Risks associated with suspected dysphagia in NICU-admitted infants in a South African public hospital: A retrospective study

by

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Title of dissertation: Risks associated with suspected dysphagia in NICU-admitted infants in a South African public hospital: A retrospective study.

I declare that this dissertation is my own original work. Where secondary material is used, this has been carefully acknowledged and referenced in accordance with university requirements.

I understand what plagiarism is and am aware of university policy and implications in this regard.

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SIGNATURE DATE

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ABBREVIATIONS

ART:	Antiretroviral treatment
BW:	Birth weight
ELBW:	Extremely low birth weight
FTT:	Failure to thrive
GA:	Gestational age
GERD:	Gastroesophageal reflux disorder
HIV/AIDS:	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
LBW:	Low birth weight
MDT:	Multidisciplinary team
MBSS	Modified Barium Swallow Study
MTCT	Mother to child transmission
NICU:	Neonatal intensive care unit
OPD:	Oropharyngeal dysphagia
PMTCT:	Prevention of mother-to-child transmission
SGA:	Small for gestational age
SLT:	Speech-language therapist
SSB:	Suck-swallow-breathing
VFSS:	Video Fluoroscopic Swallow Study
VLBW:	Very low birth weight
WHO:	World Health Organization

ABSTRACT

UNIVERSITY OF PRETORIA

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Title:
Risks associated with suspected dysphagia in NICU-admitted infants in a South African public hospital: A retrospective study.

Abstract:

Background: The prevalence of neonatal dysphagia is increasing, as medical advances contribute to the survival of critically ill and preterm infants. Additional factors such as low birth weight (LBW), gastroesoephageal reflux disorder (GERD), failure to thrive (FTT) and exposure to HIV may increase the complexity of dysphagia symptoms. Knowledge of context-specific risk factors for dysphagia in the neonatal intensive care unit (NICU) may lead to an effective pathway of diagnosis and management in vulnerable neonates.

Objective: The objective was to describe the feeding characteristics and categories of underlying medical conditions in 24 to 42 week gestational age infants while still in the NICU and who were referred for feeding and swallowing assessment.

Method: The study was a retrospective investigation of 231 purposively selected medical and speech-language therapy records. Participants had a mean stay of 28.5 days in the NICU of a peri-urban public hospital and all had feeding concerns. An existing seven-category framework for the classification of suspected dysphagia was used.

Results: Feeding characteristics of the participants demonstrated that 65.0% had previous enteral tube (NGT/OGT) feeding, and only 15.6% were referred for instrumental assessments such as a VFSS by doctors or speech-language therapists (SLTs). The majority of participants used a mixed manner of feeding such as cup and breastfeeding, or cup and syringe feeding. Only 29.7% of participants was able to breastfeed exclusively which was an indication of feeding difficulties as the hospital where the study was conducted promotes exclusive breastfeeding. Results indicated that the majority of participants (90.04%) presented with multiple medical conditions. Underlying neurological conditions (48.48%) and feeding difficulties secondary to systemic illness (65.80%) contributed mostly to suspected dysphagia in the sample. It was found that 70.99% of infants presented with feeding difficulties secondary to other conditions such as LBW and prematurity, highlighting the need for an expanded dysphagia classification framework.

Conclusion: The results are in agreement with the outcomes of previous research and confirm the need for a unique classification framework for dysphagia in South Africa. Neonatal dysphagia is a complex condition and frequently associated with multiple risk factors.

Keywords:

Feeding difficulties, neonatal dysphagia, NICU, paediatric dysphagia, public hospital, risks

CHAPTER 1

The aim of the chapter is to introduce the topic of paediatric and neonatal dysphagia, its assessment and underlying conditions, state the research problem, describe the rationale and pose the research question.

1. INTRODUCTION

Mostly due to the improved survival rate of infants and children with life threatening conditions and multiple associated health problems the incidence of paediatric dysphagia is increasing (Arvedson & Brodsky, 2002; Hawdon, Beauregard, Slattery & Kennedy, 2000; Jadcherla, 2016; Newman, 2000). This increase can be largely associated with advances in medical and surgical treatment of at-risk term, as well as preterm infants (Bell & Sheckman Alper, 2007). Infants born with risk factors such as prematurity, congenital or acquired medical conditions, or those with prolonged stays in neonatal intensive care units (NICUs) are at greater risk of developing feeding and nutritional problems than typically developing, healthy neonates (Sundseth Ross & Browne, 2002; Hawdon et al., 2000). According to Lee et al. (2011) although advanced neonatal intensive care has significantly improved the survival of infants, oral feeding difficulties frequently delay discharge from the NICU. Also, as reported by Jadcherla (2016) the consequences of dysfunctional feeding patterns in neonates, might carry over to infancy and the toddler age group.

Dysphagia is described as a swallowing disorder with a problem in one or more of the four phases of swallowing and speech-language therapists (SLTs) are uniquely qualified to treat the disorder (Arvedson, 2008). According to Newman (2000) the paediatric population with dysphagia may display different symptoms and signs than adults with dysphagia. Infants and young children with dysphagia therefore present a unique diagnostic challenge, and paediatric dysphagia must be identified as early as possible (Newman, 2000). According to Dodrill and Gosa (2015) the acts of eating are categorized as the 1.) Oral phase, 2.) Triggering of swallow reflex, 3.) Pharyngeal phase and 4.) Esophageal phase. It was also found that common presentations of

dysphagia in infants include oral phase symptoms such as absent oral reflexes, primitive, or better described as neurological oral reflexes, weak suck, uncoordinated suck, immature biting, poor bolus propulsion and poor bolus containment. Abnormalities in triggering of the swallow include absent swallow, delayed trigger of swallow, suck-swallow-breathing (SSB) incoordination, and pharyngeal phase symptoms include laryngeal penetration, aspiration, choking, pharyngeal residue and nasopharyngeal reflux (Dodrill & Gosa, 2015). As a result of the many symptoms in the four phases of swallowing, often co-occurring, dysphagia is a complex condition in infants and neonates (Dodrill & Gosa, 2015). Due to increased knowledge and focus of unique symptoms of dysphagia in the neonatal stage the term neonatal dysphagia is now used by Jadcherla et al. (2009) and Jadcherla (2016).

The early detection and management of dysphagia and swallowing disorders in infants and neonates is important to prevent or minimize associated medical and developmental complications. Left unidentified and untreated, dysphagia can lead to failure to thrive (FTT), gastroesophageal reflux disorder (GERD), aspiration pneumonia and an inability to establish and sustain vital nutrition and hydration in the young child (Prasse & Kikano, 2009). Therefore the multidisciplinary team (MDT) working with neonates need to detect those at risk for dysphagia as early as possible.

Early management or intervention for dysphagia is strongly recommended (Arvedson & Brodsky, 2002). According to Barratt and Ogle (2010) very few infants and children with neurodevelopmental disorders are referred for dysphagia assessments in the South African hospitals where their research was conducted. The outcomes of the study suggested inadequate cross-referral of patients between the different professionals involved in the assessment and management of children with neurodevelopmental impairments (Barratt & Ogle, 2010). Hawdon et al. (2000) described the difficulty for medical and nursing staff to detect infants with possible swallowing difficulties, and to predict those who will display long term feeding difficulties. Barratt and Ogle (2010) recommended that early identification of

dysphagia be improved by introducing mandatory dysphagia screenings in order to identify children who are at risk of the condition and to intervene early. A good starting point could be to screen all high-risk neonates presenting with risk factors of dysphagia, but specific protocols and procedures for neonatal dysphagia must still be agreed upon in South Africa.

According to Kakodkar and Schroeder (2013) the evaluation of an infant or child with feeding difficulties in a hospital begins with a thorough history and physical examination by a physician, which is supplemented by a clinical swallow assessment performed by a feeding specialist. Feeding and swallowing assessment includes a bedside swallow evaluation (clinical assessment), performed by a SLT to gain a preliminary understanding of the clinical signs of dysphagia a patient presents with. By introducing oral substances such as milk, the examination may help to determine the cause of dysphagia, the readiness to begin oral feeding and the ability to comply with subsequent radiographic studies such as a videofluoroscopic swallow study [VFSS] (Kakodkar & Schroeder, 2013). The VFSS is an instrumental assessment that provides dynamic imaging of the swallow process and allows visualization of some aspects of oral, pharyngeal, and upper esophageal phases of swallowing. The VFSS, also known as a modified barium swallow study (MBSS), is the most commonly used instrumental method and is specifically useful in assessing oropharyngeal dysphagia [OPD] (Romano, Schultz & Tai, 2012). The main aim of the instrumental assessment is to describe the pharyngeal phase of swallowing and to identify possible aspiration (Arvedson, 2008). During imaging, the lateral view is standard, whereas the anteroposterior view is used particularly when asymmetry is noted. The esophagus is scanned only for transit of the bolus and necessary referrals are made if a more comprehensive assessment of the structure and function of the esophagus is needed (Arvedson, 2008). The information obtained from a VFSS is invaluable to the rest of the MDT with regard to further testing and selection of aims for feeding intervention (Kakodkar & Schroeder, 2013). VFSS or MBSS can be used in neonates and is regarded safer than an upper gastrointestinal examination or esophagram due to the shorter testing time and the use of a small amount of barium, even in

premature infants (Lee et al., 2011). Assessment of paediatric dysphagia can include clinical assessment and quality of life measures, as well as instrumental assessment tools (Dodrill & Gosa, 2015). It appears that an agreement on the ideal assessment protocol for paediatric dysphagia has not been reached in the literature (Dodrill & Gosa, 2015). It was noted that in current clinical practice, many clinicians do not routinely use formal assessment tools when assessing children with suspected dysphagia (Dodrill & Gosa, 2015). Many SLTs use informal checklists based on normal swallowing and feeding development to guide their evaluation (Dodrill & Gosa, 2015). According to Romano et al. (2012) the clinical swallow assessment is an essential diagnostic tool for centers where VFSS facilities are not available. However, some studies have shown that a clinical swallow assessment is a poor diagnostic tool for assessment of aspiration, especially for infants presenting with silent aspiration (Romano et al., 2012). Clinical detection of a wet voice, wet breathing and cough are often associated with thin liquid aspiration (Dodrill & Gosa, 2015). Given the high rates of silent aspiration in the paediatric population, there are several studies which question a SLT's accuracy for predicting airway compromise, based on clinical observation alone (Lee et al., 2011, Kyeong, Sook-Hee, Hyun, Hee & Yeong-Yi, 2013). Thus regardless of clinical signs observed, if a SLT suspects airway compromise during swallowing based on respiratory symptoms, the patient should be referred for instrumental assessment to confirm the presence of airway compromise and determine aspiration risk (Dodrill & Gosa, 2015). However, disadvantages of VFSS include that the infant is exposed to radiation, the procedure is relatively expensive, requires specialist equipment and staff, and is not available to all clinicians (Romano et al., 2012). In contrast, the clinical swallow assessment is a non-invasive assessment of swallowing and oral feeding skills and is widely available to all clinicians, provided that a standardized assessment tool is used.

Early dysphagia intervention is important as a vast array of underlying medical conditions can cause dysphagia in infants and may have severe and fatal consequences (Hawdown et al., 2000). According to Newman (2000) dysphagia in neonates and infants is the result of multiple underlying medical

problems, and may further impair health and cause respiratory complications. Therefore the need exists to investigate the swallowing function in infants with specific medical diagnoses (Newman, 2000). Literature reports that causes of paediatric dysphagia can be multidimensional, existing alone or in addition to other underlying medical conditions (Prasse & Kikano, 2009). It is therefore clear why Jadcherla (2016) describes the feeding problems of neonates and infants as highly complex in nature.

Infants with neurological conditions are commonly found to have feeding difficulties (Arvedson & Brodsky, 2002; Prasse & Kikano, 2009). It is estimated that 85 to 90% of infants and children with neurological conditions such as cerebral palsy will present with dysphagia at some point in their lives (Arvedson & Brodsky, 2002). Further, the high incidence of systemic illnesses such as pneumonia in paediatric populations with dysphagia is linked to specific diagnoses such as Trisomy 21, asthma, GERD, lower respiratory tract infection, and moist cough (Dodrill & Gosa, 2015). It is therefore evident that infants can present with multiple variations and combinations of swallowing impairments. Literature indicates that paediatric patients with multisystem diagnoses, in addition to dysphagia, appear to be at greatest risk for developing pneumonia (Dodrill & Gosa, 2015). It can thus be deducted that a close relationship exists between dysphagia and the infant's medical diagnosis or associated conditions.

Different frameworks in literature are used to classify the aetiology of paediatric dysphagia (Arvedson & Brodsky, 2002; Manikam & Perman, 2000; Miller & Willging, 2003; Prasse & Kikano, 2009; Rommel, Meyer, Feenstra & Veereman-Wauters, 2003) but diverse opinions regarding the categories of classification, and the correct terminology for describing the origin of dysphagia are found. Most authors (Arvedson & Brodsky, 2002; Manikam & Perman, 2000; Miller & Willging, 2003; Prasse & Kikano, 2009; Rommel et al., 2003) use the term "aetiology" to describe the origin of dysphagia, whereas other researchers (Hawdon et al., 2000; Newman, 2000) use the term "at risk for dysphagia" indicating that it is not always possible to determine a single aetiological factor. In the current study, the term "at risk for dysphagia" was used, due to additional factors contributing directly or indirectly to neonatal

dysphagia in South Africa. In a study by Fourie (2011) the known frameworks (Arvedson & Brodsky, 2002; Manikam & Perman, 2000; Miller & Willging, 2003; Prasse & Kikano, 2009; Rommel et al., 2003) for classifying the aetiology or risk factors of dysphagia were considered to apply to the South African context. Fourie (2011) noted that none of the classification frameworks effectively describes the complex nature of paediatric dysphagia, especially in a developing country. The need for a comprehensive classification framework, acknowledging the time of presentation of the underlying cause, the biological system involved and the progression of the primary medical condition was highlighted (Fourie, 2011). Fourie (2011) then adapted Arvedson and Brodsky's (2002) classification framework for major diagnostic categories associated with paediatric dysphagia for her research in the local context. This framework includes six categories, namely neurological involvement, anatomical and structural impairments, genetic disorders, dysphagia secondary to systemic illness, psychosocial and behavioral factors as well as dysphagia secondary to resolved medical conditions. Fourie (2011) motivated the addition of a seventh category, "other" as the prevalence of prematurity, low birth weight (LBW), GERD and FTT is high in South Africa, and does not fit within one of the six other categories. Recently, Dodrill and Gosa (2015) also expanded on Arvedson and Brodsky's (2002) major diagnostic categories and reported on a number of other paediatric populations at risk for dysphagia, such as children with ingestional injuries such as ingestion of cleaning agents as well as maternal and perinatal conditions such as diabetes, jaundice and fetal alcohol spectrum disorder. The authors again indicated the need to include infants born preterm and with LBW as a population at risk for dysphagia (Dodrill & Gosa, 2015).

Although not included in Arvedson and Brodsky's major diagnostic categories associated with paediatric dysphagia, and specifically neonatal dysphagia, preterm infants frequently present with feeding difficulties due to poor coordination during the suckling and swallowing process (Kakodkar & Schroeder, 2013; Dodrill, 2011). Poor suckling in preterm infants may occur due to underdeveloped oral motor strength, coordination and immaturity (Jadcherla, 2016; Lee et al., 2011). In a study conducted by Hawdon et al.

(2000) it was found that infants with the most complex or severe medical conditions were most at risk of having disorganized or dysfunctional feeding patterns. The importance of discriminating between normal, disorganized, and dysfunctional feeding patterns were also highlighted. Numerous preterm infants present with disorganized feeding patterns, generally due to immaturity, whereas dysfunctional sucking patterns, and can be associated with neurological involvement (Hawdon et al., 2000).

1.1 Rationale and research question

Rodgers and Arvedson (2005) reported that feeding and swallowing disorders are relatively common in early infancy (1-3 months) among those born preterm and with LBW, which frequently result in significant health implications. Literature describes that dysphagia is also a common condition in full term infants less than one month of age; it is also frequently encountered in infants under one year with a clinical history of bronchitis and recurrent pneumonia (Vazquez & Buonomo, 1999). However, very few studies have investigated the clinical features and mechanisms of dysphagia in infants younger than one year (Kyeong et al., 2013). This statement was confirmed by Jadcherla (2016) who reported that neonatal dysphagia represents a major problem worldwide, although the exact prevalence is still unknown. Therefore neonates and infants are exceptionally vulnerable to present with dysphagia. Limited research regarding the risk factors associated with neonatal dysphagia is currently available, particularly in developing countries where the burden of disease is high (Olusanya, Ruben & Parving, 2006). Limited research regarding neonatal dysphagia has been conducted in the South African context, especially in NICUs of public hospitals.

Given the high incidence and prevalence of neonatal and paediatric dysphagia, and the potentially severe and even fatal consequences, appropriate diagnosis and management of swallowing and feeding disorders are critical (ASHA, 2001). Newman (2000) stated that a variety of paediatric medical conditions can affect swallowing, and the signs and symptoms of dysphagia differ from those of adults. Special skills are therefore required to identify very young patients at risk of dysphagia. The outcomes of the study

may provide a better understanding of the most common risk factors associated with neonatal dysphagia in a particular context. The results may potentially lead to improved identification and referral of neonates at risk, to be assessed for dysphagia, and potentially diagnosed and managed early, which may lead to improved outcomes.

A rich database of medical and speech therapy records for infants with suspected dysphagia were available within the hospital where the research was conducted. It was anticipated that the study would contribute to a holistic understanding of the complexity of risks present in infants with suspected dysphagia in a public hospital. The research question was therefore twofold: What were the feeding characteristics of a sample of NICU infants with suspected dysphagia, and which categories of medical conditions could be associated with the infants?

1.2 Terminology as used in the dissertation

- **Paediatric dysphagia:** The term paediatric dysphagia has been used in literature for the past decades since dysphagia has been formalized as a field of practice for SLTs (ASHA, 2001; ASHA 2016). According to Newman (2000) the population with paediatric dysphagia is diverse, ranging from premature infants to fully-grown adolescents. It is the role and responsibilities of the SLT working in the NICU to provide evaluations and intervention to paediatric patients with feeding and swallowing difficulties. This includes pre-feeding, assessment and promotion of readiness for oral feeding, evaluation of breast and bottle-feeding ability and completion of instrumental evaluations (ASHA, 2005). According to ASHA (2001) the area of paediatric dysphagia and feeding disorders is one of the most rapidly evolving patient care areas and the SLT is the primary professional involved in assessment and management of individuals with swallowing and feeding disorders.

- **Neonatal dysphagia:** The term is used with reference to Jadcherla et al. (2009) and Jadcherla (2016) who appear to have used it for the first time. Although many descriptions of feeding problems in neonates are found in the literature (Arvedson & Brodsky, 2002; Delaney & Arvedson, 2008; Hawdon, 2000) the term neonatal dysphagia was never used. Hawdon (2000) appeared to be the first study that focused specifically on the population of neonates (birth to 28 days old) at risk of developing feeding problems in infancy. The majority of other studies in the field of paediatric dysphagia used the term "*infancy*, or *infants with dysphagia"* however the term "*infants"* could range from preterm infants to infants of the age of 12 months (Kyeong et al., 2013; Mercado-Dean et al., 2001; Sundseth Ross & Brown, 2002). Arvedson and Brodsky (2002) describe birth to 3 months of life as the "neonatal and early infancy period". Therefore neonatal dysphagia is now used in this dissertation to refer to symptoms of dysphagia experienced by neonates and those in the NICU, although their chronological age may exceed 28 days.

CHAPTER 2

The aim of the chapter is to provide a literature overview of the risks and contributing factors underlying neonatal dysphagia, with particular reference to South Africa.

2. LITERATURE REVIEW

Arvedson (2008) describes that the incidence of paediatric dysphagia is high amongst typically developing children, at 25 to 45%, and even higher, up to 80%, for children with developmental disabilities. Feeding problems are also quite common in children presenting with risk factors such as chronic health problems. Prasse and Kikano (2009) found that the infant and neonatal population with specific developmental and/or medical conditions is at high risk of developing dysphagia, secondary to developmental delay or medical conditions. According to Barratt and Ogle (2010) various studies conducted in specialist feeding clinics such as cerebral palsy clinics, identified and described risk factors in children with dysphagia, but none of the studies has specifically identified risk factors associated with dysphagia in infants admitted to the NICU. Noteably, this category was also omitted by Arvedson and Brodsky's (2002) major diagnostic categories of risks for dysphagia in infants.

According to Bell and Scheckman Alper (2007) infants requiring continuing intervention for feeding difficulties are frequently those admitted to a NICU. Hawdon et al. (2000) acknowledged the need for identifying dysphagia early, for the appropriate long-term dietetic and SLT management. An increased need for improved multidisciplinary collaboration, particularly for children with complex medical conditions, is recommended in a local research study (Barratt & Ogle, 2010). The recommendation is confirmed by a number of authors that multidisciplinary teamwork is imperative for optimal and effective management of dysphagia (Arvedson & Brodsky, 2008; Steinberg, 2007). The need for appropriate assessment of the risk factors associated with dysphagia and describing the effects of early intervention within the MDT is also highlighted in literature (Barratt & Ogle, 2010; Hawdon et al., 2000). Kakodkar and Schroeder (2013) reported that the multidisciplinary approach is essential

to facilitate the early recognition of feeding problems, to identify the underlying conditions and to determine most appropriate intervention strategies.

In a developing country such as South Africa, numerous additional challenges may contribute to dysphagia in infants and neonates, such as the effects of poverty and HIV/AIDS (Fourie, 2011). According to Rabie et al. (2007) HIV/AIDS is closely associated with several neurological conditions such as encephalopathy and seizures, pulmonary conditions, renal diseases, cardiac conditions as well as conditions of the gastro-intestinal tract. HIV-exposure may affect all phases of swallowing as a result of oral thrush, odynophagia and GERD, which can in turn lead to FTT. Rabie et al. (2007) recorded that the prevalence of dysphagia and GERD among children infected with HIV is poorly quantified, but frequently encountered in clinical practice and may have a significant impact on the morbidity of infants with HIV-exposure.

HIV infection can lead to severe oral symptoms, such as blisters, ulcers and viral infections (Coogan, Greenspan & Challacombe, 2005). The oral manifestations may include Kaposi sarcoma, necrotizing ulcerative gingivitis and hairy leukoplakia; it might be painful and interfere with feeding and swallowing and can lead to weight loss, malnutrition and dehydration (Coogan et al., 2005). The authors (Coogan et al., 2005) also mentioned that dysphagia in malnourished infants with HIV infection may result in rapid clinical deterioration. It is, however, still difficult to diagnose infants with HIV/AIDS before the age of 24 months due to increased false-positive results (National Department of Health, 2013; World Health Organisation [WHO], 2007). Therefore the term generally used is HIV-exposed until the child can be tested accurately. An estimated 6.1 million adults and children living with HIV resided in South Africa in 2012 (National Department of Health, 2013). Children under the age of 15 years, account for 4.5% of the total HIV population. In South Africa the rates of infection now continue to decrease, due to the acceleration of prevention of mother-to-child transmission (PMTCT) services (National Department of Health, 2013). However, HIV is a major cause of morbidity and mortality in developing countries such as South Africa where HIV-related deaths account for more than one third of the total number

of deaths in children under the age of five years (Bradshaw, Bourne & Nannan, 2003). MTCT of HIV is the main mode of HIV acquisition in children in the absence of any interventions to prevent MTCT; approximately 25 to 35% of HIV-positive mothers will transmit HIV to their infants by six months post-delivery (The Independent Expert Panel, 2010). HIV infection in infancy can lead to severe encephalopathy with severe outcomes (Walker et al., 2007). Even in children with HIV without severe outcomes there is increased risk of delays in several developmental domains (Walker et al., 2007). Therefore, when conducting research in NICUs in South Africa, it can be expected that a certain percentage of the study population will present with exposure to HIV and is therefore at risk for dysphagia.

Social and environmental factors may also contribute to the prevalence of neonatal dysphagia (Manikam & Perman, 2000). Guralnick (2011) stipulates the importance of including social and environmental factors as a holistic intervention approach in children. The importance of family resources such as social and financial support in child development cannot be underestimated (Guralnick, 2011). Family resources include personal characteristics of the parents, such as the parent's mental and physical health and intellectual abilities, as well as material resources and social support, such as emotional sustenance and financial assets. According to Benatar (2004) many of the patients in public hospitals in South Africa are unemployed and reside in peri-urban settlements. It is also significant that a high number of children with disabilities reside in low-income settlements (Cameron, Nixon, Parnes, & Pidsadny, 2005). Disabilities are linked to poor pre- and perinatal care (Walker et al., 2007). Pregnant mothers living in poverty are at risk to give birth to preterm and LBW infants (Emerson & Hatton, 2007). Chen et al. (2007) found that teenage pregnancy is associated with increased risks for pre-term delivery, LBW and neonatal mortality. It was reported in the study by Chen et al. (2007) that the younger the maternal age, the higher the risk for complications such as pre-term delivery, LBW, low Apgar scores and neonatal mortality. It is therefore clear that special populations of women giving birth to infants at high risk exist and may contribute to the risk for neonatal dysphagia

in South Africa. Thus a need exists to examine the involvement of social and environmental factors of dysphagia in South Africa.

Another factor that contributes to the prevalence of dysphagia especially in the South African context is preterm birth, which is closely related to LBW. A study conducted by Rommel et al. (2000) was the first to demonstrate a significant correlation between prematurity and feeding difficulties in infants. According to the WHO (2015) an estimated 15 million infants are born preterm annually. Prematurity is classified as birth before 37 weeks of gestation, and categories of prematurity based on gestational age (GA) include extremely preterm (<28 weeks), very preterm (<32 weeks) and moderate to late preterm (32 to 37 weeks) [WHO, 2015]. Globally, preterm birth complications are the leading cause of death among children under five years and accounted for one million deaths in 2013. According to the WHO (2015) in almost all countries, preterm birth rates are increasing. It was found that out of 65 countries with reliable data, 62 countries displayed an increase in preterm births over the past 20 years. Possible reasons for this phenomenon included better measurement of prematurity, increases in maternal age and underlying health problems such as diabetes and hypertension, increased use of infertility treatments and changes in obstetric practices such as more caesarean births before term (WHO, 2015). It appears that in developing countries such as South Africa the rates of preterm birth are even higher, as it is reported that in the lower income countries on average 12% of infants are born preterm, compared to 9% in higher-income countries. Also, in low-income settings, half of the infants born at or below 32 weeks do not survive due to a lack of feasible, cost effective care such as warmth, breastfeeding support and basic care for infections and breathing difficulties. In contrast, almost all infants born in high-income countries survive (WHO, 2015). The prevalence of neonatal dysphagia in high-income countries should therefore be lower than in middle and low-income countries such as South Africa.

Recent studies in a public hospital in South Africa found that the survival rate of preterm VLBW and ELBW infants were low (Jardine & Ballot, 2015; Kalimba & Ballot, 2013). Results from the studies indicate that the survival

rate improved as the infants' birth weight increased. Survival rate for VLBW infants <1 500g was 78.8%, VLBW infants 1000-1499g (87.6%), ELBW infants 750-999g (55.2%) and ELBW infants with birth weight of 900g or less only 26.5%. According to The Global Action Report on Preterm Birth (March of Dimes, Partnership for Maternal, Newborn and Child Health [PMNCH], Save the Children & World Health Organization [WHO], 2012) one of the strategies to reduce deaths among premature infants include exclusive breastfeeding. However, premature infants are especially vulnerable to present with neonatal dysphagia since the coordinated SSB pattern only starts at 34 weeks gestation and they may need extra support for feeding such as feeding with a cup, spoon and/ or oral/ nasal gastric tubes (March of Dimes et al., 2012)

It is not only the survival rates of preterm LBW infants that are significantly low; the morbidities in the infants that have survived appear to be numerous as well (Dodrill, 2011; Jadcherla, 2009; March of Dimes et al., 2012). It appears that the lower the gestational age, the greater the morbidity – these infants are most at risk of early feeding difficulties (Dodrill, 2011; March of Dimes et al., 2012). It was also reported by Dodrill (2011) that although many preterm infants present with severe morbidities it is not only the morbidities, but also the medical interventions required that may further interrupt the feeding development in these infants. One example of interventions that may hinder feeding development in preterm infants is tube feeding. According to Dodrill (2011) most preterm infants will require some degree of tube feeding until they are mature and stable enough to feed exclusively orally. It was, however, noted that the presence of feeding tubes might hinder oral feeding attempts. Common problems found in studies reviewed by Dodrill (2011) included that tube feeding may induce GERD in infants, reduce upper esophageal sphincter tone, reduce swallow frequency, prolong the swallow and adaptive peristaltic reflexes, affect SSB coordination, as well as alter breathing and oral reflexes (Jadcherla et al., 2009; Peter, Wiechers, Bohnhors, Silny, & Poets, 2002; Shiao, Brooker, & DiFiore, 1996; Shiao, Youngblut, Anderson, DiFiore, & Martin, 1995).

According to Delaney and Arvedson (2008) one of the most complicated tasks required of a newborn infant is oral feeding as it involves complex integration of anatomic structures including the lips, jaw, cheeks, tongue, palate, pharynx and larynx. Since preterm infants often display difficulty establishing oral feeding they frequently present with feeding difficulties in the weeks following birth (Dodrill, 2011). The feeding difficulties are mostly due to incoordination of SSB (Kakodkar & Schroeder, 2013). Coordinated rhythmic sequences of SSB are required of infants and although full term neonates have the ability, preterm infants are neurologically immature and are rarely capable of effectively coordinating SSB (Delaney & Arvedson, 2008). Swallowing and breathing utilize a common space in the pharynx and therefore difficulties with feeding are often observed when SSB is not coordinated (Dodrill, 2011).

It was found by Mercado-Deane et al. (2001) that the incidence of dysphagia in the general (healthy) population of infants less than one year is estimated at 13% but increases significantly (26%) in preterm infants. In a study conducted by Lee et al. (2011), it was found that 68.3% of VLBW infants admitted to the NICU within 30 days of birth and who survived until discharge presented with dysphagia. It was also found that 30% of these preterm infants presented with impaired airway protection resulting in potential or obvious aspiration (Lee et al., 2011). Results from a study conducted in Seoul, Korea found similar results in a sample of 107 term and preterm infants with suspected dysphagia. It was found that aspiration was present in 39.3% of the infants and 81.0% of infants with aspiration exhibited silent aspiration (Kyeong et al., 2013). It was also found that the most common reason for referral of preterm infants for a VFSS included desaturation (Kyeong et al., 2013). The reason for desaturation appears to be inadequate SSB coordination that may cause apnea during feeding (Kyeong et al., 2013). One of the most prevalent factors associated with impaired airway protection during swallowing was low gestational age at birth, implying that the lower the gestational age, the higher the rate of impaired airway protection (Lee et al., 2011). Penetration and aspiration could therefore be expected. Appropriate and alternative feeding

options should be considered in VLBW infants with low gestational age at birth, presenting with desaturation during oral feeding (Lee et al., 2011).

Although the survival rates of preterm infants have improved significantly in recent years, one of the most common and urgent care issues that still prevails, is when and how to advance from tube to oral feedings. The ability to make a transition from tube to oral feeding depends on the infant's neurodevelopmental status, cardiorespiratory regulation and SSB coordination (Delaney & Arvedson, 2008). Although the survival rate of critically ill infants has increased, oral feeding difficulties frequently delay their discharge from NICU (Jadcherla, 2009; Lee et al., 2011). Apart from prolonging the need for tube feeding and delaying discharge to home, it appears that ongoing sucking problems in preterm infants at or around term age are predictive of poor developmental outcomes later in infanthood (Dodrill, 2011). Once infants approach term age, it is often assumed that the nutritive feeding skills of preterm infants will match those of full-term infants (Dodrill, 2011). However, numerous research studies indicate that the sucking patterns of preterm infants remain significantly less efficient than those of full-term infants at term age and beyond (DeMauro, Preeti, Medoff-Cooper, Posencheg & Abbasi, 2001; Dodrill, 2011).

Despite different authors reporting on the increase of neonates and infants with dysphagia (Jadcherla, 2016; Kakodkar & Schreuder, 2013; Sundseth Ross & Brown, 2002), and the increase of prematurity (WHO, 2015), limited studies have been conducted in the South African context. Since prematurity and dysphagia show a significant correlation it is concerning that more than 60% of the world's preterm births occur in Africa and South Asia (WHO, 2015). It is therefore important to determine and describe the feeding characteristics and multiple medical conditions associated with neonatal dysphagia in the context of a developing country such as South Africa.

CHAPTER 3

The aim of this chapter is to describe the research aims, design, ethical considerations, participants, material and procedures followed to determine which categories of underlying medical conditions were associated with neonates with suspected dysphagia in a specific public hospital. This chapter contains more methodological information than that included in the article in Chapter 4.

3. METHODOLOGY

3.1 Aims of the study

The aims of the study were to describe the feeding characteristics of 0-3 month old infants admitted to a NICU and referred for dysphagia assessments in a South African public hospital and to determine which categories of underlying medical conditions were associated with the participants.

The results of the study were compiled and described in the article “Risks associated with suspected dysphagia in NICU-admitted infants in a South African public hospital” (Chapter 4).

3.2 Research design

The study was a retrospective survey of electronic and paper medical and SLT records from 2010-2014, which included infants, aged 24 - 42 weeks gestational age at birth and admitted in a peri-urban public hospital.

According to Leedy and Ormrod (2010), the research design involves all the planning before the study is executed. The research question of this study required a quantitative research design and was non-experimental in nature (Brink, 2010). According to Brink (2010) the major purpose of non-experimental research is to describe the findings, as well as to explain the relationships between certain variables. The research question of this study required a detailed description of the risk factors associated with dysphagia within the study population. In order to obtain reliable results the largest possible number of participant records had to be included in the study. Within

the quantitative research paradigm, the researcher had the role of an objective observer, and focused on specific questions to reach the aims of the study. In the current study no direct observations of participants occurred. The data were collected from patient medical and SLT records from 2010 to 2014.

According to Struwig and Stead, (2001) quantitative research includes various methods of which a descriptive design is one example. This particular descriptive study was a retrospective review of patient records. According to Gearing, Mian, Barber and Ickowicz (2006), retrospective research often requires the analysis of data that were originally collected for goals other than research. The scientific utilization of health records is common in epidemiological investigations (Gearing et al., 2006). This is also true for the current study, as all data were originally used to assess and manage patients with suspected dysphagia in a tertiary-level, public hospital.

There are various advantages of utilizing retrospective reviews, as it is a relatively inexpensive way to investigate already existing data (Gearing et al., 2006). Within this study, a comprehensive electronic database of NICU patient records that have not been used previously was readily available. Another advantage of utilizing a retrospective review was that no harm or stress was added to the participants, as direct testing was not conducted as the assessments were already completed. This was important, especially in the target population, as infants with dysphagia are already at risk for severe complications such as aspiration, pneumonia and even death (Arvedson, 2008; Tutor & Gosa, 2012). Another advantage is the fact that a large population sample could be investigated within a limited amount of time (Gearing et al., 2006). A large representative sample could therefore be collected which improved the validity and reliability of the study. Several disadvantages are inevitable when using a retrospective review design. The disadvantages included incomplete records, a complex diversity of records, missing records, as well as difficulty interpreting the records (Gearing et al., 2006). However, in this study, the benefits of a large sample outweighed the disadvantages and therefore a retrospective review was used.

3.3. Ethical considerations

In order to conduct this study, ethical clearance was obtained from the Research Ethics Committee of the Faculty of Humanities, of the University of Pretoria before commencement of data collection (see Appendix A). Permission from the University of Limpopo, Medunsa campus (now Sefako Makghato Health Sciences University) was also obtained (see Appendix B). Consent from the study hospital Clinical Director, (see Appendix C) Head of Neonatology (see Appendix D) as well as the Head of the Department Speech Therapy and Audiology (see Appendix E) was also obtained.

The researcher was guided by the following ethical principles to act responsibly and report the findings honestly and accurately:

- Avoidance to harm

Strydom (2005) state that no unnecessary physical or psychological harm should be inflicted on participants of a research study. A researcher should attempt to protect the research participants as far as possible during the study (Leedy & Ormrod, 2010). Due to various risks involved with infants and children with dysphagia, a retrospective review of records was utilized.

- Informed consent

Acquiring informed consent involves that all information relative to the goal, procedures, advantages and disadvantages of the study to which participants may be exposed to, should be explained to the participants in written format (Strydom, 2005). According to Leedy and Ormrod (2010), when research involves public documents or records that has been previously created, the records are considered usable for investigation. Informed consent from each participant was therefore not obtained. However, consent from the institution and associated departments were required before the study commenced (see Appendix A - F).

- Confidentiality

Whitley (2002) states that research participants have a right to privacy that researchers must safeguard by keeping the information provided by each participant in strict confidence. Therefore, no participant names or the name of the hospital was disclosed in the dissertation, in the scientific article or in presentations that may result from the study. The data generated in the study are now securely stored (for 15 years) in the Department of Speech-Language Pathology and Audiology as per university regulation.

- Honesty

The research project must be conducted in an ethically correct manner. The researcher has an obligation towards other professionals to correctly record the data analysis and findings of the study in a truthful manner. During the course of the research project, no one was misled in any manner. The raw data were checked and analyzed by the research supervisor as well as a qualified statistician.

According to Struwig and Stead (2001) plagiarism occurs when a person uses the work of another without the proper acknowledgement of their contribution. The greatest care was taken to avoid plagiarism throughout the research project, through appropriate referencing of all sources utilized in the research project.

3.4 Setting

The setting was a peri-urban South African public hospital and the timeframe was 2010-2014. The hospital receives patients from surrounding townships, rural towns, neighbouring countries or patients transferred from other hospitals. Regular training initiatives in the form of presentations, posters and pamphlets were conducted independently from the study by SLTs working in the in the NICU, to assist healthcare professionals to refer infants in the unit for dysphagia assessment. Training was based on the "*Common criteria for referral of infants and children for feeding and swallowing evaluation*" (Arvedson & Brodsky, 2002: 288) which include: Suckling and swallowing incoordination, weak suck, breathing disruptions or apnea during feeding,

excessive gagging or recurrent coughing during feeds, diagnosis of disorders associated with dysphagia or under nutrition, severe irritability during feeding, history of recurrent pneumonia and feeding difficulty, concern for possible aspiration during feeds, lethargy or decreased arousal during feeds, feeding periods longer than 30 to 40 minutes, nasopharyngeal reflux during feeding and infants with a number of medical diagnoses.

3.5 Participants

A total of 312 infants were referred for assessment of possible dysphagia within the study period of which 231 complete data sets were available. There were therefore 74.04% of the original data sets available for the current study. Inclusion criteria of the data sets were that the infants had to present with one or more symptoms of dysphagia (including oral phase difficulties, abnormalities in the triggering of the swallow as well as pharyngeal phase difficulties), be referred for a feeding or swallowing evaluation by a healthcare professional, admitted to the NICU and assessed for dysphagia by a SLT. Gestational age was determined using the mother's last menstrual period. All participants were referred by medical doctors (including interns, registrar paediatricians and consultant paedaticians), professional and staff nurses, audiologists, SLTs and dieticians for a feeding and swallowing evaluation.

3.5.1 Sampling

A *non-probability sampling* technique was used to draw a research sample. The sampling technique was not random and therefore sampling is purposive. *Purposive sampling* is appropriate for this specific research problem as the researcher's judgment is used to select the participants, based on the goals of the research (Whitley, 2002). The research sample was thus selected with the purpose of the research question in mind, i.e. describing the risk factors associated with suspected dysphagia in infants, who in effect formed the participants of the study. As mentioned previously, a retrospective review design was utilized, mainly to include the largest sample size possible in the study. According to Leedy and Ormrod (2010) the trustworthiness of the results of a study relies on the representativeness of the sample, thus a large sample size should provide a representative sample and great variety of data.

A representative sample also prevents the researcher from overlooking important information (Leedy & Ormrod, 2010).

The aim was to include all complete data sets of infants seen for dysphagia assessment from 2010 to 2014. Departmental records showed that approximately 100 infants were assessed and treated annually by the seven different therapists working in the field of paediatric dysphagia, during the period 2010 to 2014. Thus approximately 500 data sets could be anticipated. However, the final number of participants was dependent on the inclusion criteria as well as the number of complete datasets in the database, as incomplete datasets cannot be used for research (Mouton, 2001).

3.5.2 Participant description

General participant characteristics are illustrated in Figure 3.1.

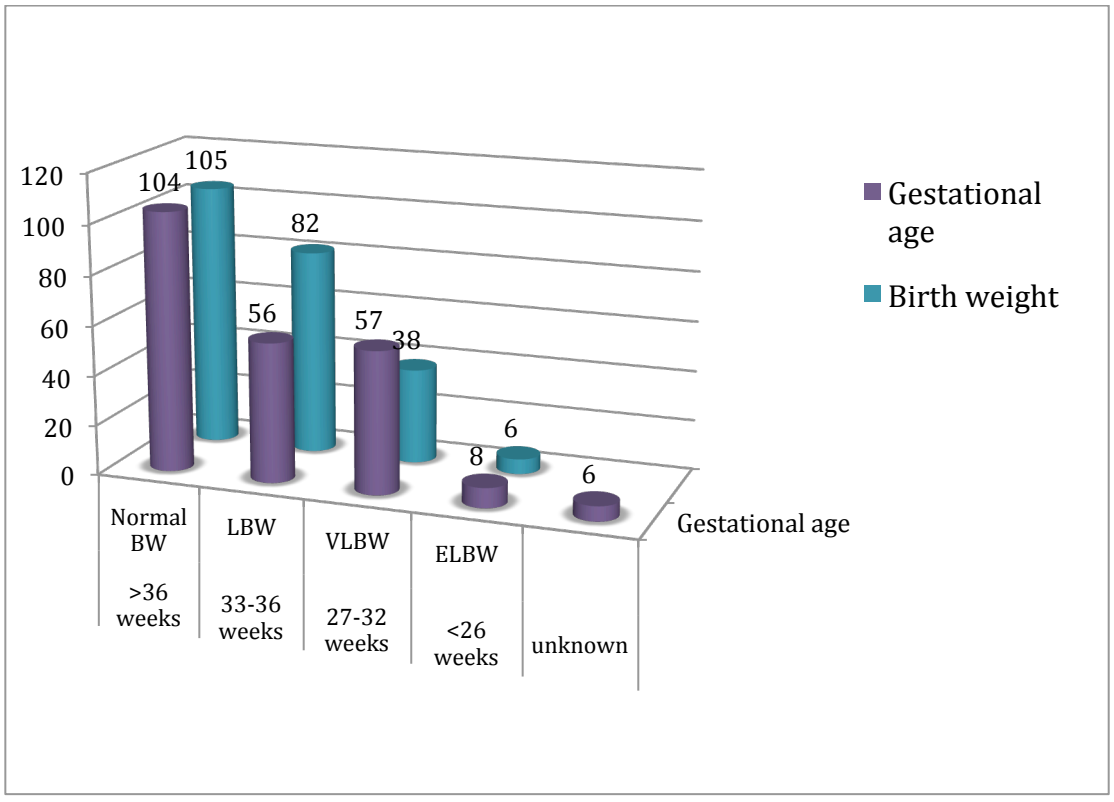

Figure 3.1: Participant weight and gestational age at birth (n=231)

According to Figure 3.1, the majority (104, or 45.02%) of participants were born full term (>37 weeks GA). However, combined (from 26 weeks to 36 weeks GA) 127 (54.98%) participants were born preterm (>37 weeks GA).

The mean gestational age was 34.9 weeks, with a median of 36 weeks. The participants were therefore mostly moderately preterm. Preterm infants of 34-36 weeks gestation, without any other conditions, demonstrate skills that show positive prognosis for becoming full oral feeders, but may not consistently take oral feeds efficiently until closer to 37 weeks gestation (Arvedson & Brodsky, 2002). Research shows that the prevalence of feeding difficulties in infants born before 37 weeks gestation is 10.5% and increases to 24.5% among those with very LBW [VLBW] (Arvedson & Brodsky, 2002). In this study the majority of participants (126 or 54.55%) had LBW (>2500g), VLBW (<1500g) or extremely LBW [ELBW] (>1000g).

According to Lee et al. (2011) safe feeding implies a minimal risk of aspiration and proper coordination of the SSB sequence. This coordination occurs between 33 to 34 weeks and matures between 33 and 36 weeks in the fetus or preterm infant (Arvedson & Brodsky, 2002; Lee et al., 2011). Immature SSB coordination may cause apnea during swallowing or aspiration and is regarded as major causes of oral feeding difficulties. In a study by Lee et al. (2011) 70% of very LBW infants who were referred for a MBSS for significant desaturation during oral feeding at postmenstrual age ≥35 weeks displayed numerous swallowing abnormalities. Thirty percent of those infants presented with impaired airway protection resulting in potential or obvious aspiration (Lee et al., 2011). The finding is in agreement with the current study as all participants presented with symptoms of dysphagia and the majority was preterm LBW infants. Further infant participant characteristics are described in the article (Chapter 4) submitted for publication.

In Table 3.1 the characteristics of the mothers of participants are presented.

Table 3.1: Characteristics of mothers of participants (n=231)

Characteristic	Description	Value
Nationality of mother	South African	88.3%
	Non-South African	11.7%
Age of mother (2 missing values)	14 -18 years	11.7%
	18-39	81.7%
	>40 years	6.6%

Maternal education (17 missing values)	< Gr 8 Gr 8-11 Completed Gr12 Tertiary level	13.6% 81.3% 5.1% 0%
HIV status of mother (37 missing values)	HIV Negative HIV Positive	69.6% 30.4%
Number of antenatal visits (1 missing value)	None 1-3 4 and more	16.1% 33.9% 50%
Type of delivery (1 missing value)	Normal vertex delivery Caesarian section delivery	59.6% 40.4%

According to Table 3.1, the majority of mothers was between the ages of 18 to 39, but 11.7% of mothers were teenagers. Teenage pregnancy may be associated with increased risks of preterm delivery, very LBW weight infants, small-for-gestational age infants, very low/low Apgar scores at 5 minutes as well as neonatal mortality (Chen et al., 2001), and therefore is per implication at increased risk of presenting with symptoms of dysphagia. The majority of mothers had an education between Gr 8 to 12, however, 13.6% of mothers were on an educational level less than Gr 8. The percentage of mothers who were HIV positive, and per implication had infants exposed to the virus, corresponds with the 2012 antenatal HIV seroprevalence survey (National Department of Health, 2013). The estimated HIV prevalence in the survey was 29.5% in pregnant women and in this study 30.4% of the participants' mothers were HIV positive. Fifty percent of mothers attended three or less antenatal visits, which imply that half of the mothers, had inadequate prenatal care. The 40% caesarian section deliveries can partly be contributed to the 30.4% of mothers who were HIV positive and undergo this procedure as per HIV treatment guidelines (National Department of Health, 2013). Increasing poverty and limited access to maternal and child health care services in developing countries may lead to increased risks of congenital and acquired neurological impairments (Barratt & Ogle, 2010), and can also be associated with several adverse perinatal conditions, such as LBW weight, birth trauma, and rubella, which can cause various forms of disability (Olusanya et al., 2006). Therefore it is important to note that maternal HIV, limited prenatal

care and low maternal educational levels can be linked with prematurity, LBW, various other associated conditions and extended stay in the NICU.

3.6 Material

The source materials used during data collection for the study included:

- *"Neonatal patient discharge report"* available in electronic format from the NICU database. An appointed nurse independently captured the medical records in a computer program designed to create discharge reports for each infant admitted to the NICU. The procedure provided a standard report with important demographic, prenatal, perinatal and medical information for all the participants. Researcher-bias was limited, as the nurse did not know the aims and objectives of the study. All discharge reports were printed by the researcher, and entered in an Excel spread sheet.
- Speech-language therapy records included the "*Dysphagia assessment form"* (based on Fraker & Walbert, 2004; Hall, 2001; McGrath, 2004) developed as part of the department protocol in the hospital where the study was conducted. Data were independently collected over five years by seven different SLTs trained to use the same assessment form.

3.7 Data collection instrument

As the material for the study included information from different documents, a tool in the form of a spreadsheet was developed to combine the information (see Appendix G). To achieve the aim of the study, the classification framework by Arvedson and Brodsky (2002) describing major diagnostic categories associated with feeding and swallowing disorders was used as point of departure in the development of the instrument. These categories included conditions with neurological involvement, anatomical and structural impairments, genetic and chromosomal disorders, dysphagia secondary to systemic illness, psychosocial factors as well as dysphagia secondary to resolved medical conditions. In a local study Fourie (2011) expanded on the framework described by Arvedson and Brodsky (2002) by adding a seventh category, "Other" as the prevalence of prematurity, LBW weight, GERD and FTT is high in South Africa, and does not fit within any of the six other categories. The classification framework was selected for the present study as

it was already effectively used and expanded upon in a previous study by Fourie (2011) in a similar context. In addition to the expanded classification framework, the following subcategories of risks were also investigated in the present study: Pre-natal, perinatal and other postnatal medical risks in order to describe the participants, their mothers and some environmental conditions in a holistic manner.

3.7.1 Validity and Reliability

Validity refers to the degree in which an instrument measures what it is intended to measure (Leedy & Ormrod, 2010), whereas reliability refers to whether the same data can be obtained at a different time, by using the same data collection tool (Babbie & Mouton, 2001; Neuman, 2000). The data collection tool (an Excel spreadsheet) was user-friendly to ensure that the information obtained was valid and reliable. The same spreadsheet entries were completed for every participant, and were thus consistent and contributed to reliability. The speech-language therapy records that were used in the study were captured according to the original dysphagia assessment form (developed as part of the paediatric dysphagia departmental management protocol). The assessment form was developed by a qualified SLT, employed in the government sector, with 10 years experience in the field of paediatric dysphagia (see Appendix F). Double entries of medical and demographic information between the medical and SLT records improved reliability of the data. Only 13 (0.24%) discrepancies were noted in 23 variables (231 files) across all the medical history variables. The assessments were conducted by seven SLTs within the time-frame of five years. The researcher was one of the seven SLTs assessing infants for dysphagia. Therefore, inter-rater bias was avoided, as the researcher alone was not responsible to collect all the data. The medical records used were in the form of a *"Neonatal patient discharge report".* The discharge report was compiled by means of a computer program by an independent nursing sister, appointed by the hospital. This procedure provides a standard report for all the infants admitted to the NICU. Researcher-bias was limited as the person compiling the *"Neonatal patient discharge report"* data was independent from the researcher and did not know the aims and objectives of the study.

3.8 Procedures

3.8.1 Data collection, processing and analysis

Data were manually captured from the data records to an electronic Excel spreadsheet to be captured into IBM SPSS (Version 22) in order to facilitate analysis. Variables included Fourie's (2011) framework for categorization of risks for dysphagia, prenatal risks (such as age of mother, number of antenatal visits), perinatal risks (such as type of delivery, presentation of infant, apgar scores), postnatal medical risks (such as enteral and parenteral feeding, meconium aspiration). Pivot tables were used to determine the distribution of each participant within the different categories of medical conditions associated with suspected dysphagia. Pivot tables provide effective ways to summarize data of an Excel spreadsheet by determining and displaying parameters such as the sum, variance, count and standard deviation (Dalgleish, 2007). Standard deviations were calculated to indicate how far the values deviated from the mean. Descriptive statistics were used to analyze data in order to identify and describe the feeding outcomes as well as the risk factors of participants.

CHAPTER 4

The article has been submitted to the South African Journal of Child Health for review. *Note: This manuscript was edited in accordance with editorial specifications of the journal and may differ from the editorial style used elsewhere in the dissertation.*

Risks associated with suspected dysphagia in NICU-admitted infants in a South African public hospital

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Background: The prevalence of neonatal dysphagia is increasing, as medical advances contribute to the survival of critically ill and preterm infants. Additional factors such as low birth weight (LBW), gastroesoephageal reflux disorder, failure-to-thrive and HIV may increase the complexity of dysphagia symptoms. Knowledge of context-specific risk factors for dysphagia may lead to an effective pathway of diagnosis and management in vulnerable neonates.
Objective: To describe the feeding characteristics and categories of underlying medical conditions in 24 - 42 week gestational age infants.
Methods: The study was a retrospective review of 231 purposively selected medical and speech-language therapy records. Participants had a mean stay of 28.5 days in a neonatal intensive care unit in a peri-urban public hospital and were referred for a swallowing and feeding assessment. An existing seven-category framework for the classification of suspected dysphagia was used.
Results: The majority of participants (90.04%) presented with multiple medical conditions. Underlying neurological conditions (48.48%) and feeding difficulties secondary to systemic illness *(65.80%)* contributed mostly to suspected dysphagia in the sample. It was found that 70.99% of infants presented with feeding difficulties secondary to other conditions such as LBW and prematurity, highlighting the need for an expanded dysphagia classification framework.
Conclusion: The results are in agreement with the outcomes of previous research and confirm the need for a unique classification framework in South Africa. Dysphagia is a complex condition and frequently cannot be attributed to a single risk factor.

Mostly due to the improved survival rate of infants and children with life threatening conditions and multiple associated health problems, dysphagia in children is ever increasing.[1,2] Dysphagia, a swallowing disorder secondary to a problem in one or

more of the four phases of swallowing, is managed by speech-language therapists (SLTs) who are qualified to assess the dysfunction and provide intervention.[3,4,5]

Infants with risks such as prematurity, congenital or acquired medical conditions, or those with prolonged stays in NICUs are at greater risk of developing dysphagia and nutritional problems than typically developing, healthy neonates.[4,6] Also, infants requiring continued intervention for dysphagia are frequently those who were previously admitted to a neonatal intensive care unit (NICU).[6] Infants with the most complex or severe medical conditions are most at risk of presenting with disorganized or dysfunctional feeding patterns.[4] When preterm infants present with disorganized feeding patterns, it is generally due to immaturity, whereas dysfunctional sucking patterns may be more severe and is usually associated with neurological involvement.[4] It therefore appears that a close relationship exists between dysphagia, the infant's medical diagnosis, associated conditions, and the severity thereof.

Limited research regarding risk factors associated with dysphagia in infants admitted to the NICU is currently available.[4,7,8] This is a concern in developing countries where the burden of disease is high.[9] In a developing country such as South Africa, numerous additional challenges such as the effects of poverty and HIV may contribute to dysphagia in infants.[9] HIV may affect all phases of swallowing as a result of oral thrush, odynophagia and gastroesophageal reflux disorder (GERD), which can in turn lead to FTT.[10] The prevalence of dysphagia and GERD among children with HIV is poorly recorded, but frequently encountered in clinical practice and may contribute significantly to the morbidity of infants with exposure to the virus.[10] The incidence of dysphagia in typically developing children is estimated at 25 to 45%, and even higher, up to 80%, in children with developmental disabilities.[11] The prevalence of neonatal dysphagia is unknown, but represent a universal problem as dysphagia may carry over to infancy and toddler-age groups.[12]

It is important to identify dysphagia as soon as possible after birth while the infant is still in the hospital, so that the appropriate short- and long-term dietetic and SLT management and parent training can commence.[4] SLTs should be able to state when an infant is not ready for oral feeding and maximize oral feeding skills and safety in those infants who are ready to feed orally.[1,5] Left unidentified and untreated, dysphagia can lead to FTT, GERD, aspiration pneumonia and an inability to establish and sustain vital nutrition and hydration.[13]

The objectives of the study were to describe the feeding characteristics of infants admitted to a NICU and referred for suspected dysphagia in a public hospital and to determine which medical conditions were associated with the participants. Identifying risk factors can contribute to a better understanding of infants with suspected dysphagia, which may lead to improved referral guidelines and SLT staff-planning to ensure adequate intervention for all. A holistic understanding of the diversity of context-specific risk factors, associated with suspected dysphagia in infants who are already compromised by medical conditions may be attained.

Methods

The study was a retrospective review of medical and SLT records from 2010-2014 and included infants aged 24 - 42 weeks gestational age (GA) at birth and admitted in a peri-urban public hospital. GA was determined using the mother's last menstrual

period. All participants were referred by medical doctors, nurses, audiologists, SLTs and dieticians for a clinical swallowing evaluation.

Participants

A total of 312 infants were referred for dysphagia assessments within the study period of which 231 complete data sets were available. Inclusion criteria were that the infants had to present with symptoms of dysphagia, be referred for a feeding or swallowing evaluation by a healthcare professional, admitted to the NICU and assessed for dysphagia by a SLT. Common symptoms of dysphagia in the participants include oral phase symptoms such as absent oral reflexes, primitive reflexes, weak suck, uncoordinated suck, immature biting, poor bolus propulsion and poor bolus containment. Abnormalities in triggering of the swallow include absent swallow, delayed trigger of swallow, suck-swallow-breathing (SSB) incoordination, and pharyngeal phase symptoms include laryngeal penetration, aspiration, choking, pharyngeal residue and nasopharyngeal reflux.[14]

Common criteria by healthcare professionals for referral of infants and children for feeding and swallowing evaluation included: Suckling and swallowing incoordination, weak suck, breathing disruptions or apnea during feeding, excessive gagging or recurrent coughing during feeds, diagnosis of disorders associated with dysphagia or under nutrition, severe irritability during feeding, history of recurrent pneumonia and feeding difficulty, concern for possible aspiration during feeds, lethargy or decreased arousal during feeds, tedious feeding times and nasopharyngeal reflux during feeding.

Material

The materials used during data collection included *"The Neonatal patient discharge report"* available in electronic format from the local NICU database, and the SLT records, including the "*Dysphagia assessment form"*.[15-17] Data was independently collected over five years by seven different SLTs trained to use the same data collection instrument. A classification framework described by Arvedson and Brodsky[1] determining the aetiology or risk factors of paediatric dysphagia was used to categorize each participant. These categories included conditions with neurological involvement (such as asphyxia and convulsions), anatomical and structural impairments (including laryngomalacia) genetic and chromosomal disorders (including Trisomy 21)**,** dysphagia secondary to systemic illness (including pneumonia), psychosocial factors (including oral deprivation) as well as dysphagia secondary to resolved medical conditions (including hospital acquired infections). In a local study Fourie[7] expanded on the framework by adding a seventh category, "Other" as the prevalence of prematurity, LBW, GERD and FTT is high in South Africa, and does not fit within any of the six other categories[7].

Procedures

The Research Ethics Committees of two different Universities granted approval for the study. Data was manually captured from the printed records to an Excel spreadsheet and IBM SPSS (Version 22). Being a retrospective study, there was no direct contact with mothers or infants. Variables included Arvedson and Brodsky's framework for categorization of risks for dysphagia and expanded by Fourie[7], prenatal risks (such as age of mother, number of antenatal visits), perinatal risks (such as type of delivery, Apgar scores), postnatal medical risks (such as enteral and

parenteral feeding). Pivot tables were used to determine the distribution of each participant within the different categories of medical conditions associated with suspected dysphagia. Standard deviations were calculated. Descriptive statistics were used to identify the feeding characteristics and risk factors.

Results

Participant description

The participant characteristics are described in Table 1.

Table 1: Participant characteristics (n=231)

Characteristic	Description	Value
Nationality of mother	South African	88.3%
	Non-South African	11.7%
Gender	Male	48.1%
	Female	51.9%
GA at birth	Mean	34.9 weeks
Birth weight	Normal	45.5%
	LBW	35.5%
	Very LBW	16.4%
	Extremely LBW	2.6%
Days in the NICU	Mean	28.5 days
HIV status of mother (37 missing values)	HIV Negative	69.6%
	HIV Positive	30.4%

The majority of mothers were South African citizens. There were slightly more female (51.9%) than male (48.1%) participants and the mean GA of participants was 34.9 weeks, with a standard deviation of 3.9 weeks. The participants were mostly late preterm. The majority of participants (54.5%) were LBW (>2500g), very LBW (<1500g) or extremely LBW (>1000g). The mean stay in the NICU was 28.5 days with a wide range of 1 day to 316 days. The percentage of mothers who were HIV positive and per implication had infants exposed to the virus, corresponds with the 2012 antenatal sentinel HIV prevalence survey.[18] The estimated HIV prevalence in the survey was 29.5% in pregnant women and in this study 30.4% of mothers were HIV positive.[18] It is not known how many of the mothers were receiving antiretroviral (ARV) treatment.

Feeding characteristics of participants

Table 2 shows the feeding characteristics in participants.

Table 2: Feeding characteristics in participants (n=231)

Characteristic	Description	Value
Previous parenteral feeding	Yes	14.4%
	No	85.6%
Previous enteral (NGT*/ OGT*) feeding	Yes	65.0%
	No	26.4%

	Unknown	8.6%
Referred for VFSS* by doctors and SLTs	Yes	15.6%
	No	84.4%
VFSS conducted (in 15.6% who were referred)	Yes	38.8%
	No	61.2%
Manner of feeding at discharge	Mixed manner of feeding	55.1%
	Exclusive breast feeding	29.7%
	Gastrostomy	6.1%
	Exclusive bottle feeding	5.2%
	Cup	2.6%
	Syringe	1.3%

*NGT= *Nasogastric tube; *OGT=Orogastric tube;* *VFSS = Video Fluoroscopic Swallow Study

All participants (100%) presented with one or more symptoms of dysphagia. This can explain the frequency of parenteral (14.4%) and enteral feeding (65.0%) as infants with dysphagia often require alternative methods of feeding to obtain adequate nutrients and fluids.[1] Thirty-six of 231 (15.6%) participants presented with severe feeding difficulties or signs of aspiration. An instrumental assessment, a VFSS was only conducted in 14 (38.8%) of these 36 participants. Instrumental assessments are recommended if there are concerns about risks for aspiration, safety of the airway or possibilities of GERD.[1] The reasons why VFSS was not conducted in the 22 remaining participants referred for the procedure included: Participants demised before VFSS could be conducted (7), VFSS screening machine not functioning (1), participants were ventilated (1), lethargic (1), unstable or desaturating during feeding (3), clinically aspirating but no suck/swallow palpable (4), clinical swallow present even though there were risks for aspiration (5). Further characteristics in Table 2 show that the majority of participants (55%) used a mixed manner of feeding such as breast and cup feeding, cup and syringe feeding. Only 29.7% of participants were able to breastfeed exclusively, which relates to preterm birth in the majority of the participants (mean gestation: 34.9 weeks) and LBW. Using mixed feeding methods among the participants may indicate that the infants experienced breastfeeding difficulties as establishing successful breastfeeding may be a challenge for many preterm infants and their mothers due to neonatal feeding difficulties.[19] These difficulties may be due to incoordination of SSB as the suckling patterns of preterm infants often remain significantly less efficient than those of full-term infants at term age and beyond.[2,19]

Furthermore, 6.1% of the participants required long term tube feeding such as a gastrostomy. In another study conducted in South Africa, it was found that infants and children requiring gastrostomies were likely to present with multiple diagnoses, of which neurological and/or gastrointestinal impairments were the most prominent medical conditions.[20]

Underlying medical conditions in participants

Underlying medical conditions in participants were classified according to the framework by Arvedson and Brodsky[1], and expanded by Fourie[7] *to* determine the aetiology or risk factors of dysphagia (see Table 3). Since most participants were not classified in a single category, and presented with multiple risks, the total in Table 3 does not add to 100%.

Table 3: Underlying medical conditions in participants (n=231)

Category	Description	Value
A	Neurological conditions	48.48%
B	Anatomical and structural conditions	8.22%
C	Secondary to systemic illness (SSI)	65.80%
D	Chromosomal/ genetic conditions	7.79%
E	Psychosocial conditions	1.73%
F	Secondary to resolved medical condition (SRMC)	13.85%
G	Other (FTT, LBW, Prematurity)	70.99%

The majority of the infants 70.99% presented with conditions that was not included in the risks of dysphagia described by Arvedson and Brodsky[1], a classification system developed for conditions in a developed country such as the United States of America. The risks included FTT, GERD, LBW as well as HIV exposure.

It was found that 65.80% of participants had feeding difficulties secondary to a systemic illness, such as respiratory distress syndrome, cardiac abnormalities and pneumonia. This can be due to the fact that preterm infants with LBW are more at risk of developing systemic illnesses,[13] even more so in a developing country such as South Africa.[7] Results indicated that 48.48% of participants had a condition with neurological involvement such as asphyxia. Literature suggests that infants with neurological conditions, birth trauma as well as pre- and perinatal asphyxia are commonly found to have feeding difficulties.[1]

The conditions that occurred the least in the participants *were* feeding difficulties secondary to resolved medical conditions (13.85%) including iatrogenic conditions such as hospital-acquired infections. A total of 8.22% of the participants presented with anatomical or structural conditions such as cleft lip and palate, laryngomalacia and tracheoesophageal fistula while only 7.79% of the 231 participants presented with genetic or chromosomal abnormalities, which included infants with Trisomies 13, 21 and 18 and other syndromes. Only 1.73% of the participants presented with psychosocial conditions such as oral deprivation and under nutrition due to social problems. When analyzing the results it became clear that a true profile of multiple underlying conditions to feeding difficulties in the participants could not have been obtained if single categories of risk were considered.

Combinations of risk conditions associated with suspected dysphagia.
Combinations of risk categories in participants are described in Table 4.

Table 4: Combinations of risks for dysphagia (n=231)

Category	Value (n=231)	Percentage
Single category risks	n= 23	9.96%
Neurological	6	2.60%
Anatomical	2	0.87%
Dysphagia secondary to systemic illness (SSI)	10	4.33%
Other	5	2.16%
Two categories of risks	n= 116	50.22%
Anatomical, Genetic	1	0.43%
Neurological, SSI	33	14.29%
Neurological, Other	7	3.03%
SSI, Other	65	28.14%
Anatomical, SSI	4	1.73%

SSI, Secondary to resolved medical condition (SRMC)	1	0.43%
SSI, Neurological	1	0.43%
SSI, Genetic	4	1.73%
Three categories of risks	n= 65	28.14%
Neurological, SSI, Other	39	16.88%
Neurological, SRMC, Other	1	0.43%
Anatomical, SSI, Other	4	1.73%
SSI, SRMC, Other	10	4.33%
SSI, Genetic, Other	2	0.87%
Neurological, SSI, SRMC	4	1.73%
SSI, Psychosocial, SRMC	1	0.43%
Neurological, Anatomical, SSI	1	0.43%
SSI, Psychosocial, Other	1	0.43%
Neurological, Other, SSI	1	0.43%
Neurological, SSI, Genetic	1	0.43%
Four categories of risks	n= 22	9.52%
Anatomical, SSI, genetic, Other	3	1.30%
Neurological, SSI, SRMC, Other	9	3.90%
Anatomical, SSI, SRMC, Other	1	0.43%
Neurological, Anatomical, SSI, Other	3	1.30%
SSI, genetic, SRMC, Other	1	0.43%
Neurological, SSI, psychosocial, Other	1	0.43%
Neurological, Genetic, SSI, Other	1	0.43%
SSI, Psychosocial, SRMC, Other	1	0.43%
Neurological, SSI, Genetic, Other	2	0.87%
Five categories of risks	n= 5	2.16%
Neurological SSI, Genetic, SRMC, Other	1	0.43%
Anatomical, SSI, Genetic, SRMC, Other	1	0.43%
Neurological, Anatomical, SSI, Psychosocial, Other	2	0.87%
Neurological, Anatomical, SSI, Psychosocial, Other	1	0.43%

The results indicate that 90.04% of participants presented with multiple medical conditions, therefore revealing the complexity of combinations of different categories. A total of 36 different combinations were found, ranging from a single category to five different combinations. Most of the participants presented with two (50.22%) or three (28.14%) categories of risk factors and a total of 11.68% participants presented with four or five categories of risks. The minority (9.96%) of participants presented with a single category of risk for dysphagia. The results display the diversity and complexity of medical conditions within infants with symptoms of dysphagia. The results are in agreement with Jadcherla who states that neonatal dysphagia can rarely be associated with a single aetiology.[12]

Discussion

Dysphagia symptoms in the majority of the participants were accompanied by multiple medical conditions. As found in other local studies[7,20] participants presented with a great variety of medical conditions and combinations of these conditions that either directly or indirectly affected their feeding ability.[7]

The high number of participants with neurological conditions in this sample can be explained by the fact that infants with neurological conditions are commonly found to have feeding difficulties.[1,13] It is estimated that 85-90% of infants and children with neurological conditions such as cerebral palsy will present with dysphagia at some point in their lives.[1] Further, *the high* incidence of systemic illnesses such as pneumonia in pediatric populations with dysphagia is linked to specific diagnoses, such as Trisomy 21, asthma, GERD, lower respiratory tract infection, and moist cough.[14] Literature indicated that pediatric patients with multisystem diagnoses, in

addition to dysphagia, appear to be at greatest risk for developing pneumonia[14]. It is therefore evident that infants can present with multiple variations of swallowing impairments, such as those found in the participants of this study.[14]

The results indicate that the seven-category framework used for classification of risks for dysphagia in participants was successful to describe the complexities of different risk categories that may underlie neonatal dysphagia. Fourie[7] found in her study that 52% participants had aetiological factors for dysphagia pertaining to the "other" category[7]. In the current study the high rate of 70.99% participants in this "other" category included those with HIV exposure, as there was no dedicated category for infants exposed to HIV. Therefore the results indicated a need for an expanded classification system and the importance of an additional risk category is highlighted. It is proposed that the framework as described by Arvedson and Brodsky should be expanded to an eight-category classification framework that includes a category for *prematurity, LBW and related conditions* (described by Fourie [7] as 'other') as well as a category for *infants exposed to HIV*. HIV-exposure in an infant is associated with preterm birth.[21] As a result of prematurity and LBW the infant is at risk for dysphagia after birth, and when HIV-infection becomes apparent, feeding and swallowing can be affected due to encephalopathy. An additional category can potentially provide information regarding feeding characteristics, and aid in early identification of dysphagia.

Conclusion

Dysphagia frequently occurs in infants and is highly complex in nature.[12] Within the context of a developing country, classifying dysphagia can be challenging and therefore an expanded framework may be beneficial. The eight-category framework can be used by healthcare personnel to refer infants for dysphagia assessment and intervention, and can be used by SLTs to identify infants at risk for dysphagia. Being a retrospective study, various limitations were present, including missing data as well as the restricted geographical location. The outcomes of the current study correspond with international research describing several risk factors for dysphagia related to the primary medical diagnosis and its sequelae, and may be present throughout the infants' hospitalization.[12,8] Due to the increased survival rate of preterm infants and infants with complex medical conditions, it is suggested that more research regarding neonatal dysphagia in developing countries should be conducted.

References

1) Arvedson JC, Brodsky L. Pediatric swallowing and feeding. Assessment and management. 2nd ed. New York: Delmar Cengage Learning; 2002.
2) Kakodkar K, Schroeder JW. Pediatric dysphagia. Pediatr Clin N Am. 2013; 60:969–977. [http://dx.doi.org/10.1016/j.pcl.2013.04.010]
3) Bell H, Sheckman Alper MA. Assessment and intervention for dysphagia in infants and children: Beyond the neonatal intensive care unit. Semin Speech Lang. 2007; 28(3):213-222. [http://dx.doi.org/10.1055/s-2007-984727]
4) Hawdon JM, Beauregard N, Slattery J, Kennedy G. Identification of neonates at risk of developing feeding problems in infancy. Dev Med Child Neurol. 2000 October; 42:235-239. [http://dx.doi.org/10.1055/s-2007-984727]
5) American Speech-Language-Hearing Association [Internet]. Roles of speech-language pathologists in swallowing and feeding disorders: Technical report. [updated 2001, accessed 2015 Aug 8]. Available from: www.asha.org/policy.

6) Sundseth Ross E, Browne V. Developmental progression of feeding skills: An approach to supporting feeding in preterm infants. Semin Neonatol. 2002; 7:469-475. [http://dx.doi.org/10.1055/s-2007-984727]
7) Fourie A. The aetiology and nature of paediatric dysphagia (0-18 months) in state hospitals [dissertation]. Johannesburg, Gauteng (SA): University of the Witwatersrand; 2011.
8) Rommel N, De Meyer AM, Feenstra L, Veereman-Wauters G. The complexity of feeding problems in 700 infants and young children presenting to a tertiary care institution. J Pediatr Gastroenterol Nutr 2003 July; 37(1):75–84. [http://dx.doi.org/10.1097/00005176-200307000-00014]
9) Olusanya BO, Ruben RJ, Parving A. Reducing the burden of communication disorders in the developing world. An opportunity for the Millennium Development Project. JAMA. 2006 July; 296(4):441-444. [http://dx.doi.org/10.1001/jama.296.4.441]
10) Rabie H, Marais BJ, van Toorn R, Nourse P, Nel ED, Goussard P, et al. Important HIV-associated conditions in HIV-infected infants and children. SA Fam Pract 2007; 49(4)19-23. [http://dx.doi.org/10.1080/20786204.2007.10873538]
11) Arvedson JC. Assessment of pediatric dysphagia and feeding disorders: Clinical and instrumental approaches. Dev Disabil Res Rev 2008 May;14:118-127. [http://dx.doi.org/10.1002/ddrr.17]
12) Jadcherla S, Dysphagia in the high-risk infant: Potential factors and mechanisms. Am J Clin Nutr, 2016 Jan 20:1-7. [http://dx.doi.org/10.3945/ajcn.115.110106]
13) Prasse JE, Kikano GE. An overview of pediatric dysphagia. Clin Pediatr. 2009; 48(3):247-251. [http://dx.doi.org/10.1177/0009922808327323]
14) Dodrill P, Gosa MM. Paediatric Dysphagia: Physiology, assessment, and management. Ann Nutr Metab. 2015; 66(5):24-31. [http://dx.doi.org/10.1159/000381372]
15) McGrath JM. Feeding. In: Kenner C, McGrath JM, editors. Developmental care of newborns & infants: A guide for professionals. USA: Mosby; 2004. p. 321-342.
16) Hall KD. Paediatric dysphagia resource guide. Canada: Singular-Thomson Learning; 2001.
17) Fraker C, Walbert L. From NICU to childhood: Evaluation & treatment of pediatric feeding disorders. Speech Dynamics; 2004.
18) National Department of Health, 2013 [Internet]. The 2012 National antenatal sentinel HIV and Herpex simplex type-2 prevalence survey in South Africa, 2012. [2012, accessed 2015 Feb, 16] available from: https://www.health-e.org.za/wpcontent/uploads/2013/05/f0980fb5107a7ce543a8bd5730e5233.pdf
19) Dodrill P. Feeding difficulties in preterm infants. ICAN, December 2011; 3 (6): 324-331.
20) Norman V, Singh, SA, Hittler T, Jones M, Kenny N, Mann R, Mc Farlane S, Moeng A. Indications, medical conditions and services related to gastrostomy placement in infants and children at a tertiary hospital in South Africa. SAJCH, September 2011; 5(3): 86-89.
21) Short CS, Taylor GP. Antiretroviral therapy and preterm birth in HIV-infected women. Expert Rev of Anti Infect Ther, March 2014; 12(3): 293-306. [http://dx.doi.org/10.1586/14787210.2014.885837]

CHAPTER 5

The aim of this chapter is to discuss the implications of the results, the strengths and limitations of the study, future research recommendations and make concluding remarks on the study.

5. IMPLICATIONS AND CONCLUSION

5.1 Summary of research results

The majority of the participants were preterm infants with LBW who previously received enteral feeding. Thirty-six of the participants presented with severe feeding difficulties and/or signs for aspiration, although instrumental assessments (VFSS) were only conducted in fourteen of these patients. The majority of the participants used a mixed manner of feeding such as breast and cup feeding, cup and syringe feeding. Only 29.7% of participants were able to breastfeed exclusively, which relates to preterm birth in the majority of the participants (mean GA at birth: 34.9 weeks) and LBW. Using mixed feeding methods was therefore an indication of feeding difficulties as the hospital where the study was conducted promotes exclusive breastfeeding in infants, as recommended by March of Dimes et al. (2012) and the National Department of Health (2013).

Dysphagia symptoms in the majority of the participants were accompanied by multiple medical conditions. The category ‘Neurological conditions and feeding difficulties secondary to systemic illnesses’ occurred mostly in the participants, indicating that neurological conditions, such as severe birth asphyxia as well as systemic illnesses such as cardiac conditions and pneumonia were high-risk conditions for neonatal dysphagia in the sample. The results indicated that the seven-category framework (based on Arvedson & Brodsky, 2002 and Fourie, 2011) used for classification of risks for dysphagia in participants was successful. The framework could be used to describe the complexities of different risk categories that may underlie neonatal dysphagia, however, the need was identified to add one more category to this framework and rename the ‘other’ category in order to

consider unique needs of the South African context. In the study the high rate of 70.99% participants that pertained to the 'other' (LBW, prematurity, FTT) category, also included participants with HIV-exposure, as there was no dedicated category for infants exposed to HIV. Therefore the results indicated a need for an expanded classification system of risks for dysphagia and the importance of an additional risk category is highlighted. It is proposed that the framework as described by Arvedson and Brodsky (2002) should be expanded to an eight-category classification framework that includes a category for *prematurity, LBW and related conditions* (described by Fourie, 2011 as 'other') as well as a separate category for *infants exposed to HIV*. Feeding difficulties in infants exposed to HIV and receiving antiretroviral treatment (ARV) has not been described comprehensively and an additional category can potentially provide information regarding feeding characteristics, and draw attention to this South African specific risk for neonatal dysphagia. Based on the research findings the proposed framework of risks for neonatal dysphagia is illustrated in Figure 5.1.

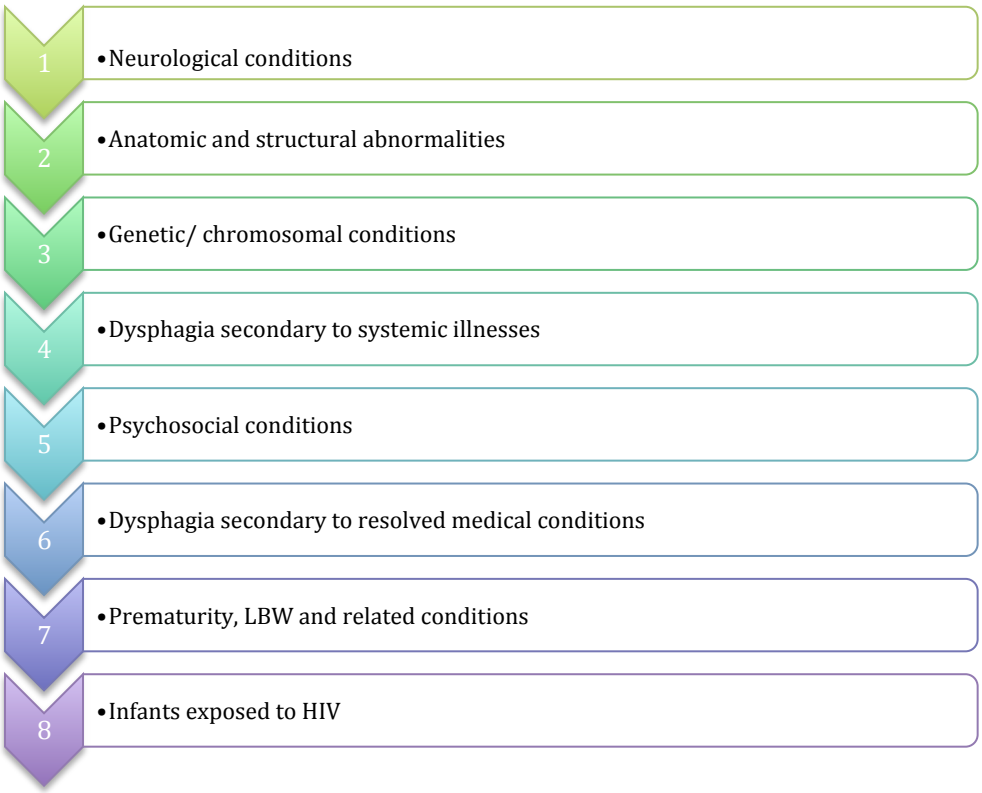

Figure 5.1: Proposed framework of risks for neonatal dysphagia

The research question: *"What were the feeding characteristics of a sample of NICU infants with suspected dysphagia, and which categories of medical conditions could be associated with the infants"* could therefore be successfully answered.

5.2 Further discussion of the results, indicating clinical and future research implications

5.2.1. Feeding characteristics of participants

- All participants (100%) in the study presented with one or more risks for dysphagia that included oral phase difficulties (such as, absent oral reflexes, immature biting, weak suck, uncoordinated suck), abnormalities in the triggering of the swallow (including absent swallow, delayed trigger of swallow, SSB incoordination) as well as pharyngeal phase difficulties (such as laryngeal penetration, aspiration, choking, pharyngeal residue and nasopharyngeal reflux). According to Dodrill and Gosa (2015), as a result of the many symptoms in the four phases of swallowing, often co-occurring, dysphagia is a complex condition in infants and neonates. The results indicating the complexity of dysphagia were expected as the sampling procedure was purposeful and therefore only infants with one or more symptom were included in the study. In future research, it is recommended that a control group of infants (without symptoms of dysphagia) should be included to determine statistical differences within the two groups of infants.
- The fact that all participants presented with symptoms of neonatal dysphagia, can also explain the frequency of parenteral (14.4%) and enteral feeding (65.0%), as infants with dysphagia often require alternative methods of feeding to obtain adequate nutrients and fluids (Arvedson & Brodsky, 2002). Jadcherla et al. (2009) reported that parents and healthcare professionals are often faced with difficult decisions regarding long term feeding strategies in neonates who are unsuccessful with oral feeding. Often these decisions include exclusive chronic tube feeding such as nasogastric tube feeding (NGT) as well as more invasive procedures such as gastrostomy placement. Dodrill (2011) reported that most preterm

infants would require some degree of feeding tube until they are mature and stable enough to feed orally exclusively. This statement is in agreement with the results of the current study as the majority of participants were born preterm and 65% of the participants previously had a feeding tube such as an NGT. The results of the study are similar to research by Pike, Pike, Kritzinger, Viviers and Krüger (2016) which found that participants with OPD were likely to be fed with feeding tubes. Future research should investigate the use of feeding tubes in neonatal dysphagia.

- Thirty-six of the 231 (15.6%) participants presented with severe, persistent feeding difficulties or signs of aspiration. An instrumental assessment, a VFSS was only conducted in 14 (38.8%) of these 36 participants. Instrumental assessments are recommended if there are concerns about risks for aspiration, safety of the airway or the possibility of GERD (Arvedson & Brodsky, 2002). VFSS can provide a reliable diagnosis of dysphagia in paediatric populations when applied and interpreted by expert clinicians (Dodrill & Gosa, 2015). According to Jadcherla et al. (2009) VFSS is the most widely available technology used to determine feeding safety. In a study conducted by Vazquez and Buonomo (1999) it was found that dysphagia with aspiration is a common cause of feeding related difficulties in infancy and the dysfunction could only be viewed on a VFSS. A systematic review of literature, conducted by Romano et al. (2012) reported that the 'gold standard' for assessment and diagnosis of oropharyngeal aspiration is a VFSS. However, it appeared that in the current study population VFSS was only conducted in severe and serious cases instead of being a standard procedure.

The reasons why VFSS was not conducted in the 22 remaining participants referred for the procedure in the current study included: Participants demised before VFSS could be conducted (7), VFSS screening machine not functioning (1), participants were ventilated (1), lethargic (1), unstable or desaturating during feeding (3), clinically aspirating but no suck/swallow palpable (4), clinical swallow present even though there were risks for aspiration (5). It was evident that various

difficulties relating to the ability to conduct VFSS procedures were also present in the study by Fourie (2011). Difficulties included the lack of using a standardized VFSS report, irregularities regarding terminology of VFSS, SLT staff not present during VFSS, missing reports, missing files and lack of experienced staff (Fourie, 2011). Further research regarding instrumental swallow studies and factors affecting the use thereof in South African public hospitals is needed. Confirmation of existing research findings could strengthen motivation to develop strategies to improve the use of VFSS, and lead to the development of standardized VFSS reporting for public hospitals in South Africa.

- The majority of participants (55%) used a mixed manner of feeding such as breast and cup feeding, cup and syringe feeding. Only 29.7% of participants were able to breastfeed exclusively, which relates to preterm birth in the majority of the participants (mean GA at birth: 34.9 weeks) and LBW. Preterm infants of 34-36 weeks gestation, without any other conditions, demonstrate skills that show positive prognosis for becoming full oral feeders, but may not consistently take oral feeds efficiently until closer to 37 weeks gestation (Arvedson & Brodsky, 2002). According to Dodrill (2011) breastfeeding is the natural method for infants to feed, but literature suggests that establishing successful breastfeeding may be a challenge especially for infants born preterm. Challenges with breastfeeding may be due to oral feeding difficulties as well as maternal lactation difficulties, including separation of mother and infant while admitted to the NICU (Dodrill, 2000). Using mixed feeding methods was therefore an indication of feeding difficulties as the hospital where the study was conducted promotes exclusive breastfeeding. The results of the study are similar to Pike et al. (2016) who found that infants with OPD were likely to experience difficulties with breastfeeding. The results indicated that participants were 8.89 times more likely to be fed with a tube and seven times more likely to experience breastfeeding difficulties (Pike et al., 2016). Arvedson and Brodsky (2002) and Dodrill (20110) report that while tube feeding is often the initial approach to manage feeding difficulties, it can also prolong dysphagia, delay treatment and negatively influence oral feeding and increase GERD. Future research could

investigate the specific feeding difficulties present during breastfeeding and the effect of feeding tubes on breastfeeding, especially in contexts where exclusive breastfeeding is encouraged.

- The results indicated that 6.1% of the participants required long term tube feeding such as a gastrostomy tube. Arvedson and Brodsky (2002) report that the use of gastrostomy tubes has made long term delivery of enteral feedings a feasible option for infants that cannot meet their nutritional needs orally. Gastrostomy tubes are particularly useful when anatomic restrictions such as tracheoesophageal fistula are present, in infants with severe developmental delay, or inadequate suck and swallow, due to a chronic condition such as aspiration (Arvedson & Brodsky, 2002). In a study conducted elsewhere in South Africa, infants and children requiring gastrostomies for feeding and swallowing difficulties were likely to present with multiple diagnoses, of which neurological and/or gastrointestinal impairments were the most prominent medical conditions (Norman et al., 2011). In the Netherlands a study by Rommel et al. (2002) indicated that 16.3% of their participants required a gastrostomy tube. This result is significantly higher than the present study. The reasons for the large discrepancy could be due that Rommel et al. (2003) included infants as well as children up to ten years of age, where the present study only included neonates. Future research is needed to determine the different medical conditions associated with gastrostomy placement, especially for infants previously admitted to the NICU and presenting with feeding difficulties.

5.2.2. Underlying medical conditions in participants

- The majority of participants, 70.99%, presented with conditions that were not included in the risk categories for dysphagia described by Arvedson and Brodsky (2002), a classification system developed for conditions in a developed country such as the United States of America. The risks in the present study included FTT, GERD, LBW as well as HIV-exposure. Results from Fourie (2011) indicated that 52% of her participants presented with conditions pertaining to the 'other' category, which included FTT, LBW, GERD and nutritional impairments. The reason why the results

of Fourie (2011) differ significantly from the current study may be that participants exposed to HIV in the current study were included in the 'other' category as they were neonates and thus HIV testing and diagnosis were not yet conclusive. In contrast, the participants in Fourie's (2011) study were older and already diagnosed with HIV and thus were included to the 'systemic illness category'. Future research is needed to determine the specific feeding characteristics of neonates and infants exposed to HIV. The PMTCT guidelines (2013) of the Department of Health stipulate all infants exposed to HIV should receive prophylactic treatment from birth. It appears that limited studies have been conducted on the feeding difficulties of infants with HIV-exposure and specifically the long-term effects of treatment on their feeding.

- It was found that 65.80% of participants had feeding difficulties secondary to a systemic illness, such as respiratory distress syndrome, cardiac abnormalities and pneumonia. This can be due to the fact that preterm infants with LBW are at increased risk of developing systemic illnesses mostly due to immaturity in development of vital organs such as the liver and lungs (Fourie, 2011; Jeena, 2008; March of Dimes et al., 2012). This finding was confirmed by Fourie (2011), but not by Pike et al. (2016). Fourie (2011) found that dysphagia in 67% of participants was related to aetiological factors secondary to a systemic illness such as pneumonia and respiratory distress syndrome. Pike et al. (2016), however, found no significant correlation between dysphagia and illnesses such as meningitis, septicaemia and hyperbilirubinaemia. Another study conducted in South Africa by Jeena et al. (2008) found that there was a strong correlation between illnesses such as neonatal hyperbilirubinaemia, pneumonia and sepsis and feeding difficulties. Further investigation is required to determine the nature of an association between systemic illness and dysphagia.
- A total of 8.22% of the participants presented with anatomical or structural conditions such as cleft lip and palate, laryngomalacia and traceoesophageal fistula. Results were similar to those presented by Fourie (2011). A total of 9.5% of participants presented with anatomical or structural conditions (Fourie, 2011). Arvedson and Brodsky (2002)

reported that dysphagia as a result of anatomical or structural difficulties could affect any stage of the feeding and swallowing process. Infants with oral anatomical conditions such as cleft lip and palate typically present with oral phase feeding difficulties. In a study by Baudon et al. (2009) it was found that newborn infants with facial malformations often had oral as well as esophageal dysfunctions. Dysphagia in these infants resulted from several mechanisms that could be isolated or in combination in the same patient (Baudon et al., 2009). Limited research in this special population has been conducted in South Africa. Therefore future research could focus on identifying the nature of dysphagia in infants with anatomical or structural impairments.

5.2.3. Combinations of risk conditions associated with suspected dysphagia in the participants.

Combinations of risk conditions in participants are illustrated in Figure 5.2.

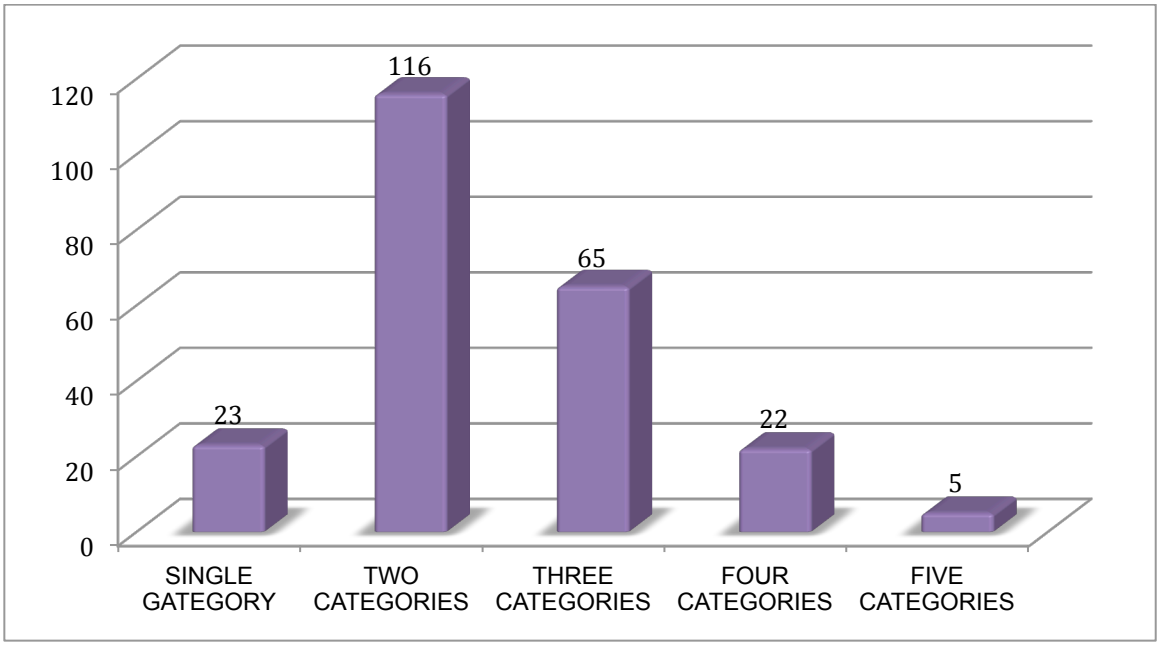

Figure 5.2: Combinations of risk conditions associated with suspected dysphagia (n=231)

- The results showed that 90.04% (or 208) of participants presented with multiple medical conditions, therefore revealing the complexity of combinations of different categories of risks for neonatal dysphagia.

According to Cowpe, Hanson and Smith (2014) dysphagia can be a symptom of different underlying conditions. Dysphagia can vary in aetiology, symptomology and severity and can affect infants and children with a variety of medical diagnoses (Cowpe et al., 2014). Rommel et al. (2003) found that 81.1% of their participants with dysphagia presented with at least one medical disorder. The results of the present study display the diversity and complexity of medical conditions within very young infants with symptoms of dysphagia. Clinical implications of this result include that infants with feeding difficulties frequently also present with multiple medical conditions and it may be difficult for the SLT to determine if the conditions are contributing factors to the feeding difficulty, or if the conditions are the result of the feeding difficulties.

- By far the minority (23, or 9.96%) of participants presented with a single category of risk for dysphagia. The results are in agreement with Jadcherla (2016) who states that neonatal dysphagia can rarely be associated with a single aetiology. A total of 36 different combinations of medical conditions were found, ranging from a single category to five different combinations. Most of the participants presented with two (50.22%) or three (28.14%) categories of risk factors and a total of 11.68% participants presented with four or five categories of risks. Fourie (2011) found similar results in three South African public hospitals. Participants presented with a single medical diagnosis to eight different diagnoses (Fourie, 2011). Jeena et al. (2008) found a correlation between the clinical profile and predictors of severe illness in infants <60 days. It was found that the basic symptoms such as feeding difficulties, tachypnea and lower chest in-drawing were useful predictors of severity of illness. The symptoms were also effective and safe indicators for prioritizing young infants for urgent hospital management at primary care centers (Jeena et al., 2008). The implication is that infants presenting with feeding difficulties also frequently present with multiple associated health concerns and care should be taken when working with this vulnerable group of infants. The results displayed the diversity and complexity of medical conditions within infants with symptoms of dysphagia. Neonates with dysphagia are often very sick.

5.3 Strengths and limitations of the study

5.3.1 Strengths of the study

- The major strength of the study was the large sample of participants as 231 participants were included. According to Leedy and Ormrod (2010) the trustworthiness of the results of a study relies on the representativeness of the sample. The large sample size can be considered as representative and yielded a great variety of results.
- As the results of the current study were similar to those of Fourie (2011) who included three other public hospitals in South Africa, the external validity of the study was improved. Therefore, according to Leedy and Ormrod (2010) the combined results of the studies provide evidence that the conclusion has validity and applicability across diverse contexts and situations. The generalizability of the results are therefore improved.
- Limited research in South Africa has been published about the feeding characteristics and medical conditions associated with infants admitted to the NICU. The research strengthens the findings of existing studies such as Fourie (2011), Pike et al. (2016) and Norman et al. (2011).
- Identification of risk factors associated with dysphagia can contribute to a better understanding of infants with suspected dysphagia, which may lead to improved referral guidelines and SLT staff-planning to ensure adequate intervention for all. A holistic understanding of the diversity of context-specific risk factors, associated with suspected dysphagia in infants who are already compromised by medical conditions was attained in the study.

5.3.2 Limitations of the study

- Data included retrospective data from SLT and medical records. Thus data were not validated against direct contact and observations of participants, as can be done in a prospective study.

- All the data used in the study was collected from only one peri-urban hospital in the Gauteng Province, which limits generalizability of the results to urban hospitals.
- A total of 312 infants were referred for dysphagia assessments and could have been included in the study. Due to a large number of missing data only 231 participant files were complete. A larger number of participants would have increased the representativeness of the sample.
- Being a retrospective study obtaining information regarding social and environmental factors was not possible.

5.4 Conclusion

In conclusion, Fourie (2011) stated that paediatric dysphagia is not only a health concern, but due to the number of communicable diseases associated with the condition, is also a social factor. International research reports that dysphagia frequently occurs in infants and is highly complex in nature (Jadcherla, 2016). However, despite the increase in survival of critically ill and preterm infants, research focusing on the feeding characteristics and risk factors associated with infants admitted in the NICU remains scant and not always relevant to the South African context. Within the context of a developing country, classifying risks for dysphagia can be challenging and therefore an expanded framework may be beneficial. The eight-category framework of risks can be used by healthcare personnel to refer infants for dysphagia assessment and intervention, and can be used by SLTs to identify infants at risk for dysphagia. The outcomes of the current study correspond with international research describing several risk factors for dysphagia related to the neonate's primary medical diagnosis and its sequelae, which may be present throughout the infants' hospitalization and beyond.

REFERENCE LIST

American Speech-Language-Hearing Association [ASHA] (2001). *Roles of speech-language pathologists in swallowing and feeding disorders: Technical report.* Retrieved online 18 March, 2016 from: www.asha.org/policy.

American Speech-Language-Hearing Association [ASHA] (2005). *Roles and responsibilities of speech-language pathologists in the neonatal intensive care unit: Guidelines.* Retrieved online 03 March, 2011 from: www.asha.org/policy.

American Speech-Language-Hearing Association [ASHA] (2016). *Scope of practice in speech-language pathology* [Scope of Practice]. Retrieved online 16 July, 2016 from: www.asha.org/policy/.

Arvedson, J.C., & Brodsky, L. (2002). *Pediatric swallowing and feeding. Assessment and management*. 2nd ed. New York: Delmar Cengage Learning.

Arvedson, J.C. (2008). Assessment of pediatric dysphagia and feeding disorders: Clinical and instrumental approaches. *Developmental Disabilities Research Reviews*, *14*(2), 118-127.

Barratt, J., & Ogle, V. (2010). Recorded incidence and management of dysphagia an outpatient paediatric neurodevelopmental clinic. *South African Journal of Child Health, 4*(2), 38-41.

Baudon, J.J., Renault, F., Goutet, J.M., Biran-Mucignat, V., Morgant, G., Garabedian, E.N., & Vazquez, M.P. (2009). Assessment of dysphagia in infants with facial malformations. *European Journal of Pediatrics, 168(2),* 187-193.

Bell, H., & Sheckman Alper, M.A. (2007). Assessment and intervention for dysphagia in infants and children: Beyond the neonatal intensive care unit. *Seminars in Speech and Language, 28*(3), 213-222.

Benatar, S.R. (2004). Health care reform and the crisis of HIV and AIDS in South Africa. *The New England Journal of Medicine, 351*(1), 81-92.

Bradshaw, D., Bourne, D., & Nannan, N. (2003). *What are the leading causes of death among South African children? Policy brief.* Burden of Disease Research Unit, Medical Research Council: Cape Town. Retrieved June 26, 2016 from: http://www.unicef.org/southafrica/SAF_publications_mrc.pdf.

Brink, H. (2010). *Fundamentals of research methodology for health care professionals.* 2nd ed. Cape Town: Juta.

Cameron, D.L., Nixon, S., Parnes, P., & Pidsadny, M. (2005). Children with disabilities in low income countries. *Pediatric Child Health, 10*(5), 269-272.

Chen, X., Shi, W.W., Fleming, N., Demissie, K., Rhoads, G.G., & Walker, M. (2007). Teenage pregnancy and adverse birth outcomes: A large population based retrospective cohort study. *International Journal of Epidemiology, 36*(2), 68-373.

Coogan, M., Greenspan, J., & Challacombe, S.J. (2005). Oral lesions in infection with human immunodeficiency virus. *Bulletin of the World Health Organization, 83*(9), 700-706.

Cowpe, E., Hanson, B., & Smith, C.H. (2014). What do parents of children with dysphagia think about their MDT? A qualitative study. *The BMJ Open, 4*(10), 1-8.

Dalgleish, D. (2007). *Beginning pivot tables in Excel.* New York City: Apress.

Delaney, A.L., & Arvedson, J.C. (2008). Development of swallowing and feeding: Prenatal through first year of life. *Developmental Disabilities Research Reviews, 14*(2), 105-117.

DeMauro, S.B., Preeti, R.P., Medoff-Cooper, B., Posencheg, M., & Abbasi, S. (2001). Post discharge feeding patterns in early- and late preterm infants. *Clinical Pediatrics*, 50(10) 957-962.

Dodrill, P. (2011). Feeding difficulties in preterm infants*. Infant, Child & Adolescent Nutrition, 3* (6), 324-331.

Dodrill, P., & Gosa, M. (2015). Pediatric dysphagia: Physiology, assessment, and management. *Annals of Nutrition and Metabolism, 66*(5), 24-31.

Emerson, E., & Hatton, C. (2007). The socio-economic circumstances of children at risk of disability in Britain. *Disability and Society, 22,* 563-58.

Fourie, A. (2011). The aetiology and nature of paediatric dysphagia (0-18 months) in state hospitals Johannesburg, Gauteng. Unpublished master's dissertation, University of the Witwatersrand, South Africa.

Fraker, C., & Walbert L. (2004). *From NICU to childhood: Evaluation & treatment of pediatric feeding disorders.* California: Speech Dynamics.

Gearing, R.E., Mian, I. A., Barber, J., & Ickowicz, A. (2006). A methodology for conducting retrospective chart review research in child and adolescent psychiatry. *Journal of Canadian Academy of Child and Adolescent Psychiatry, 15*(3), 126-134.

Guralnick, M.J. (2011). Why early intervention works: A systems perspective. *Infants and Young Children, 24*(1), 6-28.

Hall, K.D. (2001*). Paediatric dysphagia resource guide.* Canada: Singular-Thomson Learning.

Hawdon, J.M., Beauregard, N., Slattery, J., & Kennedy, G. (2000). Identification of neonates at risk of developing feeding problems in infancy. *Developmental Medicine & Child Neurology, 42*(4), 235-239.

Jadcherla, S. (2016). Dysphagia in the high-risk infant: Potential factors and mechanisms. *American Journal of Clinical Nutrition, 103*(2), 1-7.

Jadcherla, S.R., Stoner, E., Gupta, A., Bates, G., Fernandez, S., Di Lorenzo, C., & Linscheid, G. (2009). Evaluation and management of neonatal dysphagia: Impact of pharyngeoesophageal motility studies and multidisciplinary feeding strategy. *Journal of Pediatric Gastroenterology and Nutrition, 48*(2), 186-192.

Jardine, C., & Ballot, D.E. (2015). The use of nasal CPAP at the Charlotte Maxeke Johannesburg Academic Hospital. *South African Journal of Child Health, 9*(2), 45-48.

Jeena. P.M., Adhikari, M., Carlin, J.B., Qazi, S., Weber, M.W., & Hamer, D.H. (2008). Clinical profile and predictors of severe illness in very young South African infants (<60 days). *South African Medical Journal, 98*(11), 882-887.

Kakodkar, K., & Schroeder, J.W. (2013). Pediatric dysphagia. *Pediatric Clinics of North America, 60*(4), 969-977.

Kalimba, E.M., & Ballot, D.E. (2013). Survival of extremely low birth-weight-infants. *South African Journal of Child Health, 7*(1), 13-16.

Kyeong, E.U., Sook-Hee Y., Hyun J.C., Hee, J.C., & Jeong-Yi, K. (2013). Videofluoroscopic swallowing study findings in full-term and preterm infants with dysphagia. *Annals of Rehabilitation Medicine, 37*(2), 175-

182.

Lee, J.H., Chang, Y.S., Yoo, H.S., Ahn, S.Y., Seo, H.J., Choi, S.H., Jeon G.W., Koo, S.H., Hwang, J.H., & Park., W.S. (2011). Swallowing dysfunction in very low birth weight infants with oral feeding desaturation. *World Journal of Pediatrics, 7*(4), 337-343.

Leedy, P.D., & Ormrod, J.E. (2010). *Practical Research: Planning and design*. 9th ed. New Jersey: Pearson Education Inc.

March of Dimes, PMNCH, Save the Children, WHO. Born *Too Soon: The Global Action Report on Preterm Birth*. (2012). (Eds.). C.P. Howson, M.V. Kinney, J.E. Lawn. World Health Organization. Geneva, 2012.

Manikam, R., & Perman, J.A. (2000). Pediatric feeding disorders. *Journal of Clinical Gastroenterology, 30*(1), 34-46.

McGrath, J.M. (2004). Feeding. In C. Kenner & J.M. McGrath (Eds.), *Developmental care of newborns and infants: A guide for professionals*. St Louis: Mosby, Elsevier.

Meline, T. (2010). *A research primer for communication sciences and disorders.* Boston: Pearson Education Inc.

Mercado-Deane, M.G., Burton E.M., Harlow S.A., Glover A.S., Deane D.A., Guill, M.F., & Hudson V. (2001). Swallowing dysfunction in infants less than 1 year of age. *Pediatic Radiology, 31*, 423-428.

Miller, C.K., & Willging, J.P. (2003). Advances in the evalution and management of paediatric dysphagia. *Current Opinion in Otolaryngology & Head and Neck Surgery*, *11*, 442-446.

Mouton, J. (2001). *How to succeed in your master's and doctoral studies.* Pretoria: Van Schaik Publishers.

National Department of Health (2013). *The 2012 National antenatal sentinel HIV and Herpex simplex type-2 prevalence survey in South Africa*. Retrieved February 15, 2016 from: https://www.health-e.org.za/wp-content/uploads/2014/05/ASHIVHerp_Report 2014_22 May2014.pdf.

Newman, A. (2000). Optimal care patterns in paediatric patients with dysphagia. *Seminars in Speech and Language, 21*(4), 281-291.

Norman, V., Singh, S.A, Hittler, T., Jones, M., Kenny, N., Mann, R., McFarlane, S., & Moeng, A. (2011). Indications, medical conditions and services related to gastrostomy placement in infants and children at a tertiary hospital in South Africa. *South African Journal of Child Health*, *5*(3), 86-89.

Olusanya, B.O., Ruben, R.J., & Parving, A. (2006). Reducing the burden of communication disorders in the developing world. An opportunity for the Millennium Development Project. *Journal of the American Medical Association*, *296*(4), 441-444.

Peter, C.S., Wiechers, C., Bohnhorst, B., Silny, J., & Poets, C.F. (2002). Influence of nasogastric tubes on gastroesophageal reflux in preterm infants: A multiple intraluminal impedance study. *Journal of Pediatrics, 141*(2), 277-279.

Pike, C., Pike M., Kritzinger, A., Krüger E., & Viviers, M. (2016). Risk profiles of infants ≥32 weeks' gestational age with oropharyngeal and oesophageal dysphagia in neonatal care. *South African Journal of Child Health, 10(2),* 130-133.

Prasse, J.E., & Kikano, G.E. (2009). An overview of pediatric dysphagia. *Clinical Pediatrics*, *48*(3), 247-251.

Rabie, H., Marais, B.J., van Toorn, R., Nourse, P., Nel, E.D., Goussard P., Sellers, N., & Cotton, M.F. (2007). Important HIV-associated conditions in HIV infected infants and children. *South African Family Practice, 49*(4), 19-23.

Rodgers, B., & Arvedson, A. (2005). Assessment of infant oral sensorimotor and swallowing function. *Mental Retardation and Developmental Disabilities Research Reviews*, *11*, 75-82.

Romano, M., Schultz, T., & Tai, A. (2012) The diagnostic test accuracy of clinical swallow assessment for pharyngeal aspiration: A systematic review. *The Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports, 10*(52), 1-16.

Rommel, N., De Meyer, A., Feenstra, L., & Veereman-Wauters, G. (2003). The complexity of feeding problems in 700 infants and young children presenting to a tertiary care institution. *Journal of Pediatric Gastroenterology and Nutrition, 37*(1), 75-84.

Strydom, H. (2005). Ethical aspects of research in the social sciences and human service professions. In A.S De Vos, H. Strydom & C.S.L. Delport (Eds.), *Research at grass roots: For the social sciences and human service professions* (pp 57-70). 3rd ed. Pretoria: Van Schaik Publishers.

Shiao, S.Y., Brooker, J., & DiFiore, T. (1996). Desaturation events during oral feedings with and without a nasogastric tube in very low birth weight infants. *Heart & Lung: The Journal of Acute and Critical Care*, *25*(3), 236-245.

Shiao, S.Y., Youngblut, J.M., Anderson, G.C., DiFiore, J.M., & Martin, R.J. (1995). Nasogastric tube placement: Effects on breathing and sucking in very-low-birth-weight infants. *Nursing Research, 44*(2), 82-88.

Steinberg C. (2007). Feeding disorders of infants, toddlers and preschoolers.

British Columbia Medical Journal, 49(4), 183-186.

Struwig, F.W., & Stead, G.B. (2001). *Planning, designing and reporting research.* Cape Town: Pearson Education South Africa.

Sundseth Ross, E., & Browne, V. (2002). Developmental progression of feeding skills: An approach to supporting feeding in preterm infants. *Seminars in Neonatology*, *7*(6), 469-475.

The Independent Expert Panel (2010). Prevention of Mother-to-Child Transmission of HIV: Expert Panel Report and Recommendations to the U.S. Congress and U.S. Global AIDS Coordinator. Retrieved June 26, 2016, from: http://www.pepfar.gov/documents/organisation/135466.pdf.

Tutor, J.D., & Gosa, M.M. (2012). Dysphagia and aspiration in children. *Pediatric Pulmonology, 47*(4), 321-337.

Vazques, J.L., & Buonomo, C. (1999). Feeding difficulties in the first days of life: Findings on upper gastrointestinal series and the role of the videofluoroscopic swallowing study. *Paediatric Radiology, 29*(12), 894-896.

Walker, S.P., Wachs, T.D., Meeks Gardner, J., Lozoff, B., Wasserman, G.A., Politt, E., Carter, J.A., et al. (2007). Child development: Risk factors for adverse outcomes in developing countries. *The Lancet, 369,* 145-157.

Whitelaw, A. (2013). Hospital acquired infections. *Health24.com.* Retrieved October 18, 2015, from: http://www.health24.com/Medical/Diseases/Hospital-Acquired-Infections-20120721.

Whitley, B.E. Jr. (2002). *Principles of research in behavioural science.* 2nd ed. New York: McGraw-Hill.

World Health Organization. [WHO] (2007). *Antiretroviral therapy for HIV infection in infants and children: Towards universal access. Recommendations for a public health approach.* Retrieved March 8 2009. from http://who.int/hiv/pub/guidelines/paediatric020907.pdf.

World Health Organization [WHO]. (2015). *Preterm birth: Fact sheet*. Retrieved July 10, 2016 from: http://www.who.int/mediacentre/factsheets/fs363/en/.

APPENDICES

APPENDIX A: Ethical clearance letter, Faculty of Humanities, University of Pretoria

APPENDIX B: Ethical clearance, MREC, University of Limpopo

APPENDIX C: Clinical director permission letter and response

APPENDIX D: Neonatology permission letter and response

APPENDIX E: Department of Speech Therapy and Audiology permission and response letter

APPENDIX F: Dysphagia assessment form

APPENDIX G: Data collection tool

APPENDIX A: Ethical clearance letter, Faculty of Humanities, University of Pretoria

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Research Ethics Committee

17 March 2014

Dear Prof Vinck

Project:	**Risk factors associated with dysphagia in 0-3 month old infants in a South African public hospital: A retrospective study**
Researcher:	**J Schoeman**
Supervisor:	**Prof A Kritzinger**
Department:	**Speech-Language Pathology and Audiology**
Reference:	**28046707**

Thank you for your response to the Committee's letter of 9 October 2013.

The above application was **approved (with conditions)** by the **Research Ethics Committee** at an ad hoc meeting 13 March 2014 due to the following:

- Written permission is outstanding from the Department of Neonatology. The Committee is aware that final permission can only be granted once ethical clearance is granted by the University.

Please note that data collection may not commence prior to the Department of Neonatology giving written permission; proof of this permission is therefore required. To facilitate the administrative process, please respond to Ms Tracey Andrew, Room HB 7-27, at your earliest possible convenience.

Sincerely

Prof Karen Harris
Acting Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: karen.harris@up.ac.za

APPENDIX B: Ethical clearance, MREC, University of Limpopo

University of Limpopo
Medunsa Research Ethics Committee (MREC)
Prof GA Ogunbanjo: Chairperson MREC
P.O Box 163, Medunsa, 0204, South Africa
Tel: +27 12 521 5617/3359 Fax: +27 12 521 3749, Email: lorato.phiri@ul.ac.za

Ms J Schoeman
University of Pretoria
Faculty of Humalities
Department of Speech-Language Pathology and Audiology

Dear Ms Schoeman

RE: **MS J SCHOEMAN – APPLICATION TO CONDUCT A RESEARCH PROJECT AT DR GEORGE MUKHARI ACADEMIC HOSPITAL**

Researcher:	Ms J Schoeman
University:	University of Pretoria
Faculty:	Humanities
Department:	Communication Pathology
Qualification	MCommunication Pathology
Supervisor:	Prof A Kritzinger
Reference:	28026707
Approved date:	17 September 2013

Title: Risk factors associated with dysphagia in 0-3 month old infants in a South African public hospital: A retrospective study

MREC **NOTED** a letter dated 13 January 2014 from Ms J Schoeman requesting to conduct a research project at Dr George Mukhari Academic Hospital, Department of Speech Therapy and Audiology as well as the medical records.

MREC **APPROVED** and **GRANTED** the researcher a permission to conduct the research at the Medunsa Campus

Yours Sincerely,

PROF GA OGUNBANJO
CHAIRPERSON MREC

04 February 2014

UNIVERSITY OF LIMPOPO
Medunsa Campus
2014 -02- 04
MEDUNSA RESEARCH ETHICS COMMITTEE
MREC CHAIRPERSON

Finding solutions for Africa

APPENDIX C: Clinical director permission letter and response

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Department of Communication Pathology
Faculty of Humanities

3 July 2013

The Clinical Director: Dr P. Shembe
Dr George Mukhari Hospital
3111 Setlogo Drive
Ga-Rankuwa
0208

Permission to conduct research

Dear Dr Shembe

In fulfillment of the degree MCommunication Pathology (Speech-Language Pathology) I am required to conduct a research project. I am conducting a study to describe the "*Risk factors associated with dysphagia in 0-3 month old infants in a South African public hospital*"

The study will be in the form of a retrospective investigation of medical and speech therapy records. I would like to obtain your consent to use the speech therapy records stored in Dr George Mukhari Hospital, Department of Speech Therapy and Audiology as well as the medical records of participants, stored in ward 24 of Dr George Mukhari Hospital. Data from the medical records, will only include the summary sheet of treatment, which is completed after the patients are discharged. I will collect and print the needed information at my own cost and time, and would only initially need assistance from the sister currently compiling the summary sheets to get access to the program.

The following information is relevant to the study:

Background and purpose of the study

There is a high prevalence of paediatric dysphagia within South-Africa. The life threatening complications of this disorder necessitates early identification and management of infants and children. Limited local research is currently available regarding the risk factors associated with dysphagia within the 0-3 month old population. Identifying potential risk factors may lead to a targeted screening programme in the hospital and appropriate long term dietetic, speech-language

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2000). Early identification is important to prevent or minimize associated medical and developmental complications in children with dysphagia (Prasse & Kikano, 2009).

The aim of the study is to investigate the risk factors associated with dysphagia in infants 0-3 months within the South African context. Different frameworks in literature are used to classify the aetiology of paediatric dysphagia (Arvedson & Brodsky, 2002; Manikam & Perman, 2000; Miller & Willging, 2003; Prass & Kikano, 2009; Rommel et al., 2003), but diverse opinions regarding the categories of classification is currently found in literature. In a recent study by Fourie (2011), the frameworks for classifying the aetiology or risk factors of dysphagia were investigated for possible application within the South African context. Fourie (2011), noted that none of the classification frameworks effectively describe the complex nature of paediatric dysphagia, specifically for a developing country. The need for a more comprehensive classification framework acknowledging the time of presentation of the underlying cause, the biological system involved and the progression of the aetiology was highlighted (Fourie, 2011).

The outcomes of the infants with dysphagia will also be described. Literature on feeding outcomes of infants discharged from the neonatal intensive care unit is very limited and therefore a need exists to conduct this study (Hawdown, et al., 2000). This research project may contribute to future early detection and intervention of children with dysphagia.

Procedure

The study will be a retrospective review of medical and speech therapy records, thus no direct patient contact will be required. Records of infants 0-3 months who received speech therapy services for dysphagia within the time period of 2011 to 2013 will be used.

Confidentiality

Information gained will be used exclusively for research purposes and neither the identity of the participants nor the name of the Hospital will be documented in the research report. There are no risks associated with the study and all information will be kept confidential. As part of the University of Pretoria policy, all electronic as well as hardcopy data will be securely stored for a minimum of 15 years. The researcher will not obtain any personal, societal or financial gain from the study.

Permission

Permission of the, Chief Executive Officer, Principal Specialist of Paediatrics & Child Health, as well as the Assistant Director of the Department Speech Therapy & Audiology of Dr George Mukhari Hospital, will be obtained before the study will commence.

Ethical clearance from the University of Pretoria as well as the Gauteng Department of Health will also be obtained before any data collection procedures will be initiated.

Should you require any further information regarding the study, you are welcome to contact Professor Alta Kritzinger, research supervisor at the Department of Communication Pathology, University of Pretoria, at (012) 420 2949, or myself, Jacoline Schoeman, the researcher at, 0849796531.

Your consent to use the relevant records to conduct the study will be greatly appreciated.

Yours sincerely

Jacoline Schoeman
Researcher

A.M. Kritzinger
Professor A. Kritzinger
Study leader

Professor B. Vinck
HEAD: DEPT OF COMMUNICATION PATHOLOGY

Permission to conduct research

I _____ hereby grant permission to Jacoline Schoeman to conduct her research titled, *"Risk factors associated with dysphagia in 0-3 month old infants in a South African public hospital: a Retrospective study"* at the Department of Speech Therapy and Audiology and medical records at Dr George Mukhari Hospital.

Dr P. Shembe
Clinical Director

Hospital Official Stamp

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Dr. George Mukhari Academic Hospital

Office of the Director Clinical Services
Enquiries : Dr. P. Shembe
Tel : (012) 529 3880
Fax : (012) 560 0099
Email: Petunia.Shembe@gauteng.gov.za
Lydia.Mbalati@gauteng.gov.za

To : Ms. Jacoline Schoeman
Department of Communication Pathology
University of Pretoria

Date : 30 October 2013

PERMISSION TO CONDUCT RESEARCH

The Dr. George Mukhari Hospital hereby grants you permission to conduct research on "Risk factors associated with dysphagia in 0-3 month old infants in a South African public hospital: a retrospective study"

This permission is granted subject to the following conditions:

- ☐ That you obtain Ethical Clearance from the Human Research Ethics Committee of the relevant University
- ☐ That the Hospital incurs no cost in the course of your research
- ☐ That access to the staff and patients at the Dr George Mukhari Hospital will not interrupt the daily provision of services.
- ☐ That prior to conducting the research you will liaise with the supervisors of the relevant sections to introduce yourself (with this letter) and to make arrangements with them in a manner that is convenient to the sections.
- ☐ That patients medical record are used within Hospital premises.

Yours sincerely

DR. P SHEMBE
DIRECTOR: CLINICAL SERVICES

Dr George Mukhari Academic Hospital
Medunsa Drive
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0001

Private Bag X422
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0001

APPENDIX D: Neonatology permission letter and response

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Department of communication pathology
Faculty of Humanities

July 2013

Professor MPB Mawela
Adj. Professor/Principal Specialist: Department of Paediatrics & Child Health
University of Limpopo
3111 Setlogo Drive
Ga-Rankuwa
0208

Permission to conduct research

Dear Professor Mawela

In fulfillment of the degree MCommunication Pathology (Speech-Language Pathology) I am required to conduct a research project. I am conducting a study to describe the "*Risk factors associated with dysphagia in 0-3 month old infants in a South African public hospital*"

The study will be in the form of a retrospective investigation of medical and speech therapy records. I would like to obtain your consent to use the medical records stored in Dr George Mukhari Hospital. Data from the medical records will only include the summary sheet of treatment, which is completed after the patients are discharged. I will collect and print the information at my own cost and time, and would only initially need assistance from the sister currently compiling the summary sheets to access the program.

The following information is relevant to the study:

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and developmental complications in children with dysphagia (Prasse & Kikano, 2009).

The aim of the study is to investigate the risk factors associated with dysphagia in infants 0-3 months within the South African context. Different frameworks in literature are used to classify the aetiology of paediatric dysphagia (Arvedson & Brodsky, 2002; Manikam & Perman, 2000; Miller & Willging, 2003; Prass & Kikano, 2009; Rommel, et al., 2003), but diverse opinions regarding the categories of classification is currently found in literature. In a recent study by Fourie (2011), the frameworks for classifying the aetiology or risk factors of dysphagia were investigated for possible application within the South African context. Fourie (2011), noted that none of the above mentioned classification frameworks effectively describes the complex nature of paediatric dysphagia, specifically for a developing county. The need for a more comprehensive classification framework acknowledging the time of presentation of the underlying cause, the biological system involved and the progression of the aetiology was highlighted (Fourie, 2011).

The outcomes of the infants with dysphagia will also be described. Literature on feeding outcomes of infants discharged from the neonatal intensive care unit is limited and therefore a need exists to conduct this study (Hawdown, et al., 2000). This research project may contribute to future early detection and intervention of children with dysphagia.

Procedure

The study will be a retrospective review of medical and speech therapy records, thus no direct patient contact will be required. Records of infants 0-3 months who received speech therapy services for dysphagia within the time period of 2011 to 2013 will be used..

Confidentiality

Information gained will be used exclusively for research purposes and neither the identity of the participants nor the name of the Hospital will be documented in the research report. There are no risks associated with the study and all information will be kept confidential. As part of the University of Pretoria policy, all electronic as well as hardcopy data will be securely stored for a minimum of 15 years. The researcher will not obtain any personal, societal or financial gain from the study.

Permission

Permission of the Chief Executive Officer, Clinical Director, as well as the Assisting Director of the Department of Speech Therapy & Audiology, of Dr George Mukhari Hospital, will be obtained before the study will commence.

Ethical clearance from the University of Pretoria as well as the Gauteng Department of Health will also be obtained before any data collection procedures will be initiated.

Should you require any further information regarding the study, you are welcome to contact Professor Alta Kritzinger, research supervisor at the Department of Communication Pathology, University of Pretoria, at (012) 420 2949, or myself, Jacoline Schoeman, the researcher at, 0849796531.

Your consent to use the relevant records to conduct the study will be greatly appreciated.

Yours sincerely

Jacoline Schoeman
Researcher

Professor A. Kritzinger
Study leader

Professor B. Vinck
HEAD: DEPT OF COMMUNICATION PATHOLOGY

Permission to conduct research

I _____ hereby grant permission to Jacoline Schoeman to conduct her research titled, *"Risk factors associated with dysphagia in 0-3 month old infants in a South African public hospital: A retrospective study"* at the Department of Speech Therapy and Audiology at Dr George Mukhari Hospital.

Professor MPB Mawela
Principal Specialist: Department of Paediatrics & Child Health

Hospital Official Stamp

UNIVERSITY OF LIMPOPO
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MEDUNSA
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Ms J Schoeman
University of Pretoria
Faculty of Humalities
Department of Speech-Language Pathology and Audiology

Re: **PERMISSION TO CONDUCT A RESEARCH PROJECT AT DGMAH**

Title: **RISK FACTORS ASSOCIATED WITH DYSPHAGIA IN 0-3 MONTH OLD INFANTS IN A SOUTH AFRICAN PUBLIC HOSPITAL : A RETROSPECTIVE STUDY**

Ref: **28016707**

The letter from MREC dated 04 February is noted.

Permission is therefore granted to conduct the retrospective review of the medical records from the neonatal unit at Dr George Mukhari Academic Hospital.

Regards,

PROFESSOR MPB MAWELA
MBChB, MMed(Paed)
HEAD : NEONATAL UNIT DGMAH

25th March 2014

Finding Solutions for Africa

APPENDIX E: Department of Speech Therapy and Audiology permission and response letter

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Department of Communication Pathology
Faculty of Humanities

3 July 2013

Ms S. Saleh
Assistant Director: Department of Speech Therapy and Audiology
Dr George Mukhari Hospital
3111 Setlogo Drive
Ga-Rankuwa
0208

Permission to conduct research

Dear Ms Saleh

In fulfillment of the degree MCommunication Pathology (Speech-Language Pathology) I am required to conduct a research project. I am conducting a study to describe the "*Risk factors associated with dysphagia in 0-3 month old infants in a South African public hospital* "

The study will be in the form of a retrospective investigation of medical and speech therapy records. I would like to obtain your consent to use the speech therapy records stored in Dr George Mukhari Hospital, Department of Speech Therapy and Audiology.

The following information is relevant to the study:

Background and purpose of the study
There is a high prevalence of paediatric dysphagia within South-Africa. The life threatening complications of this disorder necessitates early identification and management of infants and children. Limited local research is currently available regarding the risk factors associated with dysphagia within the 0-3 month old population. Identifying potential risk factors may lead to a targeted screening programme in the hospital and appropriate long term dietetic, speech-language therapy and psychological management (Hawdown, Beauregard & Kennedy, 2000). Early identification is important to prevent or minimize associated medical

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The aim of the study is to investigate the risk factors associated with dysphagia in infants 0-3 months within the South African context. Different frameworks in literature are used to classify the aetiology of paediatric dysphagia (Arvedson & Brodsky, 2002; Manikam & Perman, 2000; Miller & Willging, 2003; Prass & Kikano, 2009; Rommel et al., 2003), but diverse opinions regarding the categories of classification is currently found in literature. In a recent study by Fourie (2011), the frameworks for classifying the aetiology or risk factors of dysphagia were investigated for possible application within the South African context. Fourie (2011), noted that none of the above mentioned classification frameworks effectively describes the complex nature of paediatric dysphagia, specifically for a developing county. The need for a more comprehensive classification framework acknowledging the time of presentation of the underlying cause, the biological system involved and the progression of the aetiology was highlighted (Fourie, 2011).

The outcomes of the infants with dysphagia will also be described. Literature on feeding outcomes of infants discharged from the neonatal intensive care unit is very limited and therefore a need exists to conduct this study (Hawdown, et al., 2000). This research project may contribute to future early detection and intervention of children with dysphagia.

Procedure

The study will be a retrospective review of medical and speech therapy records, thus no direct patient contact will be reqired. Records of infants 0-3 months received speech therapy services for dysphagia within the time period of 2011 to 2013 will be used.

Confidentiality

Information gained will be used exclusively for research purposes and neither the identity of the participants nor the name of the Hospital will be documented in the research report. There are no risks associated with the study and all information will be kept confidential. As part of the University of Pretoria policy, all electronic as well as hardcopy data will be securely stored for a minimum of 15 years. The researcher will not obtain any personal, societal or financial gain from the study.

Permission

Permission of the CEO, clinical director, as well as the Principal Specialist of Paediatrics & Child Health, of Dr George Mukhari Hospital, will be obtained before the study will commence.

Ethical clearance from the University of Pretoria as well as the Gauteng Department of Health will also be obtained before any data collection procedures will be initiated.

Your consent to use the relevant records to conduct the study will be greatly appreciated.

Yours sincerely

Jacoline Schoeman
Researcher

Professor A. Kritzinger
Study leader

Professor B. Vinck
HEAD: DEPT OF COMMUNICATION PATHOLOGY

Permission to conduct research

I Safia Saleh hereby grant permission to Jacoline Schoeman to conduct her research titled, *"Risk factors associated with dysphagia in 0-3 month old high-risk infants in a South African public hospital: a Retrospective review"* at the Department of Speech Therapy and Audiology at Dr George Mukhari Hospital.

Ms Safia Saleh
Assistant Director: Department of Speech Therapy and Audiology

Hospital Official Stamp

SPEECH THERAPY AND
AUDIOLOGY DEPT
DR GEORGE MUKHARI HOSPITAL
2013 -06- 11
PRIVATE BAG X422
PRETORIA
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3

APPENDIX F: Dysphagia assessment form

FIRST ASSESSMENT: PAEDIATRIC DYSPHAGIA

Name: _____ M / F DOB: _____ Hospital number: _____

Address: _____ Tel no: _____

HISTORY Verbal consent ☐ Implied consent ☐

Antenatal	Antenatal visits: __ Nr of children: __	RVD + ☐ / - ☐ unknown ☐	Other maternal illness / family history	
Birth	NVD ☐ C-Section ☐	Assisted delivery ☐	Prolonged labour ☐	Breech ☐
	GA: ___ weeks. Prem ☐	Birth weight: _____ g	APGAR: _/10, _/10, _/10	
	Multiples ☐	Other ☐		
Medical	Reason for referral to NICU/KMC	Resp. problems ☐ IPPV ☐ SIPAP ☐ O2 ☐ RDS ☐ BPD ☐	NNJ ☐ Photo ☐ Blood ☐	Convulsions ☐ Resolved ☐ Meds:
	Birth Asphyxia ☐ HIE grade _____	Heart problems ☐ PDA ☐	Cleft lip and palate ☐ Type:	Dysmorphic features ☐
	NEC ☐	Meningitis ☐	Pneumonia ☐ Aspiration pn ☐	Sepsis ☐
	Other ☐			
Feeding	Previous feeding methods NGT ☐ Cup / spoon ☐ Breast / bottle ☐	Temp spikes Absent ☐ Present ☐	Weight gain Normal ☐ Lost ☐ Fluctuating ☐ FTT ☐	GER Vomiting ☐ Posseting☐
	Comments:			

CURRENT FEEDING EBM ☐ / Formula ☐

	ml	*minutes*	*ml*	*ml*	*ml*
NPO ☐	NGT ☐	Breast ☐	Spoon ☐	Cup ☐	Bottle☐
Comments:					

GENERAL BEHAVIOUR

State	Before		During		After		**Stress cues**	Before		During		After	
	NNS	NS	NNS	NS	NNS	NS		NNS	NS	NNS	NS	NNS	NS
Deep sleep							Finger/toe splaying						
Active sleep							Arching / Fisting						
Drowsy							↑ RR (Apnea)						
Quiet awake							↑ 180 HR (Tachycardia)						
Active awake							↓ 100 HR (Bradycardia)						
Crying (Hoarse: X)							↓ 90% O2 Saturation						
Tone	hypo ☐		hyper ☐		normal ☐		Change in colouring						
Posture	extension ☐		floppy ☐		normal ☐		Nasal flaring						
Comments													

ORAL STRUCTURES

	Tongue	Jaw	Lips	Cheeks	S Palate	Structural abnormalities
Symmetric (VII)	Y / N	Y / N	Y / N	Y / N	Y / N	
Tone	N / ↑ / ↓	N / ↑ / ↓	N / ↑ / ↓	N / ↑ / ↓	N / ↑ / ↓	
Optimal ROM	Y / N	Y / N	Y / N	Y / N	Y / N	
Comments						

NNS (NON-NUTRITIVE SUCK) (after oral stimulation)

Initiation Immediately ☐ After oral stimulation ☐	Nr of sucks per burst:		Rooting (V)	Lip closure	Tongue cupping	Strength	Endurance
		good					
	Nr of burst cycles	limited					
		none					
Abnormal oral movements	hyperactive gag ☐	biting ☐	disorganized tongue movements ☐	poorly graded jaw opening ☐	Other ☐		
	absent gag (IX) ☐	Fasiculations / quivering (XII) ☐					
Dry swallow: Present ☐ Absent ☐	Comments						

ORAL FEEDING: Breast ☐ / Bottle ☐

Positioning Optimal ☐ Other:		Latching	Lip closure	Endurance	Initiation of suck Immediately ☐ Other:	Nr of sucks per burst: __ Nr of burst cycles: __	SSB coordination Good ☐ Other:
	good						
	limited						
	none						
Swallow Hyo-laryngeal elevation ☐ Anterior movement ☐ Creps / residue palpable ☐	**Risk signs**	Coughing ☐	Hyperactive gag ☐	Vomiting / reflux ☐			
		Gulping ☐	Multiple swallows ☐	Gurgly breathing ☐			
		Anterior loss ☐	Aspirating ☐	Other ☐			
Comments:							

ORAL FEEDING: Cup ☐ / Spoon ☐

Positioning Optimal ☐ Other:	Presentation by caregiver Optimal ☐ Other:	Initiation of "suck" Immediately ☐ Poor awareness of bolus ☐ Other:	SSB coordination Good ☐ Other:	Able to finish feed Yes ☐ / No ☐
Swallow Tongue base movement ☐ Laryngeal elevation ☐	**Risk signs**	Coughing ☐	Hyperactive gag ☐	Vomiting / reflux ☐
		Gulping ☐	Multiple swallows ☐	Gurgly breathing ☐
		Anterior loss ☐	Aspirating ☐	Other ☐
Comments:				

RECCOMMENDATIONS

Therapist: _____

Date: _____

V (Trigeminal), VII (Facial), IX (Glossopharyngeal), X (Vagus), XII (Hypoglossal)

APPENDIX G: Data collection tool

RESPONDENT NUMBER

HOSPITAL NUMBER

SECTION 1. DEMOGRAPHIC INFORMATION

1.1			
1.1.1	Nationality	1. South African 2. Non South African	
1.1.2	Race	1. Black 2. White 3. Asian 4. Coloured	
1.1.3	Gender	1. Male 2. Female	
1.1.4	Age (D.O.B)	_____	
1.1.5	Residence	_____	

SECTION 2: CLASSIFICATION

2.1	**A. Neurological conditions**		
2.1.1	Encephalopathy	1. No 2. Yes 3. Unknown	
2.1.2	Birth asphyxia	1. No 2. Yes 3. Unknown	
2.1.3	Hypoxic ischemic encephalopathy (HIE) grade	1. HIE 1 2. HIE 2 3. HIE 3 4. None 5. unknown	
2.1.4	Traumatic brain injury	1. No 2. Yes 3. Unknown	
2.1.5	Neoplasms	1. No 2. Yes 3. Unknown	
2.1.6	Spina bifida	1. No 2. Yes 3. Unknown	
2.1.7	Microcephaly	1. No 2. Yes 3. Unknown	
2.1.8	Seizures	1. No 2. Yes 3. Unknown	

2.1.9	Peri-ventricular leucomalacia	1. No 2. Yes 3. Unknown	
2.1.10	Cephalhematoma	1. No 2. Yes 3. Unknown	
2.1.11	Other, specify	_____	
2.2	**B. Anatomical risks**		
2.2.1	Cleft lip	1. No 2. Yes 3. Unilateral 4. Bilateral	
2.2.2	Cleft lip and palate	1. No 2. Yes 3. Unilateral 4. Bilateral 5. Unknown	
2.2.3	Cleft lip and palate unilateral	1. No 2. Yes 3. Unknown	
2.2.4	Cleft lip and palate bilateral	1. No 2. Yes 3. Unknown	
2.2.5	Pierre robin sequence	1. No 2. Yes 3. Unknown	
2.2.6	Laryngomalacia	1. No 2. Yes 3. Unknown	
2.2.7	Esophageal stricture / atresia	1. No 2. Yes 3. Unknown	
2.2.8	Tracheal esophageal fistula	1. No 2. Yes 3. Unknown	
2.2.9	Other	1. No 2. Yes 3. Unknown	
2.3	**C. Risks secondary to systemic illness**		
2.3.1	Respiratory (chronic lung disease)	1. No 2. Yes 3. Unknown	
2.3.2	Broncho-pulmonary dysplasia	1. No 2. Yes 3. Unknown	
2.3.3	Patent ductus arteriosus (PDA)	1. No 2. Yes 3. Unknown	
2.3.4	Gastrointestinal conditions (including NEC)	1. No 2. Yes	
		3. Unknown	
2.3.5	Congenital cardiac anomalies	1. No 2. Yes 3. Unknown	

2.3.6	Respiratory Distress syndrome (RDS)	1. No 2. Yes 3. Unknown	
2.3.7	Meningitis	1. No 2. Yes 3. Unknown	
2.3.8	Pneumonia	1. No 2. Yes 3. Unknown	
2.3.9	Septicaemia	1. No 2. Yes 3. Unknown	
2.3.10	Hyperbilirubenaemia/ Neonatal jaundice (NNJ)	1. No 2. Yes 3. Unknown	
2.3.11	Anaemia	1. No 2. Yes 3. Unknown	
2.3.12	Kidney involvement/ renal failure.	1. No 2. Yes 3. Unknown	
2.3.13	Other, specify	1. No 2. Yes 3. Unknown	
2.4	**D. Chromosomal anomalies**		
2.4.1	Trisomy 13	1. No 2. Yes 3. Unknown	
2.4.2	Trisomy 21(Down syndrome)	1. No 2. Yes 3. Unknown	
2.4.3	Trisomy 18	1. No 2. Yes 3. Unknown	
2.4.4	Syndromic, not diagnosed	1. No 2. Yes 3. Unknown	
2.4.5	Syndromic, diagnosed	1. No 2. Yes 3. Unknown	
2.4.6	Other, specify	_____	
2.5	**E. Psychosocial and behavioural risks**		
2.5.1	Oral deprivation	1. No 2. Yes 3. Unknown	
2.5.2	Malnutrition	1. No 2. Yes 3. Unknown	
2.5.3	Under nutrition	1. No 2. Yes 3. Unknown	
2.6	**F. Risks secondary to resolved medical condition**		
2.6.1	Iactrogenic	1. No 2. Yes	

		3. Unknown	
2.6.2	Klebsiella sepsis	1. No 2. Yes 3. Unknown	
2.6.3	Methicillin-resistant staphylococcus areus (MRSA)	1. No 2. Yes 3. Unknown	
2.6.4	Candida sepsis	1. No 2. Yes 3. Unknown	
2.6.5	Other, specify	_____	
2.7	**G. Other risks**		
2.7.1	Preterm	1. No 2. Yes 3. Unknown	
2.7.2	Grade of prematurity	1. Premature 2. Extremely premature 3. Not applicable	
2.7.3	Birth weight	_____	
2.7.4	Birth weight classification	1. Normal 2. Low birth weight 3. Very low birth weight 4. Extreme low birth weight	
2.7.5	Gastro esophageal reflux disorder	1. No 2. Yes 3. Suspected, not diagnosed 4. Unknown	
2.7.6	Failure to thrive	1. No 2. Yes 3. Unknown	
2.7.7	HIV exposure	1. No 2. Yes 3. Unknown	

A B C D E F G

SECTION 3. RISK FACTORS

	Condition	Risk	
3.1	**Prenatal risks**		
3.1.1	Age of mother	1. <14 2. 14-17 3. 18- 37 4. >38	
3.1.2	Number of antenatal visits	1. None 2. 1- 3 3. 4- 8 4. > 8	
3.1.3	HIV status of mother	1. HIV negative	

		2. HIV positive 3. Unknown	
3.1.4	Gravida	1. 1 2. 2 3. 3 4. >4	
3.1.5	Parity	1. 0 2. 1 3. 2 4. >3	
3.1.6	Previous still births	1. None 2. 1-3 3. 3- 5 4. >5	
3.1.7	Previous abortions	1. No 2. Yes 3. Unknown	
3.1.8	Multiple pregnancy	1. No 2. Yes 3. Unknown	
3.1.9	Birth order of infant	1. 1 2. 2 3. 3 4. 4	
3.1.10	Viral infections	1. No 2. Yes 3. Unknown	
3.1.11	Premature rupture of membranes	1. No 2. Yes 3. Unknown	
3.1.12	Pre-eclampsia	1. No 2. Yes 3. Unknown	
3.1.13	Duration of pregnancy	1. < 26 weeks 2. 27- 32 3. 33-36 4. > 36	
3.1.14	Place of birth	1. Home 2. Hospital 3. Clinic 4. Non of above-specified 5. Unknown	
3.1.15	Reason for premature birth	1. Premature rupture of membranes 2. Hypertension 3. Placental problems 4. Pre-eclampsia 5. Unknown 6. Not applicable 7. Foetal distress	

3.2	Environmental risks		
3.2.1	Information available	1. Yes 2. No	
3.2.2	Employment of mother	1. Employed 2. Unemployed 3. Unknown	
3.2.3	Maternal education	1. < Gr 8 2. Gr 8-12 3. Matric 4. Tertiary level	
3.2.4	Literate	1. Not literate 2. Low literacy 3. Literate	
3.2.5	Transport	1. Private 2. Public	
3.2.6	Living conditions	1. Good 2. Poor	
3.2.7	Health of parents	1. Good 2. Poor	
3.2.8	Paternal and maternal involvement	1. Both involved 2. Mom involved 3. Dad involved 4. None involved	

3.3	Perinatal risks		
3.3.2	Presentation	1. Vertex 2. Breech 3. Unknown	
3.3.3	Gestational age	_____	
3.3.4	Gender	1. Male 2. Female 3. Unknown	
3.3.5	Cord	1. Normal 2. Prolapse 3. Around neck 4. Unknown	
3.3.6	Instruments used	1. No 2. Yes 3. Unknown	
3.3.7	Meconium aspiration	1. No 2. Yes 3. Unknown	
3.3.8	Apgar 1min	_____	
3.3.9	Apgar 5 min	_____	
3.3.10	Apgar 10 min	_____	
3.3.11	Temperature	1. Normal 2. Hyperthermia 3. Hypothermia 4. Unknown	
3.3.12	HIV status of infant	1. Negative 2. Positive 3. Exposed 4. Unknown	

3.4	Postnatal medical risks		
3.4.1	Small for gestation	1. No 2. Yes 3. Unknown	
3.4.2	Intra uterine growth retardation	1. No 2. Yes 3. Unknown	
3.4.3	Oxygen received	1. No 2. Yes 3. Unknown	
3.4.4	Duration of oxygen received	_____	
3.4.5	Ventilation	1. No 2. Yes 3 Unknown	
3.4.6	Duration of ventilation	_____	
3.4.8	Broncopulmonary dysplasia	1. No 2. Yes 3. Unknown	
3.4.9	Bradycardia	1. No 2. Yes 3. Unknown	
3.4.10	Apnoea	1. No 2. Yes 3. Unknown	
3.4.11	Tacyapnoea	1. No 2. Yes 3. Unknown	
3.4.12	Retinopathy of prematurity	1. No 2. Yes 3. Unknown	
3.4.13	Patent ductus arteriosus	1. No 2. Yes 3. Unknown	
3.4.14	Intra ventricular hemorrhage	1. No 2. Yes Grade_____	
3.4.15	Neonatal convulsions	1. No 2. Yes 3 Unknown	
3.4.17	Hydrocephalus	1. No 2. Yes 3. Unknown	
3.4.18	Necrotising enterocolitis	1. No 2. Yes 3. Unknown	
3.4.19	Ototoxic medication	1. No 2. Yes 3. Unknown	
3.4.20	NNJ phototherapy	1. No 2. Yes 3. Unknown	
3.4.21	NNJ blood transfusion	1. No 2. Yes 3. Unknown	
3.4.22	Hypoglycemia	1. No 2. Yes	

		3. Unknown	
3.4.23	Hyperglycemia	1. No 2. Yes 3. Unknown	
3.4.24	Blood transfusion non NNJ	1. No 2. Yes 3. Unknown	
3.4.25	TPN	1. No 2. Yes 3. Unknown	
3.4.26	Metabolic acidosis	1. No 2. Yes 3. Unknown	
2.4.27	Hypotension	1. No 2. Yes 3. Unknown	
2.4.28	Cardiomyopathy/ heart problems	1. No 2. Yes 3. Unknown	
2.4.29	Previous NGT/OGT	1. No 2. Yes 3. Unknown	
2.4.30	Warm table/ incubator	1. No 2. Yes 3. Unknown	
2.4.31	Number of days in NICU	_____	
2.4.32	Dehydration	1. No 2. Yes 3. Unknown	
2.4.33	Kidney involvement/ renal failure	1. No 2. Yes 3. Unknown	

SECTION 4. FEEDING CHARACTERISTICS

4.1.1	Attended follow up appointment	1. Yes 2. No 3. Unknown	
4.1.2	Status of patient	1. Alive 2. Demised 3. Unknown	
4.1.3	Hospital Feeding method	1. Exclusive Breast feeding 2. Exclusive formula feeding 3. Mixed feeding methods 4. Supplementation feeding 5. Other	
4.1.4	Hospital feeding manner	1. Breast feeding 2. Bottle feeding 3. Cup feeding 4. Gastrostomy feeding 5. Spoon feeding 6. Syringe feeding 7. Mixed utensils	
4.1.5	Feeding problems in hospital according to parent	1. No 2. Yes	

		3. Unknown	
4.1.6	Signs of aspiration in hospital	1. No 2. Yes 3. Unknown	
4.1.7	Signs of reflux in hospital	1. No 2. Yes 3. Unknown	
4.1.8	Milestones as noted by SLT or OT at follow up clinic	1. Age appropriate 2. Delayed 3. Unknown	
4.1.9	Current feeding method <6 months	1. Exclusive Breast feeding 2. Exclusive formula feeding 3. Mixed feeding methods 4. Supplementation feeding 5. Other	
4.1.10	Feeding manner < 6months	1. Breast feeding 2. Bottle feeding 3. Cup feeding 4. Gastrostomy feeding tube 5. Spoon feeding 6. Syringe feeding 7. Mixed utensils	
4.1.11	Current patient status post discharge	1. Alive 2. Demised 3. Unknown	

REFERENCES

Arvedson, J. C., & Brodsky, L. (2002). *Pediatric Swallowing and feeding, assessment and management*. 2nd ed. New York: Delmar Cengage.

Fourie, A. (2011). The aetiology and nature of paediatric dysphagia (0-18 months) in state hospitals in Johannesburg, Gauteng. Unpublished Masters dissertation, University of Witwatersrand, South Africa.

Kritzinger, A. (2002). *Risk Assessment form.* Unpublished.

Van Heerden, H. (2010). *Dysphagia Assessment Form.* Unpublished

Manikam, R., & Perman, J.A. (2000). Pediatric feeding disorders. *Journal of Clinical Gastroenterology, 30,* 34-46.

Rossetti, L. M. (2001). *Communication intervention, Birth to three*. 2nd ed. New York: Singular Thomson Learning.