair broken toys
35. Stacks and assembles toys and objects

page 111 **Language Comprehension**

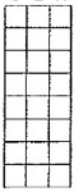
O E R



57. Chooses one object from a group of five upon verbal request
58. Follows novel commands
59. Follows a two-step related command
60. Understands new words rapidly

page 153 **Language Expression**

O E R



63. Uses two-word phrases frequently
64. Uses 50 different words
65. Uses new words regularly
66. Relates personal experiences
67. Uses three-word phrases occasionally
68. Refers to self by name
69. Uses early pronouns occasionally
70. Uses a mean length of 1.25–1.50 morphemes per utterance

24–27 Months

Notes

page 35 Interaction–Attachment

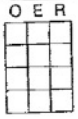
No items at this age level

page 49 Pragmatics

No items at this age level

page 61 Gesture

O E R



21. Pretends to write or type
22. Pretends to talk on the telephone
23. Wipes hands and face
24. Slaps a palm in response to "give me five"

page 80 Play

O E R



36. Performs many related activities during play
37. Chooses toys selectively
38. Uses most toys appropriately

page 113 Language Comprehension

O E R



61. Points to four action words in pictures
62. Recognizes family member names
63. Understands the concept of *one*
64. Understands size concepts

page 156 Language Expression

O E R



71. Imitates two numbers or unrelated words upon request
72. Uses three-word phrases frequently
73. Asks for assistance with personal needs
74. Uses action words
75. Uses a mean length of 1.50–2.00 morphemes per utterance

27–30 Months

page 35 **Interaction–Attachment**

Notes

No items at this age level

page 49 **Pragmatics**

No items at this age level

page 62 **Gesture**

No items at this age level

page 81 **Play**

O E R



39. Demonstrates parallel play with other children
40. Talks and verbalizes more in play around other children
41. Shares toys with other children

page 115 **Language Comprehension**

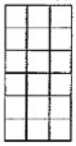
O E R



65. Responds to simple questions
66. Identifies four objects by function
67. Understands location phrases

page 159 **Language Expression**

O E R



76. Names one color
77. Refers to self by pronoun consistently
78. Uses two sentence types
79. Responds to greetings consistently
80. Uses negation
81. Uses a mean length of 2.00–2.50 morphemes per utterance

30–33 Months

page 35 **Interaction–Attachment**

Notes

No items at this age level

page 49 **Pragmatics**

No items at this age level

page 62 **Gesture**

No items at this age level

page 82 **Play**

O	E	R

42. Performs longer sequences of play activities
43. Acts out familiar routines
44. Pretends to perform the caregiver's routines

page 117 **Language Comprehension**

O	E	R

68. Understands five common action words
69. Follows two-step unrelated commands
70. Understands the concepts of *one* and *all*
71. Answers *yes* and *no* questions correctly

page 162 **Language Expression**

O	E	R

82. Answers questions with "yes" or "no"
83. Imitates a series of three numbers or unrelated words
84. Uses plurals
85. Uses prepositions
86. States gender
87. States first and last name

2

33–36 Months

page 35 **Interaction–Attachment**

Notes

No items at this age level

page 49 **Pragmatics**

No items at this age level

page 62 **Gesture**

No items at this age level

page 84 **Play**



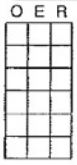
45. Acts out a new ending to a familiar routine
46. Uses a doll as a playmate
47. Uses one object to represent many objects

page 119 **Language Comprehension**



72. Shows interest in why and how things work
73. Follows a three-step unrelated command
74. Identifies parts of an object
75. Responds to *wh*- questions
76. Follows commands with two familiar attributes

page 165 **Language Expression**



88. Relates recent experiences through verbalization
89. Uses verb forms
90. Expresses physical states
91. Converses in sentences
92. Counts to three
93. Uses a mean length of 2.50–3.00 morphemes per utterance

Spontaneous Language Sample

4

Language Expression Protocol Items

The following Language Expression items may be scored directly from the spontaneous language sample. Circle the behaviors the child demonstrates as part of the language sample and credit the corresponding item in the protocol.

Utterance Types

48. Modifiers (*big, pretty, hot*)
51. Uses /t, d, n, h/ sounds
54. Asks "What's that?"
55. Says "more"
57. Single words frequently
62. Two-word phrases occasionally
63. Two-word phrases frequently
67. Three-word phrases occasionally
69. Pronouns (*I, me, you*)
72. Three-word phrases frequently
74. Uses action words
76. Two sentence types (declarative, question)
77. Pronouns (*I, me, my, mine*)
80. Negation (*no, not, don't*)
84. Plural forms (*-s, -z*)
85. Prepositions (*in, on, under, beside*)
89. Verb forms (*-ing, -ed*) and past tense irregular

Mean Length of Utterance (in morphemes)

70. 1.25 – 1.50
75. 1.50 – 2.00
81. 2.00 – 2.50
93. 2.50 – 3.00

Total Morphemes	÷	Total Utterances	=	Mean Length of Utterance
_____	÷	_____	=	_____

15

Notes

APPENDIX F

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Speech-Language Pathology and Audiology

PARENT OR GUARDIAN INFORMATION & INFORMED CONSENT DOCUMENT

TITLE OF STUDY: Feeding and developmental outcomes of neonates with Hypoxic Ischaemic Encephalopathy (HIE)

Dear Parent/Guardian

1) INTRODUCTION

We invite you, on behalf of your baby, to participate in a research study on the feeding and developmental outcomes of neonates with Hypoxic Ischaemic Encephalopathy (HIE). This information leaflet should help you decide if you want your baby to participate. Before you agree to take part, you should fully understand what is involved. If you have any questions, please do not hesitate to ask the head investigator, Roxanne Malan.

2) THE NATURE AND PURPOSE OF THIS STUDY

Your baby is in the hospital and gets special care because s/he is ill. Babies like yours may have feeding difficulties such as problems with sucking/swallowing. The aim of this study is to investigate the feeding of babies with HIE and to link this with their development at 6, 12 and 18 months. Your baby may be able to help us obtain more information to achieve our aim and we therefore request that you give consent for your baby to participate in this study.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

Firstly, the study involves assessment of your baby's feeding when s/he is still admitted to hospital. This will be done at your baby's bedside and by using a swallow x-ray. For the bedside assessment, the investigator will make general observations of your baby at rest, as well as using her finger to assess your baby's suck. Observations of your baby's sucking and swallowing will also be made by while you are feeding your baby. For the swallow x-ray, a liquid that looks like water will be given to your baby via a Tommy Tippee bottle. This liquid is specially prepared so that you can see it clearly on the x-ray. Your baby will be positioned on the x-ray machine's bed while drinking from the bottle and the hospital speech therapist will have a look at the x-ray images to assess your baby's feeding.

Secondly, the study involves assessment of your baby's development at the ages of 6, 12 and 18 months. This part of the study will be done while your baby is an out-patient, on days that you already have follow-up appointments at the hospital, so that you don't have to come in especially for the research study. The developmental assessment will include observation of your baby during various tasks and play activities and questions about your child's development will be asked to you as parent/guardian.

4) RISK AND DISCOMFORT INVOLVED

There will be no risk involved during the bedside feeding assessment or during your baby's developmental assessment. There may only be minimal risk associated with the radiation from

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the swallow x-ray. However, past studies have found that radiation doses during these x-rays are minimal.

It should take 45 minutes to complete the bedside assessment of your baby's feeding and a total of 15 minutes to complete your baby's swallow x-ray. (This includes the time taken to position your baby on the machine, to take the x-rays and to write the report). Each developmental assessment (6, 12 and 18 months) may take up to 60 minutes to complete.

5) POSSIBLE BENEFITS OF THIS STUDY

The results obtained from investigating your baby's feeding and development will allow you as parent/guardian to better understand your baby's functioning. If feeding difficulties or developmental delays are identified, your baby will be referred for early intervention, which has been found to significantly improve children's long-term outcomes. Additionally, the results obtained from this study will help health care professionals better understand how they can help similarly ill babies in future.

6) WHAT ARE YOUR RIGHTS AS A PARTICIPANT?

Your participation in this study is entirely voluntary. You can refuse to participate or stop at any time during the study without giving any reason. Your withdrawal from the study will not affect your baby, his/her treatment or access to healthcare in any way. You are free to ask any questions to better understand the study at any point during the research process.

7) HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This study has received written approval from the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria, medical campus, Tswelopele Building, Level 4-59. The committee's telephone numbers are 012 356 3084 / 012 356 3085. Approval has also been obtained from the CEO of Steve Biko Academic Hospital.

8) INFORMATION AND CONTACT PERSON

The contact person for the study is the head investigator, Roxanne Malan. If you have any questions about the study, please contact her on 078 8031992. Alternatively, you can contact her supervisors at jeannie.vanderline@up.ac.za or alta.kritzinger@up.ac.za .

9) COMPENSATION

Your participation in this study is voluntary. A snack will be provided when you and your baby attend the developmental screenings at 6, 12 and 18 months.

10) CONFIDENTIALITY

All information that you give during this study will be kept strictly confidential and will only be seen by the head investigator. Once the information is analysed, no one will be able to identify you or your baby. Additionally, any research reports or articles in scientific journals about this study will not include any information that may identify you, your baby or your hospital. All data obtained from the study will be stored securely for 15 years as hard copies at the University of Pretoria, Department of Speech-Language Pathology and Audiology, as well as electronically on a password protected database.

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CONSENT TO PARTICIPATE IN THIS STUDY

I confirm that the person asking my consent to take part in this study has told me about the nature, processes, risks, discomforts and benefits of the study. I have also received, read and understood the above written information regarding the study. I am aware that the results of the study, including personal details, will be confidentially processed into research reports. I am willingly allowing my baby to participate in the study. I have had time to ask questions and have no objection to participate in the study. I understand that there is no penalty should I wish to discontinue with the study and my withdrawal will not affect my baby, his/her treatment or access to healthcare in any way. I have received a signed copy of this informed consent agreement.

Participant's name ……..... (Please print)

Parent/guardian's name ……..... (Please print)

Parent/guardian's signature …….. Date.....

Investigator's name ……..... (Please print)

Investigator's signature ……..... Date.…..

Witness's Name ……..... (Please print)

Witness's signature ……..... Date.…..

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VERBAL INFORMED CONSENT

I, the undersigned, have read and have fully explained the participant information leaflet, which explains the nature, process, risks, discomforts and benefits of the study to the parent/caregiver whose baby I have asked to participate in the study.

The parent/caregiver indicates that s/he understands that the results of the study, including personal details, will be confidentially processed into a research report. The participant indicates that s/he has had time to ask questions and has no objection to participate in the study. S/he understands that there is no penalty should s/he wish to discontinue with the study and his/her withdrawal will not affect any treatment/ access to services in any way. I hereby certify that the parent/guardian has agreed for their baby to participate in this study.

Participant's name ……..... (Please print)

Parent/guardian's name ……..... (Please print)

Parent/guardian's signature …… Date.....

Investigator's name ……..... (Please print)

Investigator's signature ……..... Date…….....

Witness's Name ……..... (Please print)

Witness's signature ……..... Date…….....

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Faculty of Humanities
Department of Speech-Language Pathology and Audiology

OUER OF VOOF INLIGTING & INGELIGTE TOESTEMMINGSDOKUMENT

TITEL VAN DIE STUDIE: Voeding en ontwikkelingsuitkomste van pasgeborenes met Hipoksiese-Iskemiese Enkefalopatie (HIE)

Geagte Ouer/Voog

1) INLEIDING

Ons nooi u uit, namens u baba, om deel te neem aan 'n studie oor die voeding en ontwikkelingsuitkomste van pasgeborenes met Hipoksiese-Iskemiese Enkefalopatie (HIE). Hierdie inligtingspamflet behoort u te help om te besluit of u, u baba wil laat deelneem aan ons studie. Voordat u besluit om deel te neem, behoort u volledig te verstaan wat die studie behels. Indien u enige vrae het, moet asseblief nie huiwer om die hoof-ondersoeker, Roxanne Malan, te kontak nie.

2) DIE AARD EN DOEL VAN DIE STUDIE

U baba is in die hospitaal en benodig spesiale sorg omdat hy/sy siek is. Babas soos u s'n mag voedingsprobleme hê soos bv. probleme met suig en sluk. Die doel van hierdie studie is om die voeding van babas met HIE te ondersoek en om hierdie aan hulle ontwikkeling op 6, 12 en 18 maande te koppel. U baba kan ons help om meer inligting te kry, sodat ons ons studiedoelwit kan bereik. Ons vra dus u toestemming vir u baba om aan ons studie deel te neem.

3) VERDUIDELIKING VAN PROSEDURES WAT GEVOLG WORD

Eerstens, behels die studie assessering van u baba se voeding terwyl hy/sy nog in die hospitaal is. Dit sal by u baba se bed gedoen word, asook deur 'n sluk x-straal. Vir die assessering by u baba se bed, sal die ondersoeker algemene waarnemings maak van u baba in rus, asook om haar vinger te gebruik om u baba se suig te assesseer. Waarnemings van u baba se suig en sluk sal ook gedoen word terwyl u, u baba voed. Vir die sluk x-straal, sal 'n vloeistof wat soos water lyk vir u baba met 'n Tommy Tippee bottel gegee word. Hierdie is 'n spesiale vloeistof wat op die x-straal sal vertoon. U baba sal op die x-straalmasjien se bed lê terwyl hy/sy aan die bottel drink en die hospitaal se spraakterapeut sal na die x-strale kyk om u baba se voeding te assesseer.

Tweedens, behels die studie assessering van u baba se ontwikkeling op 6, 12 en 18 maande. Hierdie deel van die studie sal gedoen word terwyl u baba 'n buitepasiënt is, op dae wat u alreeds afsprake het by die hospitaal, sodat u nie spesiaal vir die studie hoef in te kom nie. Die ontwikkelingsassessering behels waarneming van u kind tydens verskeie take en speelaktiwiteite, asook vrae oor u kind se ontwikkeling wat aan u as ouer/voog sal gevra word.

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4) RISIKO EN ONGEMAK BETROKKE

Daar sal geen risikos by u baba se voedingsassessering by die bed betrokke wees nie en daar sal ook nie risikos by u kind se ontwikkelingsassessering betrokke wees nie. Daar mag moontlik slegs minimale risikos by die sluk x-straal betrokke wees. Daar is egter vorige studies wat bevind het dat bestraling dosisse tydens dié x-strale minimaal is.

Dit behoort 45 minute te neem om u baba se voeding by die bed te assesseer en 15 minute om u baba se sluk x-straal te voltooi. (Dit sluit in die tyd wat dit vat om u baba op die masjien te posisioneer, om die x-strale te neem, asook om die verslag te skryf). Elke ontwikkelingsassessering mag tot 60 minute neem om te voltooi.

5) MOONTLIKE VOORDELE VAN DIE STUDIE

Die resultate wat uit hierdie studie behaal word, sal u as ouer/voog toelaat om u baba se funksionering beter te verstaan. Indien voedingsprobleme of ontwikkelingsagterstande geïdentifiseer word, sal u baba vir vroeë intervensie vewys word. Daar is bevind dat vroeë intervensie kinders se langtermynuitkomste aansienlik verbeter. Die resultate wat uit hierdie studie behaal word sal ook gesondheidswerkers beter laat verstaan hoe om soortgelyke siek babas in die toekoms te help.

6) WAT IS U REG AS DEELNEMER?

U deelname aan die studie is heeltemal vrywillig. U kan weier om deel te neem of ophou op enige tydstip gedurende die studie sonder om 'n rede te gee. U onttrekking uit die studie sal nie u baba, sy/haar behandeling of toegang tot gesondheidsorg beïnvloed nie. U kan enige vrae vra om die studie beter te verstaan op enige stadium tydens die navorsingsproses.

7) HET DIE STUDIE ETIESE GOEDKEURING ONTVANG?

Hierdie studie het geskrewe goedkeuring ontvang van die Navorsingsetiekkomitee by die Universiteit van Pretoria, mediese kampus, Tswelopelegebou, vlak 4-59. Die komitee se telefoon nommers is 012 356 3084 / 012 356 3085. Goedkeuring is ook ontvang van die hoof uitvoerende beampte van Steve Biko Akademiese Hospitaal.

8) INLIGTING EN KONTAKPERSOON

Die kontakpersoon vir die studie is die hoof-ondersoeker, Roxanne Malan. Indien u enige vrae het oor die studie, kontak haar gerus op 078 803 1992. Alternatiewelik, kan u haar toesighouers kontak op jeannie.vanderlinde@up.ac.za of alta.kritzinger@up.ac.za .

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9) VERGOEDING

U deelname aan die studie is vrywillig. Verversings sal aan u voorsien word wanneer u en u baba die ontwikkelingsassesserings bywoon op 6, 12 en 18 maande.

10) VERTROULIKHEID

Al die inligting wat deur u tydens die studie verskaf word, sal streng vertroulik gehou word en sal slegs deur die hoof-ondersoeker gesien word. Sodra die inligting ontleed is, sal niemand u baba kan identifiseer nie. Enige navorsingsverslae of artikels wat in wetenskaplike joernale verskyn oor hierdie studie sal geen inligting bevat wat u, u baba, of u hospitaal kan identifiseer nie. Alle data verkry uit die studie sal veilig as gedrukte kopieë vir 15 jaar gestoor word by die Universiteit van Pretoria, Departement van Spraak-Taal Patologie en Oudiologie, sowel as elektronies op 'n wagwoord beskermde databasis.

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TOESTEMMING OM DEEL TE NEEM AAN DIE STUDIE

Ek bevestig dat die persoon wat my toestemming vra om deel te neem aan die studie vir my die aard, prosesse, risikos, ongemak en voordele van die studie verduidelik het. Ek het ook die bogenoemde skriftelike inligting oor die studie ontvang, gelees en verstaan. Ek is bewus dat die resultate van die studie, my persoonlike besonderhede ingesluit, vertroulik in navorsingsverslae verwerk sal word. Ek is gewillig vir my baba om aan die studie deel te neem. Ek het tyd gehad om vrae te beantwoord en het geen beswaar om aan die studie deel te neem nie. Ek verstaan dat daar geen straf is as ek my deelname aan die studie staak nie en my onttrekking sal nie my baba, sy/haar behandeling of toegang tot gesondheidsorg beïnvloed nie. Ek het 'n getekende afskrif van hierdie ingeligte toestemmingsdokument ontvang.

Deelnemer (baba) se naam ..... (Drukskrif asseblief)

Ouer/voog se naam ..... (Drukskrif asseblief)

Ouer/voog se handtekening ..... Datum.....

Ondersoeker se naam ..... (Drukskrif asseblief)

Ondersoeker se handtekening ..... Datum.....

Getuie se naam ..... (Drukskrif asseblief)

Getuie se handtekening ..... Datum.....

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MONDELINGE INGELIGTE TOESTEMMING

Ek, die ondergetekende, het ten volle die deelnemende inligtingspamflet wat die aard, prosesse, risikos, ongemak en voordele van die studie verduidelik, vir die ouer/voog wie se baba deelneem aan die studie, voorgelees en verduidelik.

Die ouer/voog dui aan dat hulle verstaan dat die resultate van die studie, persoonlike besonderhede ingesluit, vertroulik in navorsingsverslae verwerk sal word. Die deelnemer dui aan dat hulle genoeg tyd gehad het vir hulle vrae om beantwoord te word en dat hulle geen beswaar het om aan die studie deel te neem nie. Hulle verstaan dat daar geen straf is as hulle deelname aan die studie wil staak nie en dat hulle onttrekking nie hul baba, sy/haar behandeling of toegang tot gesondheidssorg sal beïnvloed nie. Hiermee sertifiseer ek dat die ouer/voog ingestem het vir hul baba om aan die studie deel te neem.

Deelnemer (baba) se naam …….. (Drukskrif asseblief)

Ouer/voog se naam …….. (Drukskrif asseblief)

Ouer/voog se handtekening …… Datum……

Ondersoeker se naam ……. (Drukskrif asseblief)

Ondersoeker se handtekening …… Datum…….

Getuie se naam ……..…….. (Drukskrif asseblief)

Getuie se handtekening ……..…… Datum…….

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TSEBIŠO YA MOTSWADI GOBA MOHLOKOMEDI & TOKUMENTE YA TUMELELANO

SEHLOGO SA THUTO: Ditlamorago tša phepo le tlhokomelo ya masea ka Hypoxic Ischaemic Encephalopathy (HIE)

Motswadi/Mohlokomedi yo a rategago

1) MATSENO

Legatong la gago le lesea la gago, re go laletša go tšea karolo thutong ya phepo le tlhokomelo ya masea a nago le Hypoxic Ischaemic Encephalopathy (HIE). Tsebišo ye le tokumente ye di swanetše go go thuša go dira phetho ya ge e ba o nyaka gore ngwana wa gago a tšee karolo thutong ye. Pele o dumela go tšea karolo, o swanetše go kwešiša ka botlalo seo e se akaretšago. Ge e ba o na le potšišo le ge e le efe, hle o se dikadike go botšiša molaodimogolo wa tlhahlobo, Mohumabadi Roxanne Malan.

2) SEBOPEGO LE MORERO WA THUTO YE

Lesea la gago le sepetlele gore le alafše. Masea a go swana le la gago a na le mathata a go ja a go swana le go goga le go metša. Morero wa thuto ye ke go hlahloba go fepša ga masea a nago le HIE gomme se sa tswalanywa le go gola ga masea a dikgwedi tše 6, 12 le 18. Lesea la gago le ka re thuša go hwetša tsebišo yeo e tla re thušago go phetha morero wa rena ka gona re kgopela gore o dumelele lesea la gago go tsenela thuto ye.

3) GO HLALOSA MEGATO YEO E SWANETŠEGO GO LATELWA

Sa pele, thuto ye e akaretša go hlahlobja ga tsela yeo ngwana a jago ka yona ge a sa le sepetlele. Se se tla dirwa malaong a lesea la gago gomme go dirišwa x-ray ya go metša. Tlhahlobong ya malaong, mohlahlobi o tla hlahloba lesea ka botlalo ge le robetše, gotee le go diriša menwana ya gagwe gore a kwe ge lesea le goga. Go hlahloba tsela yeo lesea la gago le gogago ka gona le go metša go tla dirwa ge o dutše o fepa lesea la gago. Ge go tliwa go x-ray ya go metša, lesea le tla nweša selo seo se swanago le meetse go dirišwa lepotlelo la Tommy Tippee. Selo seo se hlametšwe gore o se bone gabotse mo go x-ray. Lesea le tla bewa mpeteng wa motšhene wa x-ray ge a dutše a enwa go tšwa lepotlelong leo gomme ngaka ya sepetlele ya *therapist* o tla hlahloba dinepe tša x-ray go hlahloba tsela yeo ngwana a jago ka yona.

Sa bobedi, thuto ye e akaretša go hlahlobja ga kgolo ya lesea la gago ge le na le dikgwedi tše 6, 12 le 18. Karolo ye ya thuto e tla direga ge lesela le tšwile sepetlele, matšatšing ao o tlago sepetlele gore le hlolwe, e le go phema gore o tle sepetlele ka go lebanya bakeng sa morero wo. Tlhahlobo ya kgolo ya lesea e tla akaretša go hlola lesea la gago ge le dira mediro e itšego le ge le raloka gomme wena motswadi/mohlokomedi wa botšišwa dipotšišo mabapi le kgolo ya lesea la gago.

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4) DIKOTSI TŠEO DI KA TŠWELELAGO

Ga go na kotsi le ge e le efe yeo e ka tšwelelago nakong ya ge lesea la gago le hlahlobelwa dijo goba le hlahlobelwa kgolo. Go ka ba feela le dikotsi tše dinyenyane tšeo di sepedišanago le go duma ga motšhene wa go metša wa x-ray. Lega go le bjalo, dithuto tša nakong e fetilego di bontšhitše gore medumo ya metšhene ye ke e menyenyane kudu.

Go tla tšea metsotso e 45 gore go phethwe tlhahlobo ya malong ya go ja ga lesea la gago le palomoka ya metsotso e 15 go phetha x-ray ya go metša. (Se se akaretša nako yeo e tšewago go bewa lesea motšheneng, go tšea x-rays le go ngwala pego). Tlhahlobo e nngwe le e nngwe ya kgolo (ya dikgwedi tše 6, 12 le 18) e ka tšea metsotso e 60 gore e phethwe.

5) MEHOLA YA THUTO YE

Dipoelo tšeo di tla hwetšwago ge lesea la gago le hlahlobelwa dijo le kgolo, di tla dira gore wena motswadi/mohlokomedi o kgone go kwešiša lesea la gago. Ge go ka lemogwa gore lesea le na le mathata a go ja le a go gola, lesea la gago le tla newa tlhokomelo yeo e thušitšego masea a mantši gore a kgole a phetše gabotse. Go oketša moo, dipoelo tšeo di tlago go hwetšwa go thuto ye di tla thuša baoki gore ba kgone go kwešiša kamoo ba ka thušago masea a swerego ke bolwetši bja mohuta wo nakong e tlago.

6) MOTŠEAKAROLO O NA LE TOKELO EFE?

O tsenela thuto ye ka go rata, e sego ka kgapeletšo. O ka gana go tšea karolo goba wa kgaotša go tšea karolo ntle le gore o re nee mabaka. Go kgaotša go tšea karolo thutong ye go ka se kgome lesea la gago, tlhokomelo ya gago goba go hwetša tlhokomelo le ge e le efe ya tša maphelo. O lokologile go botišiša potšišo le ge e le efe gore o kwešiše gabotse thuto ye nakong le ge e le efe ya thuto.

7) NA THUTO YE E HWEDITŠWE E DUMELELANA GABOTSE LE MEALO YA BOITSHWARO?

Thuto ye e hweditše tumelelo e ngwadilwego go tšwa Komiting ya Nyakišišo ya Boitshwaro go tšwa go Lefapha la Thutamahlale ya tša Kalafo Yunibesithing ya Pretoria, kampus ya medisine, ho monyako o ngotsoeng 4-59 ho moago o bitšwago Tswelopele (dinomoro tša bona ke 012 356 3084 / 012 356 3085), le go tšwa go CEO ya Sepetlele sa Thuto sa Steve Biko.

8) BOITSEBIŠO LE MOTHO YO O KA IKGOKAGANYAGO LE YENA

Motho yoo o ka ikgokaganyago le yena thutong ye ke molaodimogolo ya nyakišišo, Mohumabadi Roxanne Malan. Ge e ba o na le potšišo le ge e le efe ka thuto ye, hle ikgokaganye le yena go 078 8031992. Goba o ka ikgokaganya le molaodi wa gago go jeannie.vanderline@up.ac.za goba alta.kritzinger@up.ac.za .

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9) DITEFO

O tsenetše thuto ye ka boithaopo. Wena le lesea la gago le tlo newa dijo tše bohwefo ge le tlile go hlola kgolo ya dikgwedi tše 6, 12 le 18.

10) SEPHIRI

Tsebišo ka moka yeo o re neago yona nakong ya thuto ye e tla bolokwa e le sephiri gomme e tla bonwa ke molaodi wa tlhahlobo feela. Ge tsebišo e se na go hlahlobja, ga go motho yoo a tla kgonago go utolla wena goba lesea la gago. Go oketša moo, pego goba dihlogo le ge e le efe dife go dingwalwa tša thutamahlale di ka se diriše tsebišo le ge e le efe yeo e ka utollago wena, lesea la gago goba sepetlele sa gago. Tsebišo ka moka yeo e hwetšwago go tšwa thutong ye e tla bolokwa e šireletšegile ka mengwaga e 15 e le dikopi Yunibesithing ya Pretoria, Lefapha la Speech-Language Pathology and Audiology, gotee le go bolokwa dikhomphutheng gomme di šireleditšwe ka phasewete.

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TUMELELO YA GO TSENELA THUTO YE

Ke tiišetša gore motho yoo a kgopelago tumelelo ya ka ya gore ke tšee karolo thutong ye o mpoditše mohuta, megato, dikotsi, go se lokologe gote le mehola ya thuto ye. E bile ke hweditše tsebišo e lego ka mo godimo ya thuto ye, ka e bala le go e kwešiša. Ke a lemoga gore dipoelo tša thuto ye, go akaretša boitsebišo bja sephiri, di tla bolokwa e le khupamarama ge e dirišwa dipegong tša nyakišišo ye. Ke dumelela leseana la ka go tšea karolo thutong ye. Ke bile le nako ya go botšiša dipotšišo gomme ga ke ganane le selo seo se diregago thutong ye. Ke a kwešiša ga go kotlo yeo ke tla e hwetšago ge ke nyaka go kgaotša go tšwela pele thutong ye gomme go kgaotša ga ka go ka se kgome ngwana, tlhokomelo ya gagwe ya tša mapheo goba go hwetša tlhokomelo yeo. Ke hweditše kopi e saenwego ya tumelelano ye.

Leina la motšeakarolo …….. (Hle ngwala)

Leina la motswadi/mohlokomedi …….. (Hle ngwala)

Mosaeno wa motswadi/mohlokomedi …… Letšatši……

Leina la monyakišiši …….. (Hle ngwala)

Mosaeno wa monyakišiši …… Letšatši……

Leina la Hlatse …….. (Hle ngwala)

Mosaeno wa Hlatse …….. Letšatši……

Communication Pathology Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 3517

TUMELELANO YA MOLOMO

Nna, yoo a saennego, ke badile le go hlalosetša ka botlalo motšeakarolo boitsebišo bjo bo lego fomon ye, bjoo bo hlalosago sebopego, megato, dikotsi, go se lokologe le mehola ya thuto ye go motswadi/mohlokomedi yoo ke kgopetšego ngwana wa gagwe gore a tšee karolo thutong ye.

Motswadi/mohlokomedi o bontšha gore o kwešiša mehola ya thuto ye, go akaretša ditaba tša sephiri tša go utolla batho, di tla dirišwa ka tsela e ka se utollego boitsebišo bja batho ge go dirwa pego ya nyakišišo ye. Motšeakarolo o bontšha o bile le nako e lekanego ya go botšiša dipotšišo gomme ga a na bothata bja go tšea karolo thutong ye. O kwešiša gore ga go na kotlo yeo a tla e hwetšago ge a kgetha go kgaotša tsenela thuto ye le gore go kgaotša ga gagwe go ka se kgome go hwetša ga gagwe thušo tirelong ye ka nako le ge e le efe ka morago. Ke tiišetša gore motswadi/mohlokomedi o dumeletše lesea la gagwe go tsenela thuto ye.

Leina la motšeakarolo …….. (Hle ngwala)

Leina la motswadi/mohlokomedi …….. (Hle ngwala)

Mosaeno wa motswadi/mohlokomedi …… Letšatši……

Leina la monyakišiši ……. (Hle ngwala)

Mosaeno wa monyakišiši ……. Letšatši…….

Leina la Hlatse ……. (Hle ngwala)

Mosaeno wa Hlatse …….. Letšatši…….

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APPENDIX G

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Speech-Language Pathology and Audiology

Permission to access Records / Files / Data base at Steve Biko Academic Hospital

TO: The Chief Executive Officer (CEO) of Steve Biko Academic Hospital (SBAH)

Re: Permission to do research at SBAH

TITLE OF STUDY: Feeding and developmental outcomes of neonates with Hypoxic Ischaemic Encephalopathy (HIE)

This study is approved by the relevant Head of Department [HOD]: Dr Jeannie van der Linde. Signature:

This request is lodged with you in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000.

I am a PhD student at the Department of Speech-Language Pathology and Audiology at the University of Pretoria, under the supervision of Dr Jeannie van der Linde and Prof Alta Kritzinger. I am also currently working as a speech therapist at SBAH. I herewith request permission on behalf of all of us to conduct a study on the above topic on the hospital grounds. This study involves access to patient records for the past ten years from the Department of Neonatology to investigate the environmental and biological risk factors associated with HIE. It also includes the investigation of the sucking/swallowing abilities of neonates with HIE by means of bedside evaluation and Video Fluoroscopic Swallow Study (VFSS), as well as assessment of their development at 6, 12 and 18 months by means of the *Bayley Scales of Infant Development- Third Edition (BSID-III).*

The researchers request access to the following information: clinical files, record books and data bases. The researchers also request permission to approach the mothers/ caregivers of neonates diagnosed with HIE who are admitted to the hospital, to request their neonates' participation in the study.

We intend to publish the findings of the study in a professional journal and/ or to present them at professional meetings like symposia, congresses, or other meetings of such a nature.

We intend to protect the personal identity of the patients by assigning each individual a random code number.

We undertake not to proceed with the study until we have received approval from the Faculty of Health Sciences Research Ethics Committee, University of Pretoria.

Yours sincerely

Roxanne Malan
Principle researcher

Communication Pathology Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 3517

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Speech-Language Pathology and Audiology

Permission to do the research study at this hospital / clinic and to access the information as requested, is hereby approved, on condition that there will be no cost to the hospital.

Title and name of Chief Executive Officer/ Chairperson of the research committee: Dr TS Mangwane

Name of hospital: Steve Biko Academic Hospital

Signature: _____

Date: 2018/06/19

GAUTENG PROVINSIALE REGERING
DEPT VAN GESONDHEID
STEVE BIKO AKADEMIESE HOSPITAAL
STEVE BIKO ACADEMIC HOSPITAL
2018 -06- 19
PRIVAATSAK/PRIVATE BAG X160
PRETORIA 0001
GAUTENG PROVINCIAL GOVERNMENT
DEPT OF HEALTH

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APPENDIX H

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.
- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 03/14/2020.

13/09/2018

Approval Certificate
New Application

Ethics Reference No: 380/2018

Title: Feeding and developmental outcomes of neonates with Hypoxic Ischaemic Encephalopathy (HIE)

Dear Miss Roxanne Malan

The **Amendment** as described in your documents specified in your cover letter dated 10/09/2018 received on 10/09/2018 was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 12/09/2018.

Please note the following about your ethics approval:
- Ethics Approval is valid for 1 year
- Please remember to use your protocol number (**380/2018**) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

Dr R Sommers; MBChB; MMed (Int); MPharMed,PhD
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health).

Research Ethics Committee
Room 4-60, Level 4, Tswelopele Building
University of Pretoria, Private Bag X323
Arcadia 0007, South Africa
Tel +27 (0)12 356 3084
Email deepeka.behari@up.ac.za
www.up.ac.za

Fakulteit Gesondheidswetenskappe
Lefapha la Disaense tša Maphelo

APPENDIX I

Gmail **Roxanne Malan <malanroxanne@gmail.com>**

Fwd: Your Submission

---------- Forwarded message ---------
From: **SAJCH** <em@editorialmanager.com>
Date: Wed, 28 Jul 2021 at 09:29
Subject: Your Submission
To: Esedra Krüger <esedra.kruger@up.ac.za>

You are being carbon copied ("cc:'d") on an e-mail "To" "Roxanne Malan" malanroxanne@gmail.com
CC: "Jeannie Van Der Linde" jeannie.vanderlinde@up.ac.za, "Alta Kritzinger" alta.kritzinger@up.ac.za, "Melantha Coetzee" mel.coetzee@up.ac.za, "Marien Graham" marien.graham@up.ac.za, "Esedra Krüger" esedra.kruger@up.ac.za

Ref.: SAJCH01901R2
South African neonates with mild and moderate hypoxic-ischaemic encephalopathy
South African Journal of Child Health

Dear Mrs Malan,

We are pleased to let you know that your manuscript has now been accepted for publication in South African Journal of Child Health.

Please find payment form attached herewith. As soon as proof of payment and the completed form have been received, we will send your article into production. (Please note that we are unable to process American Express card payments). Please send proof of payment to claudian@samedical.org

Nearer the date of publication you will receive page proofs from the copy editor, please check these carefully for errors.

Thank you for submitting your work to the journal.

Best wishes

John Pettifor, MBBCh; PhD
Editor In Chief
South African Journal of Child Health

Reviewers' comments:

There is additional documentation related to this decision letter. To access the file(s), please click the link below. You may also login to the system and click the 'View Attachments' link in the Action column.
****

In compliance with data protection regulations, you may request that we remove your personal registration details at any time. (Remove my information/details). Please contact the publication office if you have any questions.

This message and attachments are subject to a disclaimer.
Please refer to http://upnet.up.ac.za/services/it/documentation/docs/004167.pdf for full details.

SAJCH 2020 page fees - 1901.pdf
287K

APPENDIX J

Gmail Roxanne Malan <malanroxanne@gmail.com>

International Journal of Speech-Language Pathology - Decision on Manuscript ID TASL-2022-0157.R2

International Journal of Speech-Language Pathology <onbehalfof@manuscriptcentral.com>
Reply-To: e.cardell@griffith.edu.au
To: malanroxanne@gmail.com

Mon, Nov 7, 2022 at 5:03 AM

06-Nov-2022

Dear Ms Malan:

Ref: Evolution of swallowing and feeding abilities of neonates with hypoxic-ischaemic encephalopathy during hospitalisation: a case series

Our referees have now considered your paper and have recommended publication in International Journal of Speech-Language Pathology. Congratulations! We are pleased to accept your paper in its current form which will now be forwarded to the publisher for copy editing and typesetting.

You will receive proofs for checking, and instructions for transfer of copyright in due course.

The publisher also requests that proofs are checked and returned within 48 hours of receipt.

Thank you for your contribution to International Journal of Speech-Language Pathology and we look forward to receiving further submissions from you.

Sincerely,
Professor Elizabeth Cardell
Editor, International Journal of Speech-Language Pathology
e.cardell@griffith.edu.au

APPENDIX K

Gmail

Roxanne Malan <malanroxanne@gmail.com>

Submission received for Early Child Development and Care (Submission ID: 221386876)

GECD-peerreview@journals.tandf.co.uk <GECD-peerreview@journals.tandf.co.uk> Wed, Jul 20, 2022 at 10:10 AM
To: malanroxanne@gmail.com

Routledge
Taylor & Francis Group

Dear Roxanne Malan,

Thank you for your submission.

Submission ID	**221386876**
Manuscript Title	**Evolution of feeding and developmental outcomes in infants with moderate hypoxic-ischaemic encephalopathy**
Journal	**Early Child Development and Care**

You can check the progress of your submission, and make any requested revisions, on the Author Portal.

Thank you for submitting your work to our journal.
If you have any queries, please get in touch with GECD-peerreview@journals.tandf.co.uk.

Kind Regards,
Early Child Development and Care Editorial Office

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Registered office: 5 Howick Place, London, SW1P 1W.