

The validation of a screening tool for the identification of feeding and swallowing difficulties in the paediatric population aged 0 - 2years admitted to general medical wards

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Dissertation presented for the degree of Master of Science in Speech-Language Pathology

Dissertation submitted in August 2019

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Declaration

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Abstract

Background: Feeding and swallowing difficulties (FSD) have been found in typically developing children as well as in children with complex medical conditions and developmental disabilities. These difficulties cause negative health consequences such as aspiration pneumonia, chronic lung disease, failure to thrive, prolonged hospital stay and even death. The early identification and management of feeding and swallowing difficulties is important as it prevents the negative effects on health and quality of life. Hence, there is a need for a validated screening tool to use in the general hospitalized paediatric population.

Research Aims: The aim of this study was to validate the *Feeding and Swallowing Questionnaire* as a screening tool, in the paediatric population aged 0 – 2 years admitted to general medical wards. The secondary aim was to describe the FSD presenting in the paediatric population aged 0 - 2 years who are hospitalized in the general medical wards.

Methodology: A prospective, descriptive, clinimetric design was utilized. A sample of 107 participants admitted to the general medical wards at Steve Biko Academic Hospital were included in the study. Participants' feeding and swallowing was screened by a research assistant using the *Feeding and Swallowing Questionnaire*. After the screening, a clinical feeding and swallowing assessment was conducted for comparison, the assessment was conducted by the student researcher using the Clinical Feeding and Swallowing Assessment Tool.

Results: There was a 27% FSD prevalence, with the majority of cases (92%) occurring in children under one year of age. One hundred and three children (63% male; median (IQR) age 5.2 (2.1 – 12.8) months) underwent screening and clinical assessment for feeding and swallowing disorders. The criterion validity of the *Feeding and Swallowing Questionnaire* was established with a sensitivity of 88% and a specificity of 32%. Internal consistency was achieved with an acceptable Cronbach's alpha of 0.79, and good inter-rater reliability (80%).

Participants presented with feeding difficulties in all the phases of swallowing, while some participants had behavioural feeding difficulties. Those who had FSD had the following medical conditions: cardiorespiratory, neurological and gastrointestinal disorders namely acute gastroenteritis and liver disease. Feeding and swallowing difficulties were associated with increased mealtime duration ($p=0.005$) and supplementary oxygen support ($p=0.03$).

Conclusion: The results confirm that the *Feeding and Swallowing Questionnaire* shows promising findings as a reliable and valid tool for the identification of FSD in the general hospitalized paediatric population. However, further research in other setting with general paediatric medical wards is required to increase the robustness of the screening tool.

Keywords: *feeding and swallowing difficulties, validity, reliability, screening, general paediatric population, hospitalized, medical wards,*

Author's Note

Acknowledgements:

I would like to express my sincere gratitude to the following people who helped me throughout this journey:

Firstly, I would like to thank God for giving me strength to endure this journey. I would have never made it without you Lord.

To my supervisors Mrs Vivienne Norman and Professor Brenda Morrow, thank you for being patient with me. Thank you for your invaluable input and sharing your vast wealth of knowledge. Thank you for your guidance and motivation- I would have never achieved this without you.

To my research assistants, Daniella Moodley and Maxine Alves thank you for dedication throughout the data collection process.

A heartfelt thank you to my late mother Lucy Sibanda, this journey would have never started if it wasn't for your encouragement. Thank you for all your support and prayers.

To my friend Olebeng Mahura, thank you for unwavering support.

Thank you to the staff members of the Dietetics Department and Speech-Therapy Department at Steve Biko Academic Hospital, for your assistance during data collection.

Glossary - Selected Terms

Aspiration

This occurs when a bolus enters the airway below the level of the true vocal cords (Dodrill & Gosa, 2015).

Clinical feeding and swallowing assessment

This refers to the comprehensive clinical evaluation of feeding and swallowing that is conducted to provide diagnostic information regarding the safety and efficacy of an infant and child's feeding and swallowing ability (Arvedson & Brodsky, 2002; Groher & Crary, 2010).

Behavioural feeding difficulties

Behavioural difficulties also referred to as food or fluid aversions, occur when a child is not willing to eat a particular food consistency e.g. lumpy food, despite being physically able to do so (Dodrill & Gosa, 2015).

Construct validity

The extent to which a measurement actually tests the hypothesis or theory it is measuring (Bruce, Pope & Stanistreet, 2008).

Criterion Validity

The process of statistically testing a new measurement technique against an independent standard. Therefore, this is the extent to which a measure compares with a gold standard (Bellamy, 2015).

Dysphagia

Any disruption to the swallow process that results in the compromise to the safety, efficiency, or adequacy of nutritional intake (Dodrill & Gosa, 2015).

Enteral feeding

The process of delivering nutritionally complete feeds directly into the stomach, duodenum or jejunum via the nose or mouth through a tube (National Collaborating Centre for Acute Care (UK), 2006).

Feeding and swallowing difficulties

These are difficulties that affect the normal process of eating and drinking which may cause difficulties in feeding such as sucking, manipulating a bolus and chewing. Additionally, they may cause difficulties in one or more phases of the swallow mechanism namely oral preparatory, oral phase, pharyngeal and oesophageal phase. (Van den Engel-Hoek et al., 2015)

Gastrostomy tube feeding

Gastrostomy tube feeding is a method of providing enteral feeds through the stomach. This method is often initiated for long-term feeding purposes and helps to ensure optimal nutrition and growth in children with feeding and swallowing difficulties coupled with poor growth (Lee & Spratling, 2013)

Growth faltering (previously called 'failure to thrive')

This is the term used to describe a slower rate of weight gain in childhood than that which is expected for age and sex (Gonzalez-Viana et al., 2017)

Internal consistency

This reflects the extent to which items within a screening tool, assessment or questionnaire, measure various aspects of the same construct (Revicki, 2014).

Nasogastric tube feeding

Nasogastric tube feeding is a method of providing enteral feeds through the nose. A tube is inserted from the nose to the stomach. It is usually placed for short-term periods, so as to ensure the maintenance of a patients' nutritional status during hospitalization. (Chang et al., 2015)

Negative predictive value

The percentage of patients with a negative test result, who do not have the disease measured (Parikh et al., 2007).

Positive predictive value

The percentage of patients with a positive test result, who actually do have the disease measured (Parikh et al., 2007).

Screening of feeding and swallowing

Screening refers to an initial, short examination of feeding and swallowing, which is not diagnostic in nature, but is able to identify the need for further comprehensive assessment of feeding and swallowing (Arvedson & Brodsky, 2002; Grover & Crary, 2010).

Sensitivity

Sensitivity refers to the ability of a test to correctly identify patients with a disease, when the patient truly has the disease (Lalkhen & McCluskey, 2008).

Specificity

Specificity refers to the ability of a test to correctly identify patients without a disease, when the patient truly does not have the disease (Lalkhen & McCluskey, 2008).

Supplemental oxygen therapy

This is the provision of extra (supplemental) oxygen in order to bring oxygen levels to a healthier level. This form of therapy is often used in infants and children with low oxygen levels in their bodies due to a precipitating medical condition such as lung disease or congenital heart defect (Walsh & Smallwood, 2017).

Abbreviations

ABFS-C	Ability for basic feeding and swallowing scale for children
AIDS	Acquired Immune Deficiency Syndrome
AUC	Area under the curve
BASOFF	Behavioural Assessment Scale of Oral Functions in Feeding
CEBQ	Child Eating Behavior Caregiver Questionnaire
CFSAT	Clinical Feeding and Swallowing Assessment Tool
DDS	Dysphagia Disorders Survey
FSD	Feeding and swallowing difficulties
FSQ	Feeding and Swallowing Questionnaire
FFAm	Functional feeding assessment modified
GORD	Gastro-oesophageal reflux disease
GRADE	Grading of Recommendations, Assessment, Development and Evaluation
HPCSA	Health Professions Council of South Africa
HIV	Human Immunodeficiency Virus
ICF	International Classification of Functioning, Disability and Health
MBQ	Mealtime Behavior Questionnaire
MCH-FS	Montreal children's hospital feeding scale
NPV	Negative predictive value
PEDI-EAT	Pediatric Eating Assessment tool
PPV	Positive predictive value
ROC	Receiver operator characteristic
SOMA	Schedule for Oral Motor Assessment

STEP-CHILD	Screening tool of Feeding Problems applied to children
SLT	Speech-Language Therapist
SBAH	Steve Biko Academic Hospital
VFSS	Video fluoroscopic swallow study
WHO	World Health Organization

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1. Literature review

1.1 Introduction

Feeding and swallowing difficulties, which are also referred to as dysphagia, occur in both healthy, typically developing children as well as children with developmental disabilities and complex medical conditions (Miller, 2009; Ramsay, Martel, Porporino & Zygmuntowicz, 2011; Thoyre et al., 2014). Feeding and swallowing difficulties (FSD) are particularly prevalent in infants and children who have a history of preterm birth, respiratory difficulties, congenital heart defects, anatomic abnormalities and various syndromes and neurological abnormalities (Borowitz & Borowitz, 2018; Costello, Gellatly, Daniel, Justo & Weir, 2014; Jackson et al., 2016; Mizuno et al., 2007; Sassi et al., 2018; Srivastava, Jackson & Barnhart, 2010). International studies have reported a 25% to 40% prevalence of FSD in typically developing children; 80% in children with developmental difficulties and 85% in children with complex medical conditions (Kakodkar & Schroeder, 2013; Lima, Cortes, Bouzada & de Lima Friche, 2015; Malas, Trudeau, Chagnon & MacFarland, 2015; Thoyre et al., 2014). The prevalence of FSD in the South African paediatric population is unknown, however it is expected that prevalence is similar to international findings. Most FSD in the paediatric population are reported in children under two years of age (Kakodkar & Schroeder, 2013), therefore this age range was selected for this study.

Feeding and swallowing difficulties may cause negative health consequences including: aspiration pneumonia, chronic lung disease, growth faltering, prolonged hospital stay and even death (Garg, 2003; Prasse & Kikano, 2009; Svystun et al., 2017; Tutor & Gosa, 2012;). Feeding and swallowing difficulties may also affect cognitive, social and emotional development in children and impacts on the quality of life of both children and their parents (Kim et al., 2017). Therefore, early identification and management of FSD through screening and assessment is required to ameliorate the negative impacts of FSD on health and quality of life.

1.2 Aetiology and conditions associated with feeding and swallowing difficulties in children

Feeding and swallowing skills, or the development thereof, may be impaired as a result of medical, psychological and/or behavioural problems (Borowitz & Borowitz, 2018; Coppens, van den Engel-Hoek, Scharbatke, de Groot & Draaisma, 2016; Duffy, 2018; Horton, Atwood, Gnagi, Teufel & Clemmens, 2018; Malas et al., 2015). The focus of this section will be to describe the medical conditions that are commonly associated with FSD. Additionally, it will provide the context for why FSD needs to be identified and managed, but this will be discussed further in later sections.

The following categories of medical conditions are associated with FSD: neurological, cardiorespiratory, gastrointestinal, structural anomalies of the aerodigestive system, genetic and developmental disabilities, prematurity as well as other conditions such as HIV/AIDS and sepsis (Borowitz & Borowitz, 2018; Coppens et al., 2016; Duffy, 2018; Horton et al., 2018). These conditions may occur in isolation, or in combinations, as would be seen in children with genetic syndromes such as Trisomy 21 (with congenital heart disease, developmental delay, and tracheomalacia) (Jackson, Maybee, Moran, Wolter-Warmerdam & Hickey, 2016). The FSD associated with these categories of medical conditions will be discussed below.

1.2.1 Neurological

Neurologic conditions are the aetiologies most frequently associated with FSD (Lefton-Greif, 2008). Infants and children with upper motor neurological impairments such as cerebral palsy and hydrocephalus, are at risk of developing FSD due to the impairment of normal eating, swallowing and airway protection mechanisms (Srivastava et al., 2010). It is estimated that 55%-89 % of children with neurological impairments have FSD (Sullivan et al., 2010).

Infants and children with upper motor neurological impairments usually present with FSD in the oral and pharyngeal phases of the swallow (Benfer et al., 2017). The oral phase difficulties consist of reduced tongue range of movement, which results in difficulty with bolus control, bolus formation and bolus propulsion (Benfer et al., 2017).

Additionally, anterior spillage due to poor lip closure; increased duration of feeding are common oral phase difficulties (Benfer et al., 2017). Pharyngeal phase swallowing difficulties resulting in aspiration are common in this population due to the lack of maturity of the neuromuscular coordination that is required during swallowing (Sheikh et al., 2001).

The pharyngeal phase difficulties in infants and children with neurological impairments consist of coughing and/ or choking during feeding; and chronic aspiration, with recurrent lower respiratory infections or pneumonia (Seddon & Khan, 2003; Srivastava et al., 2010). Pneumonia is associated with significant morbidity, which potentially prolongs hospital stay in infants and children hospitalized with neurological conditions (Morgan, Mageandran & Mei, 2009). Feeding difficulties in infants and children with upper motor neurological pathologies may negatively affect their oral intake, nutritional status and general health (Srivastava et al., 2010).

The nature of FSD in children with progressive neuromuscular diseases (lower motor neuron pathology) is variable, and likely to develop with disease progression (Serel Arslan, Aydin, Alemdaroglu, Tunca Yilmaz & Karaduman, 2018). As the disease progresses, children may present with insufficient lip closure, which results in anterior spillage of food or liquids; they may also have reduced tongue movements which result in poor bolus formation and increased oral transit time (Serel Arslan et al., 2018).

Choking (due to pharyngeal muscle weakness and inadequate chewing) may also occur in this population resulting in hypoxia and aspiration, which further compromises their health (Serel Arslan et al., 2018). Eventually, the swallowing efficacy becomes severely compromised therefore requiring the need for a long-term feeding method such as the insertion of a gastrostomy tube (Serel Arslan et al., 2018).

1.2.2 Cardiorespiratory

Congenital heart defects such as Ventricular Septal Defect (VSD) and Patent Ductus Arteriosus (PDA) have been associated with FSD (Costello et al., 2014; Hehir, Easley & Byrnes, 2016). In the context of South Africa, it is estimated that 11 000 children are born annually with congenital heart defects which may require both medical and surgical intervention to correct the defect (Hoosen et al., 2011).

Therefore, congenital heart defects affect quite a large number of infants and children and at some point, during their disease process they may develop FSD (Costello et al., 2014; Hehir et al., 2016). Infants and children with congenital heart defects may present with FSD that affect the oral phase of the swallow; infants may have difficulties sucking and older children may have difficulty manipulating the bolus in their mouth due to poor endurance (Costello et al., 2014; Hehir et al., 2016).

These oral phase difficulties may affect oral intake as well as an increase in the duration of mealtimes (Bejiqi et al, 2017; Costello et al., 2014). This is because infants and children with cardiac defects are prone to lower respiratory tract infections, particularly respiratory syncytial virus (Jung, 2011). Lower respiratory tract infections in infants and children with congenital heart defects affect oxygen uptake and result in increased work of breathing (Jung, 2011). This further compromises their already compromised endurance causing them to tire easily during activities that require the exertion of energy; in this case feeding and swallowing (Bejiqi et al, 2017; Costello et al., 2014; Jung, 2011). Reduced endurance coupled with the respiratory difficulties may affect oral skills resulting in difficulty sucking or poor bolus manipulation which affect the suck-swallow-breathing coordination of swallowing which may further result in aspiration (Bejiqi et al, 2017; Costello et al., 2014).

Consequently, poor oral intake may occur as a result of reduced endurance and possible respiratory consequences from aspiration (Bejiqi et al, 2017; Costello et al., 2014). This may result in malnutrition and poor weight gain, which may require enteral feeding (e.g. nasogastric tube feeding), to assist in weight gain, particularly in preparation for cardiac surgery (Bejiqi et al, 2017; Costello et al., 2014).

Surgery may be required to correct some congenital heart defects (Kohr et al., 2003). However, surgery carries the risk of iatrogenic injury to the recurrent laryngeal nerve and its anatomic course (Kohr et al., 2003), which may lead to postoperative vocal fold dysfunction (paralysis or paresis) (Clement, El-Hakim, Phillipos & Cote., 2008) Damage to the recurrent laryngeal nerve may result in vocal fold paralysis or paresis, which impacts optimal laryngeal airway closure during swallowing, potentially resulting in aspiration (Kohr et al., 2003).

Respiratory difficulties also have a significant negative impact on the ability to swallow because they affect the suck-swallow-breathe coordination, placing infants and children at risk of aspiration (Sassi et al., 2018). In young infants such as preterm infants, respiratory difficulties may be as a result of immature lungs (Mizuno et al., 2007). Other respiratory conditions such as bronchiolitis and lower respiratory infections also affect the swallow-breathe coordination, due to the compromised respiratory mechanism (Borowitz & Borowitz, 2018). A disturbance in the respiratory mechanism affects the process of laryngeal airway protection thereby increasing the risk of aspiration with associated sequelae including pneumonia and prolonged hospital stay (Borowitz & Borowitz, 2018).

1.2.3 Structural anomalies of the aerodigestive tract

Structural anomalies of the aerodigestive system have been associated with FSD, with effects on different phases of the swallow (Borowitz & Borowitz, 2018; Irace et al., 2019; Tutor & Gosa, 2012). For example, infants and children with cleft lip and/ palate present with difficulties latching; poor sucking; reduced intraoral pressure, which make it difficult for the infant to extract milk from the breast or bottle; and causes anterior spillage due to incomplete lip closure (Borowitz & Borowitz, 2018; Tutor & Gosa, 2012). Difficulties in the oral phase affect feeding time and efficiency, which impact negatively on intake and consequently weight gain (Borowitz & Borowitz, 2018; Tutor & Gosa, 2012).

Pharyngeal phase difficulties are also common in infants and children with structural anomalies of the aerodigestive system (Irace et al., 2019); with signs such as coughing, gagging, choking and a disruption in the suck-swallow-breathe coordination which compromise the respiratory system (Irace et al., 2019). Considering that feeding is an essential aspect of caregiver-child bonding and communication, FSD in this population may also affect parent or caregiver's quality of life, as feeding times become increasingly stressful (Irace et al., 2019; Ngubane & Chetty, 2017).

1.2.4 Prematurity

Prematurity is a complex medical condition which is often further complicated by other medical conditions which affect the development of feeding and swallowing skills (Mizuno et al., 2007). According to Newman, Keckley, Peterson & Hamner (2001), approximately 33%-40% of infants and children who present with FSD are born prematurely.

Feeding and swallowing difficulties in preterm infants may present in various phases of the swallow (Lefton-Greif, 2008). Premature infants may present with difficulty sucking due to immature oral motor skills (Lau, Smith & Schanler, 2003). Poor sucking skills may impact on an infant's oral intake therefore compromising nutrition and weight gain which are both important for brain development (Lau et al., 2003).

Weight gain is a challenge in premature infants especially those who are born with a very low birth weight (Bingham, 2009). Therefore, feeding and swallowing difficulties may act as catalytic factors in infants who have existing weight gain problems (Bingham, 2009). Enteral feeding may be initiated in this population so as to assist with weight gain (Lima et al., 2015). Additionally, enteral feeding is also initiated in premature infants due to physiological and neurological immaturity which hinders these infants from being able to feed orally during the first weeks of life (Lima et al., 2015). Feeding and swallowing difficulties may also occur in the pharyngeal phase where due to underdeveloped lungs, the respiratory system is affected (Mizuno et al., 2007). Moreover, premature infants may develop respiratory illnesses such as chronic lung disease and bronchopneumonia which further compromise the respiratory system (Lefton-Greif, 2008).

The aforementioned affect the suck-swallow breathe coordination, which is an integral part of the respiratory system, therefore placing infants at risk of aspiration (Lefton-Greif, 2008). Chronic aspiration may further compromise the developing lungs and also increases the risk of these infants developing aspiration-induced chronic lung disease (Lefton-Greif, 2008).

1.2.5 Genetic syndromes and developmental disorders

Genetic and developmental disorders are also associated with FSD (Jackson et al., 2016; Kleinert, 2017). The feeding and swallowing difficulties that occur in this population are usually related to, but are not limited to, gastro-oesophageal reflux disease (GORD), oral motor dysfunction, dyskinesia, and aversive feeding behaviours (Jackson et al., 2016; Kleinert, 2017; Schwartz, 2003). Feeding and swallowing difficulties in this population present in various ways depending on the medical condition (Kleinert, 2017). For instance, infants and children with down syndrome may present with oral phase feeding difficulties such as poor lip closure due to hypotonia which results in anterior spillage (O'Neil & Richter, 2013).

Whereas children with Autism Spectrum Disorder (ASD) may present with sensory-based feeding difficulties such as restrictive rigid preferences in their diet which affect their nutritional intake (Lefton-Greif, 2008).

1.2.6 Gastrointestinal disorders

Gastrointestinal disorders are frequently associated with FSD (Field, Garland & Williams, 2003). Feeding and swallowing difficulties in this category of medical conditions are related to food refusal, fussy eating behaviours such as food selectivity and crying during mealtimes (Field et al, 2003). The most common gastrointestinal disorder that is associated with FSD is GORD (Coppens et al., 2016)

Infants and children with GORD present with signs such as frequent regurgitation, irritable behaviour, poor weight gain and upper respiratory tract infections, as well as food refusal, food selectivity and difficulty swallowing. Additionally, regurgitation may be aspirated into the lungs which is evidenced by choking and coughing, back aching may also be observed and in some instances acute life-threatening events such as apnea may occur (Fishbein et al., 2012). Due to the nature of feeding difficulties that occur in this population and the negative impact on growth, enteral feeding is often required to support nutritional intake (Field et al, 2003). Depending on the severity of the GORD proton pump inhibitors are used as treatment, however a Nissen Fundoplication may be conducted should the symptoms be severe (Coppens et al., 2016).

1.2.7 Enteral feeding

Although this is not a medical condition, many infants and children with the medical conditions described above require enteral feeding due to the medical condition itself or because of FSD. Some may require long term enteral feeding such as a gastrostomy while others may require short term enteral feeding which may be administered through a nasogastric or orogastric tube (Benoit, Wang & Zlotkin, 2000). For instance, gastrostomy tube feeding is often recommended in children with neurological conditions who cannot safely and efficiently feed orally which either places them at risk of aspiration or malnutrition (Mahant, Jovcevska & Cohen, 2011; Sullivan, 2013). Nasogastric tube feeding is often used for short term purposes in paediatric populations who present with various medical conditions such as prematurity, congenital heart defects, children who are post-surgery i.e. transplants (Mirete

et al., 2018; Although enteral feeding ensures sufficient nutritional intake and weight gain, it has also been associated with complications, including the development of oral aversion to certain food textures (Benoit et al., 2000). Moreover, recently there has been an increase in feeding tube dependency which a reliance on enteral feeds despite being able to feed safely and efficiently orally (Krom, de Winter & Kindermann, 2017; Wilken, Bartmann, Dovey & Bagci, 2018). Infants and children with feeding tube dependency present with signs of oral aversion such as gagging, swallowing resistance and food refusal (Wilken et al., 2018). Prolonged enteral feeds may later result in food refusal, as critical periods of introducing different food textures may have been missed during the period of enteral feeds (Benoit et al., 2000).

1.3 Summary

In conclusion, it is evident that FSD are multifaceted, with various presentations and aetiologies depending on the associated medical condition. While the causes and presentation of FSD in infants and children with different medical conditions are multifaceted and may differ, the health consequences, namely poor growth and nutrition, and respiratory health, are similar. The findings from the literature review emphasize the importance of early identification and management of FSD which can be achieved by having a validated screening tool. Feeding and swallowing difficulties not only affect the health of infants and children, they also negatively impact quality of life. The effects of feeding and swallowing difficulties on quality of life will be discussed in the next section.

1.4 The effects of feeding and swallowing difficulties on Quality of Life

The quality of life of children and parents is affected by feeding and swallowing difficulties, due to prolonged hospital stay, stressful feeding times, parents' inability to feed their children orally and financial constraints that may arise (Howe, Sheu, Wang & Hsu, 2014; Kim et al., 2017). Prolonged hospital stay has been associated with various stressors that arise from being in the unnatural hospital environment as well as the physical and emotional isolation of caregivers (Howe et al., 2014). Having a child with FSD also contributes to parent stress (Ones, Yilmaz, Centikaya & Ciglar, 2005). These stressors may affect family dynamics; with impact on parental relationships with each other and with other children, as well as having financial implications (Kim et al., 2017).

Prolonged hospital stays result in infants and children being isolated from their parents and the rest of the family (Kim et al., 2017). Assuming that one parent is able to stay with the infant or child during the hospitalization period, that parent also becomes isolated from the rest of the family (Kim et al., 2017). Prolonged hospital stays also affect the way in which parents tend to their ill infant or child, such that they are restricted by hospital practices such as only feeding their child at certain times or not being able to hold their infant or child as often as they would like (Kim et al., 2017).

There are various financial constraints associated with having a child with a complex medical condition (Ngubane & Chetty, 2017). The burden of having an ill, hospitalized infant or a child that requires multiple follow up visits to feeding clinics is felt by the whole family. In a traditional, two-parent household, one parent usually assumes the role of the breadwinner while the other becomes the primary caregiver for the child (Kim et al., 2017; Ngubane & Chetty, 2017). In single parent or child-headed households, the financial burden as well as emotional burden may be experienced at a larger scale (Kim et al., 2017; Ngubane & Chetty, 2017).

Feeding and swallowing difficulties in children bring about concern in parents as they tend to worry about their child's weight gain, potential developmental consequences and the social impact of their child eating a limited diet (Borowitz & Borowitz, 2018). Mealtimes tend to be stressful as parents are concerned about the safety of oral feeding, adequate oral intake and the interaction that occurs during difficult mealtimes (Sullivan, 2014).

Mealtimes often take longer, increasing the stress for parents, as well as their concern for their child's weight gain (Sullivan, 2014).

Enteral feeds, whether nasogastric, orogastric or gastrostomy feeding, have a significant negative impact on early feeding development and may affect the bonding process between a mother, father and child during feeding (Bingham, 2009). One of the roles that a parent fulfills in their child's life is the ability feed their child, but enteral feeds take away this responsibility and deviates from the typical way of feeding (Sullivan, 2014). Some mothers may perceive their child's inability to feed orally by mouth as a confirmation that they are incapable of fulfilling their maternal role (Sullivan, 2014).

Enteral feeding, especially long-term enteral feeding, hinders a child's ability to participate during meals across different contexts i.e. at home, at family gatherings and at creche (Sullivan, 2014).

Identifying FSD early to avoid the negative consequences on both health and quality of life is therefore an important clinical area of assessment and management for Speech-Language Therapists (SLTs).

1.5 Speech-Language Therapy services in the South African context

Speech-Language Therapists (SLTs) play an integral role in identifying and managing FSD (Duffy, 2018). The South African public health system has substantial health challenges which include, but are not limited to, lack of accessibility to health care services as well as a lack human resources (Barratt, Khoza-Shangase & Msimang, 2012). According to the Health Professions Council of South Africa (HPCSA), in 2017 there were 1024 registered SLTs and 1541 dually qualified SLT/audiologists for a population of 56 million; of whom 8 million were children between the ages of 0- 6 years (Khoza-Shangase & Mophosho, 2018; StatsSA, 2018).

Additionally, 67 % of SLTs work primarily in the private sector, hence there is limited access to SLTs by the general population that relies largely on the public health sector (HPCSA, 2017). The ratio of SLTs to the population in the public health sector is clearly disproportionate, meaning that a large proportion of the population, including children, will not have access to SLT services. It is therefore likely that many infants and children with FSD are either missed or under-diagnosed owing to the limited accessibility of SLT services.

This under-recognition and under-management may result in negative health consequences for the individuals, and an increased burden on the health system (Barratt et al., 2012; Ostrofsky & Seedat, 2016). There is therefore a need to develop a validated screening tool that could identify infants and children who are at an increased risk of having FSD, who require referral for further comprehensive assessment and management (Barratt et al., 2012; Ostrofsky & Seedat, 2016). A validated screening tool will aid in identifying FSD earlier and because a screening tool is easy to administer, other health professionals could possibly use it and then refer for further assessment and management, thereby relieving the strain on the already heavy burdened health system.

1.6 Paediatric dysphagia assessment and screening tools

Screening would assist in the early identification of FSD in at-risk populations. However, there are no validated screening tools to use in the general paediatric population to identify children at risk of FSD (Suiter, Leder & Karas, 2009). Moreover, there is no validated clinical assessment tool that can be used as a “gold standard” comparator, when determining the reliability of screening tools.

Table 1-1 provides a summary of the feeding and swallowing screening and assessment tools described in literature, which can be used in the paediatric population. The table presents the mode of assessment, age ranges, the target population, assessment domains and validity of the tools. An adapted version of the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) system was used to critically review the quality of evidence supporting the feeding and swallowing screening and/or assessment tools (GRADE Working Group, 2018)

Table 1-1: An analysis of the available tools used to identify feeding and swallowing difficulties in the paediatric population, using an adapted version of GRADE

Name	Type of tool	Age Range	Target population	Domains assessed				Validity
				Oral motor skills	Oral phase dysphagia	Oral +Pharyngeal dysphagia	Behavioural feeding difficulties such as Food selectivity and/or Food refusal	
NFAS (Viviers et al., 2016)	Assessment tool	Neonates	High-risk neonates			X		-Face and content validity have been established -Criterion validity (established in neonates born with low birth weight) -Inter-rater reliability

PEDI-EAT (Thoyre et al., 2014)	Assessment tool	6 months- 7 years	General Paediatric Population			X	X	-Content validity has been established -Construct validity was established were the total scores of the PEDI-EAT were strongly related to the MBQ scores (p<0.001)
CEBQ (Heckathorn et al., 2016; Webber et al., 2010)	Screening tool	2 years and older	General Paediatric Population				X	Validity not determined
FSQ (Vermeulen, 2015)	Screening tool	Birth- 13 years	Children with HIV/AIDS			X	X	Content and Face Validity
STEP-CHILD (Heckathorn et al., 2016 Seiverling et al., 2011)	Screening tool	2 years- 7 years	Children with special needs such as Autism				X	Validity not determined

MBQ (Sanchez et al., 2015)	Screening tool	2 years- 6 years	General Paediatric population			X	X	Only construct validity was determined
3-ounce water test (Suiter et al., 2009)	Screening tool	2 years- 18 years	Paediatric population with various medical conditions			X		Specificity= 51.2 % and sensitivity= 48.8 %
DDS (Benfer et al., 2012; Heckathorn et al., 2016)	Assessment tool	3 years- 13 years	Intellectual and developmental disabilities			X		Convergent: specificity = 0.50 and sensitivity = 0.99 (This was determined in children 18-36 months with cerebral palsy)
BASOFF (Benfer et al., 2012; Heckathorn et al., 2016)	Assessment tool	10-38months	Developmental disabilities	X				Validity not determined

<p>SOMA</p> <p>(Benfer et al., 2012)</p>	<p>Assessment tool</p>	<p>8- 24 months</p>	<p>-Nonorganic failure to thrive -Cerebral palsy -Normal healthy children</p>			<p>X</p>		<p>-Only validated on preschool children with cerebral palsy</p> <p>- Convergent validity: sensitivity of 0.50 and a specificity of 1.00</p>
<p>ABFS-C</p> <p>(Kamide et al., 2015)</p>	<p>Assessment tool</p>	<p>2 months- 14 years</p>	<p>Developmental disabilities</p>	<p>X</p>				<p>Concurrent validity:</p> <p>Spearman rank correlation coefficient between Fujishima's Grade and test components ($r = 0.009-0.470$)</p>
<p>FFAm</p> <p>(Benfer et al., 2012)</p>	<p>Assessment tool</p>	<p>Entire paediatric population</p>	<p>Cerebral Palsy</p>	<p>X</p>				<p>Construct validity was determined where a correlation was found between feeding performance of drooling children as compared those who did not drool ($p < 0.05$)</p>

MCH-FS (Ramsay et al., 2011; Sanchez et al., 2015)	Screening tool	6 months- 6 years	General Paediatric population				X	Convergent validity: specificity = 0.82 and sensitivity= 0.87
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NFAS, Neonatal Feeding Assessment Tool; PEDI-EAT, Pediatric Eating Assessment tool; CEBQ, Child Eating Behavior Caregiver Questionnaire; FSQ, Feeding and Swallowing Questionnaire; STEP-CHILD, Screening tool of Feeding Problems applied to children; MBQ, Mealtime Behavior Questionnaire; DDS, Dysphagia Disorders Survey; BASOFF, Behavioural Assessment Scale of Oral Functions in Feeding, SOMA, Schedule for Oral Motor Assessment; ABFS-C, Ability for basic feeding and swallowing scale for children; FFAM, Functional feeding assessment modified; MCH-FS, Montreal children's hospital feeding scale

The following tools were not reviewed as they did not assess the target population, they did not assess feeding and swallowing function or the primary focus was gastrointestinal conditions such as eosinophilic esophagitis: Dysphagia Symptom Questionnaire, Pediatric Quality of Life Inventory Gastrointestinal Symptoms Module, Symptom Questionnaire for Eosinophilic esophagitis, Child Feeding Questionnaire, Checklist of items for dysphagia screening, Drooling rate scale and the Gisel Video.

The tools that were reviewed have limitations which affect their usability for the study population. The limitations that were found were the following; the age ranges did not include children in the zero to two years age range; a limited variety of food consistencies are assessed; a focus on specific medical conditions such as neurological conditions; focus mainly on the feeding aspect and not the swallowing process; and, most importantly, the validity of some tools was not established.

The PEDI-EAT tool, for example, can only be used in children who have started solid foods, meaning that it cannot be used in children between zero and six months, who are exclusively breast or bottle fed (Thoyre et al., 2014). The FFAM and the SOMA were designed specifically for children with cerebral palsy while the DDS, BASOFF and ABFS-C were designed for children with development and intellectual disabilities, therefore making this tool inappropriate for use in other medical conditions (Benfer et al., 2012; Heckathorn, Speyer, Taylor & Cordier, 2016; Kamide, Hashimoto, Miyamura & Honda, 2015). The NFAS, a South African based tool, could also not be used in this study because it was designed specifically for neonates. As previously stated, the validity of some of the tools has not been determined (Viviers, Kritzinger & Vinck, 2016). Some of the tools without established validity include; the CEBQ, 3-ounce water test, STEP-CHILD and the BASOFF (Heckathorn et al., 2016; Seiverling, Hendy & Williams, 2011).

There are tools available for the general paediatric population, such as the CEBQ, PEDI-EAT, MBQ and the MCH-FS, however these tools only assess behavioural aspects of feeding such as food refusal or food selectivity and they were developed for children who are two years and older (Ramsay et al., 2011; Sanchez, Spittle, Allison & Morgan, 2015; Thoyre et al, 2014; Webber, Cooke, Hill & Wardle., 2010). Moreover, most of the tools listed in Table 1-1 were developed for well-resourced countries; and are only available in English.

Therefore, they may not be applicable to lower income countries such as South Africa, owing to differences in populations, environments, culture, socio-economic status and health systems (Mamdani, 2011). The Feeding and Swallowing Questionnaire (*FSQ*) on the other hand was developed for the South African context and has been validated in the context of HIV in the country.

1.7 Summary

The currently available assessment and screening tools cannot be utilized to identify infants and children at risk of all-cause feeding and swallowing disorders, using a range of food textures, in the general hospitalized paediatric South African population aged zero to two years. This is due to a number of reasons namely: context, age range, food consistency restrictions, target population and domains assessed i.e. phases of the swallow. Therefore, for the purposes of this study the *Feeding and Swallowing Questionnaire (FSQ)* is the most appropriate tool that meets the criteria. This will be discussed further in the next section.

1.8 Importance of validating a screening tool

A valid, reliable paediatric feeding and swallowing screening tool would provide early, reliable and efficient ways of identifying this condition in the paediatric population (Cade, Thompson, Burley & Warm, 2002). The availability of a feeding and swallowing screening tool may relieve the demand on staff and resources (Freyenhagen, Baron, Gockel & Thomas, 2006). This is essential in South Africa where we have a limited number of SLTs, particularly within the public health sector (Khoza-Shangase & Mophosho, 2018).

The validation of a screening tool is imperative in order to ensure the usefulness and accuracy of results obtained in the population being screened (Cade et al., 2002). Validated screening tools enable at-risk infants and children to be appropriately identified using a few key symptoms and signs in a short space of time (Freyenhagen et al., 2006). Additionally, a validated screening tool also enables one to make accurate predictions of outcomes (Tropha, Gramatica & Gombar, 2003). Therefore, unlike comprehensive assessments, screening tools are short and easy to administer (Freyenhagen et al., 2006).

For a screening tool to be considered valid it should possess the following qualities; it should be reliable; it should ideally have a high sensitivity and specificity; be quick to administer; the terminology used should be easy to understand; it should be context specific and should aid in conserving resources (Lalkhen & McCluskey, 2008; Ostrofsky & Seedat, 2016). Some of these qualities were identified in the *FSQ*. The reliability and validity of the *FSQ* in a paediatric population with HIV/AIDS was established in a study conducted by Vermeulen (2015).

The *FSQ* was developed by Nel, Ellis and Norman in 2012 to be used in their study to identify FSD in the paediatric population with HIV/AIDS. The questionnaire was also translated into isiXhosa and Afrikaans. The validity and reliability of the *FSQ* as a screening tool in the paediatric population with HIV/AIDS was determined by Vermeulen (2015).

With regards to validity, the study on the paediatric population with HIV/AIDS found that the questionnaire demonstrated face and content validity. This was established by an expert panel who reviewed the *FSQ*. Vermeulen (2015) determined the criterion validity by calculating the sensitivity and specificity of the *FSQ*. The test sensitivity was found to be 92% while the test specificity was 59%. The gold standard that was used to compare to the *FSQ* was the Clinical Feeding and Swallowing Assessment Tool (CFSAT) (see Appendix B) which was developed by two SLTs experienced in paediatric dysphagia through in-depth literature review (Table 2-1). The predictive values were also calculated, and it was found that the positive predictive value was 58% while the negative predictive value was 92%.

The inter-rater reliability was established as a kappa statistic of one, which indicated a 100% agreement between two raters (Vermeulen,2015). A Cronbach's alpha of 0.78 was obtained, this was an acceptable level of inter-item consistency (Vermeulen,2015). Based on the study by Vermeulen (2015), the revised questionnaire demonstrated linguistic appropriateness for English (second language), Afrikaans and isiXhosa speaking individuals. The revised questionnaire, English version, will be used for this study as well as the Afrikaans version.

1.9 Summary of literature review

The majority of feeding and swallowing screening tools described have been validated on children older than two years, despite the greatest prevalence being in the under-two-year age group (Kakodkar & Schroeder, 2013). Moreover, they do not focus on all aspects of feeding and swallowing; and they focus on population groups with specific pathologies (Kakodkar & Schroeder, 2013). There is therefore a clear need to validate a screening tool that assesses all aspects of feeding and swallowing; can be utilized in the general paediatric population; and is reliable in children two years of age and younger.

Accurately identifying FSD in this population would allow for early intervention, which could reduce the risk of potentially serious negative sequelae, and associated financial and other costs, of untreated FSD. Furthermore, a reliable screening tool would be able to be applied by professionals other than SLTs, thereby ensuring that referrals to SLTs for assessment and management are only made for those children at high risk of feeding and swallowing disorders, thereby optimizing use of the limited SLT resources in South Africa.

Although the *FSQ* has been validated in the ambulant, HIV-infected paediatric population, it cannot be assumed that this screening tool will be valid for use in the general population of hospitalized children and infants.

1.10 Aim of the study

The aim of this study was to validate the revised version of the *Feeding and Swallowing Questionnaire* for identifying children with feeding and swallowing difficulties in the general hospitalized paediatric population, aged 0 – 2 years, admitted to general medical wards. The secondary aim of this study was to describe the FSD presenting in the paediatric population aged 0 - 2 years who are hospitalized in general medical wards.

2. Methodology

2.1 Aims and Objectives

2.1.1 Primary aim

The primary aim of this study was to determine the validity and reliability of the *Feeding and Swallowing Questionnaire (FSQ)* as a screening tool in identifying feeding and swallowing difficulties (FSD) in the paediatric population aged 0 – 2 years admitted to general medical wards.

Objectives:

The following objectives were identified to achieve the primary aim:

1. To determine the criterion validity of the *FSQ*.
 - To determine the **sensitivity** of the *FSQ*, compared to the Clinical Feeding and Swallowing Assessment Tool (CFSAT) in correctly identifying FSD.
 - To determine the **specificity** of the *FSQ* as compared to the CFSAT, in correctly identifying participants without FSD.
2. To determine the **construct validity** of the *FSQ*.
 - To determine the **predictive values** (negative and positive) of the *FSQ* as compared to the CFSAT.
3. To determine the **intra-rater and inter-rater reliability** of the *FSQ*
4. To determine the **internal consistency** of the *FSQ*.

2.1.2 Secondary Aim

The secondary aim of this study was to describe the FSD presenting in the paediatric population aged 0 - 2 years who are hospitalized in general medical wards.

Objectives:

The following objectives were identified to achieve the secondary aim:

- 1 To describe the prevalence and nature of FSD in the study population.
- 2 To describe the underlying medical conditions associated with FSD.
- 3 To determine the relationship, if any, between underlying medical conditions and the a) prevalence and b) nature of FSD.

2.2 Research Design

A descriptive, prospective clinimetric research design was used in this study. A clinimetric research design focuses on the quality of a measurement (de Vet, Terwee & Bouter, 2003). Essentially, this research design aims to assess the properties of a measurement instrument and to improve the quality of measurements (Cappelleri, Zou, Bushmakina, Alemayehu & Symonds, 2014). The clinimetric research design was chosen to determine the sensitivity, specificity, predictive values and the construct validity of the *FSQ*.

A descriptive research design aims to describe a phenomenon and variables or conditions in a situation (Terre Blanche, Durrheim & Painter, 2006). The descriptive research design was used to describe the prevalence and nature of FSD amongst research participants as well as the associated underlying medical conditions. A limitation of using a descriptive research design is that one cannot determine cause and effect relationships (Terre Blanche et al., 2006).

A prospective research design facilitates the collection of new data in real time. This design was chosen in order to conduct interviews with parents or legal guardians of participants during the hospitalization period. This was also done so as to conduct comprehensive feeding and swallowing assessments on the infant or child participants in real time. Prospective research designs offer the advantage that information is collected in a uniform manner, thereby improving accuracy and minimizing missing data (Portney & Watkins, 2009). Furthermore, prospective research designs have fewer sources of bias (particularly recall, information and selection bias) than retrospective studies (Portney & Watkins, 2009). Prospective research is often time consuming and may be expensive. However, this limitation was addressed by using a convenience sampling method which is cost effective and time efficient.

2.3 Study Location

The research site was Steve Biko Academic Hospital (SBAH) a tertiary, academic hospital located in Pretoria. Steve Biko Academic Hospital is a referral hospital which meant that it provided the researcher with a population that had a variety of patients within the zero to two age group. Infants and children between the ages of zero and two years were selected for this study as FSD are commonly reported in this population (Kakodkar & Schroeder, 2013).

2.4 Selection criteria

Inclusion and exclusion criteria:

2.4.1 Primary Aim

To determine the validity and reliability of the Feeding and Swallowing Questionnaire as a screening tool in identifying feeding and swallowing difficulties in the paediatric population aged 0 – 2 years admitted to general medical wards

2.4.1.1 Inclusion criteria

All infants and children aged 0-2 years, admitted to the general medical wards of SBAH and without a known diagnosis of FSD were eligible for inclusion in this study. Infants and children who were fed via a nasogastric tube (NGT) were eligible for inclusion, as this feeding method does not necessarily signify a feeding or swallowing difficulty; NGTs are usually placed for short term feeding purposes.

2.4.1.2 Exclusion criteria

Infants and children who had previously been diagnosed with FSD were excluded from participating in the primary study, owing to a number of concerns:

- These infants and children may have already received speech therapy intervention and may no longer present with the initial signs and symptoms of FSD.
- Including infants and children with a known FSD diagnosis may increase the potential for bias when evaluating a diagnostic screening tool.
- Reassessing infants with known FSD may cause harm, with the potential for complications such as aspiration.

Infants and children feeding via a percutaneous endoscopic gastrostomy (PEG) were excluded from the study, as these children would already have an established feeding and/ or swallowing difficulty.

Infants and children who were medically unstable were excluded as they were too sick to participate in the study.

2.4.2 Secondary Aim:

To describe the feeding and swallowing difficulties presenting in the paediatric population aged 0 - 2 years who are hospitalized in the general medical wards.

2.4.2.1 Inclusion criteria

- Participants who were diagnosed with FSD during the primary phase of the study.
- Children aged 0-2 years, admitted to a general medical ward, with a known diagnosis of FSD (only included in calculating the prevalence of FSD and description of medical conditions).

2.4.2.2 Exclusion criteria

There were no exclusion criteria.

2.5 Recruitment Strategy

An information session (both verbal and via email) was conducted with the heads of the Paediatric, Dietetics and Speech Therapy departments, the nursing sisters in charge of the two wards and the ward consultants. The participants were recruited from the two general paediatric wards in the hospital. A list of all the new admissions in the wards were sent to the student researcher by the resident dietitians in these wards. Additionally, the student researcher would also check each ward cubicle to identify any potential participants that may not have been included on the list. Participants who met the inclusion criteria were identified and recruited by the student researcher. The student researcher also recruited participants in the evenings so as to cater for parents or legal guardians who were only available after normal work hours. Recruitment occurred on an ongoing basis throughout the data collection period.

Parents were then given a study information sheet which also included the informed consent form (Appendix C); the student researcher verbally explained the study in detail to the parent or legal guardian; and any questions were answered. Once the parent agreed for their infant or child to participate in the study, they were asked to sign an informed consent form. The consent forms and information sheet were also available in Afrikaans and Setswana (see Appendix D and E). The student researcher spoke in a language that the parent or legal guardian preferred.

2.6 Sampling

A convenience, consecutive sampling method was used. Convenience sampling enabled the student researcher to use participants who were readily available, in this instance infants and children who were admitted to the general medical wards (Gravetter & Forzano, 2012). Moreover, convenience sampling enabled the researcher to have access to infants and children presenting with a range of medical conditions in a single setting. Parents and legal guardians of young children usually stay at the hospital when their children are admitted, hence the student researcher had access to infants, children and their parents or legal guardians.

Lastly, convenience sampling was used because it is inexpensive and time efficient (Gravetter & Forzano, 2012). Consecutive sampling enabled the student researcher to invite every infant and child (with the permission of the parent or legal guardian) who was admitted to the wards and met the inclusion criteria to participate in the study until the sample size was achieved (Hulley, Cummings, Brower, Grady & Newman, 2007).

2.7 Sample Size

The sample size was calculated using EpiInfo software, version 7.2 (2017; Centers for Disease Control and Prevention; Atlanta, United States of America). This software is used to create electronic surveys and for data entry and data analysis. The estimated population size was 660, with an expected 50% prevalence of feeding and swallowing difficulties. This percentage was based on the statistics provided by SBAH. The required sample size was calculated as 103, with a 90% confidence level and five percent margin of error.

2.8 Child and parent/ legal guardian participants

A total of 103 paediatric participants were included in this study (n= 65 (61.3%) male; n= 38 (37%) female). A detailed description of the participants will be provided in the results section. The parent and legal guardians provided information about their children in the FSQ and the CFSAT. Four participants (n=4) were included in the calculation of the prevalence. These participants had a pre-existing diagnosis feeding and swallowing difficulties, therefore in accordance with the exclusion criteria they were excluded from the primary aim.

2.9 Research Personnel

2.9.1 Student Researcher

The student researcher is a qualified Speech-Language Therapist (SLT) who is registered with the Health Professions Council of South Africa (HPCSA). The student researcher was responsible for meeting with the Head of Paediatrics, Dietetics, Head of Speech Therapy, nurses in charge of the medical wards, as well as other health professionals who work in these wards such as dietitians and SLTs. The student researcher previously worked in SBAH as a SLT, she was the main SLT in the general medical wards. Therefore, she was familiar with the wards as well as the hospital in general. As part of the research, the student researcher was responsible for recruiting new participants and obtaining consent. Furthermore, the student researcher conducted the clinical feeding and swallowing assessments using the CFSAT and referred participants found to have FSD, to the resident SLTs.

2.9.2 Research Assistant 1

The first research assistant was a qualified SLT, registered with the HPCSA, who has experience in working with the paediatric population. The assistant has master's degree in Speech-Language Therapy. The assistant was also familiar with SBAH as she previously completed her undergraduate clinical practical's at the hospital. The assistant conducted screenings using the *FSQ* before the student researcher conducted the clinical assessment using the CFSAT, ensuring that the student researcher was blinded to the screening results. The assistant audio recorded the screenings, for the purpose of evaluating intra-rater reliability on the *FSQ*.

2.9.3 Research Assistant 2

The second research assistant was also a qualified SLT, registered with the HPCSA, and has experience in working with the paediatric population. The assistant also has a master's degree in Speech-Language Therapy. The assistant conducted reliability checks (inter-rater reliability) for the *FSQ* as well as the CFSAT.

2.10 Materials and Instrumentations

2.10.1 The Feeding and Swallowing Questionnaire (FSQ)

The *FSQ* was developed by Nel, Ellis and Norman in 2012 as a screening tool to identify children at risk of having FSD in the paediatric population with HIV/AIDS. The questionnaire was also translated into IsiXhosa and Afrikaans. The questionnaire was validated by Vermeulen (2015) in the paediatric population with HIV/AIDS, however, the validity of the screening tool in the general paediatric medical context has not been established.

Data collection was conducted in Tshwane (Pretoria) hence the *FSQ* was translated into Setswana (Appendix F), one of the main languages spoken in and around the city. This was done by two first language speakers of Setswana; one speaker translated the tool from English to Setswana, while the second speaker translated it from Setswana back to English. This process of back translation was followed to ensure that the translated tool targets concepts included in the original tool. This also ensured that the information that was gathered was reliable and accurate. As previously mentioned, the *FSQ* was also translated into Afrikaans (Appendix G).

The *FSQ* took between 10 - 15 minutes to complete. The questionnaire includes the following areas: types of feeds the child is currently receiving; characteristics of the feeding session (e.g. length and difficulty); distress signals exhibited by the infant and child during feeds (e.g. difficulty breathing, vomiting); difficulty eating different consistencies of food; weight of the child (e.g. weight gain/ weight loss); and the presence of gagging, refusal of food, coughing or choking.

The items in the *FSQ* were colour coded, blue or red, according to the severity of the sign or symptom the item assesses. Blue items indicated less severe signs or symptoms such as fatigue during feeding, difficulty completing feeds or fussiness during feeding. Red items indicated more severe signs or symptoms, such as difficulty breathing while feeding, a “gurgly” voice after feeding, nasal regurgitation, coughing or choking while feeding.

Additionally, items were rated as blue or red depending on the potential negative health consequences related to the difficulty in feeding or swallowing. The *FSQ* has a pass/ fail criterion. Blue items were scored as 0.5 and red items as 1, if the total score was 1, the

participant would be referred to the resident SLT for further assessment and management of feeding and swallowing.

2.10.2 Clinical Feeding and Swallowing Assessment Tool (CFSAT)

As indicated in chapter one, there are no published and validated tools in the South African context for the assessment of feeding and swallowing in children from birth to two years of age, who are not only hospitalized in general medical wards but who also present with a range of medical conditions.

In standard clinical practice, FSD is diagnosed by the SLT based on a comprehensive clinical assessment. A clinical feeding and swallowing assessment begins with a detailed case history which includes birth and medical/surgical history, developmental and feeding milestones, feeding and swallowing history and current feeding abilities. After this a pre-feeding examination is conducted. A pre-feeding examination includes observation of factors that may influence feeding such as posture, level of arousal and alertness, drooling and secretions in the mouth. Additionally, a pre-feeding examination also includes an oral motor and oral sensory examination. The feeding and swallowing assessment assesses the oral preparatory, oral and pharyngeal phases of swallowing, although the SLT can only make clinical inferences about the pharyngeal phase as it cannot be accurately assessed clinically (Arvedson,2008).

Some patients who demonstrate signs of pharyngeal phase difficulties during the clinical assessment would be referred for instrumental assessment, such as a video fluoroscopic swallow study (VFSS). A VFSS is only conducted when substantial evidence from the clinical assessment is thought to justify the associated risk of radiation exposure.

Therefore, while the VFSS is considered the gold standard to assess the pharyngeal phase of the swallow, it is not necessarily always justified or indicated in standard clinical practice for the assessment of FSD and can therefore not be used as a comparator to determine the sensitivity and specificity of the *FSQ*.

A standard protocol, the CFSAT was used as a proxy "gold standard" against which the *FSQ* was compared in order to determine the validity of the questionnaire as a screening tool. Two

SLTs experienced in paediatric dysphagia developed the CFSAT based on paediatric dysphagia literature. The CFSAT represents a typical comprehensive clinical feeding and swallowing assessment and the items included have been justified with rationales and reference to paediatric dysphagia literature (*Table 2-1*).

Table 2-1: Literature on clinical feeding and swallowing assessment

ASSESSMENT AREAS	FACTORS TO CONSIDER	RATIONALE
Case History		
Prenatal and Birth History	Type of birth Birth weight Gestational Age Apgar scores Trauma during delivery	Factors that occur during the prenatal and birth period may contribute to feeding and swallowing difficulties (Arvedson & Brodsky, 2002). For instance, preterm infants have difficulty coordinating the different skills that are required during oral feeding (Prasse & Kikano, 2009). This is due to under-developed oral motor and respiratory systems and structures (Prasse & Kikano, 2009).
Medical and surgical history	Medical diagnoses Previous hospitalizations Significant medical history Medication	Previous illnesses and hospital admissions may be linked to existing feeding and swallowing difficulties. Surgical interventions such as open-heart surgery are associated with the development of feeding and swallowing difficulties (Kohr et al., 2003). Certain conditions such as cleft lip and palate, anoxic brain injury and laryngomalacia, have been

	<p>Feeding related illnesses</p> <p>Surgical interventions</p>	<p>linked to feeding and swallowing difficulties in the paediatric population (Newman, Keckley, Petersen & Hamner, 2001). These medical conditions may result in oral, pharyngeal or oesophageal phase difficulties (Newman et al., 2001).</p>
<p>Developmental milestones</p>	<p>Smiled</p> <p>Sit</p> <p>Crawl</p> <p>Stand</p> <p>Walk</p>	<p>Development milestones, both fine and gross motor movements, are a pre-requisite for the development of feeding skills (Delaney & Arvedson, 2008; Martorell et al., 2006). For example, sitting independently, which requires good head and neck control and good trunk stability, enables the child to not only reach for a spoon but also</p>

	Communication development	finger feed (Delaney & Arvedson, 2008). Additionally, it is important to obtain information about a child's general development, because a child might not have an isolated feeding developmental delay but also a global developmental delay.
Feeding Milestones	<p>0-6 months- nutritive suck</p> <p>Breast/bottle feeding</p> <p>6+ months- Semi-solids</p> <p>8+ months- Cup drinking</p> <p>9+ months- Solid</p>	There are critical periods in which different consistencies and utensils are used during the child's feeding development (Carruth, Zeigler, Gordon & Hendricks, 2004; Delaney & Arvedson, 2008). Participants' feeding development will be compared to expected norms (<i>listed in the CFSAT</i>) to determine feeding delays or disorders.
Feeding Swallowing History and current feeding abilities	<p>Primary feeder</p> <p>History of tube feeding</p> <p>History of previous feeding difficulties and interventions</p> <p>Weight gain/ loss</p>	Feeding history is important because it contributes to the process of determining treatment plans and it also provides information about the caregivers' knowledge about the child's feeding difficulties (Arvedson & Brodsky, 2002). Perceptions of children's feeding ability and skills may differ from one feeder to another as children demonstrate

	<p>24hr diet recall</p> <p>Hunger and satiety indication</p> <p>Duration of feeding</p> <p>Respiratory status during feeding</p> <p>Food that the child likes and dislikes</p> <p>Food that the child has difficulty eating and drinking</p> <p>Overt behaviors observed during feeding e.g. Gagging, coughing, fatigue, irritability</p>	<p>different behaviours with each feeder (Arvedson & Brodsky, 2002). According to Arvedson (2008), if the duration of feeding is longer than 30 minutes it is usually an indication that a feeding difficulty may be present.</p> <p>Food refusal has been found to result in children not eating enough food to either meet their caloric or nutritional needs (Field et al., 2003). There are a variety of reasons as to why food refusal occurs, it may be due to respiratory difficulties, gastrointestinal problems or behavioural feeding difficulties (Arvedson, 2008).</p> <p>According to Prasse & Kikano (2009), steady weight gain is important during the first 2 years of life as it is essential for brain development and general growth. Thus, it is important to find out whether the child has gained or lost weight, the Road to Health Booklet would assist to give a clear indication of this.</p> <p>Gagging, vomiting and coughing are some of the signs that may occur during feeding that are indicative of a feeding or</p>
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		swallowing difficulty (Arvedson, 2008). Irritability during feeding may indicate GI discomfort, airway problems or behavioural issues (Arvedson, 2008).
Physical examination		
Pre-feeding Observation	Postural control and muscle tone Level of arousal and alertness Drooling Voice quality Secretions in the mouth Muscle tone	Observing pre-feeding factors enables the assessor to obtain much needed information that directly influences the infant's feeding ability (Rogers & Arvedson, 2005). For instance, an open mouth posture can be an indication of hypotonia or upper airway obstruction, as infants use nasal breathing (Rogers & Arvedson, 2005). The examination of postural control and muscle tone is important as it has an influence on the safety and efficacy of the swallow (Arvedson & Brodsky, 2002; Hall, 2001).

<p>Oral sensory motor examination and oral reflexes</p>	<p>Dentition</p> <p>Lips</p> <p>Tongue</p> <p>Gums</p> <p>Uvula</p> <p>Cheeks</p> <p>Jaw</p> <p>Gag</p> <p>Phasic bite</p> <p>Tongue protrusion, retraction and transverse tongue movement</p> <p>Rooting</p> <p>Tonic Bite</p> <p>Hyper/ Hyposensitivity</p>	<p>The examination is conducted to assess the structure, functioning and strength of the oral musculature and facial symmetry (Dikeman & Kazandjian, 2003; Field et al., 2003).</p> <p>The information gathered during this examination directly impacts the oral preparatory and oral phases of swallowing (Dikeman & Kazandjian, 2003).</p>
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Feeding and swallowing assessment

Ages, consistencies and utensils	Phases of swallowing	Rationale
<p>O-6 months- nutritive suck Breast/bottle feeding</p> <p>6+ months- Semi-solids (Spoon feeding)</p> <p>8+ months- Cup drinking</p> <p>9+ months- Solids</p>	<p>Oral preparatory and oral phase</p>	<p>Examining nutritive sucking is important as it enables one to observe the infants suck-swallow-breathe pattern which is important during oral feeding. Thus, one will be able to observe the organization and coordination of this pattern (Arvedson& Brodsky, 2002). As any disturbance to this pattern may result in for instance, aspiration, anterior loss of a bolus, coughing and choking (Arvedson& Brodsky, 2002).</p> <p>Poor lip closure or latching during feeding results in anterior loss of the bolus (Arvedson, 2008). The anterior loss of the bolus may also be due to tongue thrusting, reduced tongue control and poor bolus formation (Arvedson, 2008).</p> <p>Bolus formation and manipulation is largely dependent on tongue movements; thus it is important to assess tongue movements during the oral motor examination (Arvedson, 2008; Borowitz & Borowitz 2018, Bruns & Thompson, 2010). Moreover, without bolus control which is also dependent on tongue movement and strength, the bolus could either be lost anteriorly or it could be</p>

		<p>lost posteriorly through premature spillage which may result in aspiration (Arvedson, 2008; Borowitz & Borowitz 2018; Bruns & Thompson, 2010).</p> <p>Chewing is important as it transforms the bolus into a consistency that is suitable for passage into the pharynx and esophagus (Borowitz & Borowitz, 2018; Bruns & Thompson, 2010). It is important to assess the different consistencies and utensils used during feeding as these are indicative of feeding milestones (Bruns & Thompson, 2010). For instance, children with cerebral palsy often have delayed feeding milestones, they may only be able to eat soft food consistencies and not progress to solids due to difficulty chewing (Otapowics et al., 2010).</p>
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	Pharyngeal phase	<p>Nasal regurgitation occurs when there is incoordination of the pharyngeal contractions or when there is an insufficient nasopharyngeal seal (van den Engel-Hoek et al. 2015). This results in nasopharyngeal reflux of liquids or food (van den Engel-Hoek et al. 2015). A delay in the triggering of the swallow is an indication of pharyngeal phase dysphagia (Arvedson & Brodsky, 2002). A delay in the triggering of the swallow may result in the spillage of the bolus into the pharyngeal recesses which potentially increases the risk of aspiration due to the open airway (van de Engel-Hoek et al. 2015; Jackson et al, 2016). Coughing, choking and/ or respiratory distress during and after feeding is an indication that the child may be aspirating i.e. the entry of food into the away during swallowing (Chau et al., 2005). It should be noted though that aspiration can also be silent, with no overt signs (Chau et al., 2005). A wet or gurgly voice quality after swallowing is indicative of hypopharyngeal or laryngeal pooling of secretions or pharyngeal residue of food materials (Wier et al., 2009).</p>
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2.11 Data Collection

Figure 2-1 depicts the procedures followed in the study. Once consent was obtained, the first research assistant conducted screening of participants using the *FSQ* in the participant's language of preference (English, Afrikaans or Setswana). The screening took approximately 10- 15 minutes to complete for each participant. Parents' or legal guardians' responses were audio recorded (with consent) in order to establish intra-rater reliability.

A comprehensive feeding and swallowing clinical assessment, using the *CFSAT*, was conducted within 24 hours after the screening, by the student researcher, who was blinded to the screening findings. The assessment began with obtaining case history information, followed by a pre-feeding examination, then a feeding and swallowing assessment of the three phases of swallowing (oral preparatory, oral and pharyngeal phases). The student researcher assessed the participants' feeding and swallowing using small amounts of three consistencies: liquids, semi-solids, and solids. The consistencies used for each participant were dependent on the child's age, for example all children below the age of 6 months were given liquids - either breastmilk or formula depending on what the child was being fed.

The student researcher observed for oral phase difficulties such as poor lip closure, poor bolus formation, poor bolus control, poor bolus manipulation, increased oral phase time as well oral residue. The student researcher also observed for clinical signs of aspiration including coughing, choking and increased respiratory rate. Participants were also observed for other pharyngeal phase difficulties such as a delay in the triggering of the swallow and pharyngeal residue. If an infant or child was found to have *FSD* they were referred to the resident *SLTs* in the hospital for further assessment, i.e. instrumental studies such as *VFSS*, and/ or management. The student researcher always communicated these referrals telephonically or in person, to the *SLTs* who worked in the two wards.

The first research assistant, who conducted the screenings, reviewed 15% of the audio-recorded screening questionnaires two weeks after the screening, while blinded to the initial results. The research assistant then completed a new questionnaire while listening to the recordings and then compared these new results with the original results that were obtained to check whether the intra-reliability was achieved.

Inter-rater reliability for the *FSQ* was assessed by having the second research assistant present for 15% of the screenings. Both research assistants completed the questionnaire while blinded to each other's results. The results of the completed questionnaires were compared to determine the inter-rater reliability of the questionnaire. Where there were disagreements, the research assistants discussed the disagreements and where necessary also listened to the recordings again so as to reach a consensus.

Inter-rater reliability for the *CFSAT* was assessed by having the second research assistant present for 15% of the clinical assessments. The student researcher and the research assistant were blinded to each other's results during this process. Once the assessments were completed, the results were compared to determine the inter-rater reliability. Where there were disagreements, the student researcher and the research assistant discussed the disagreements so as to reach a consensus.

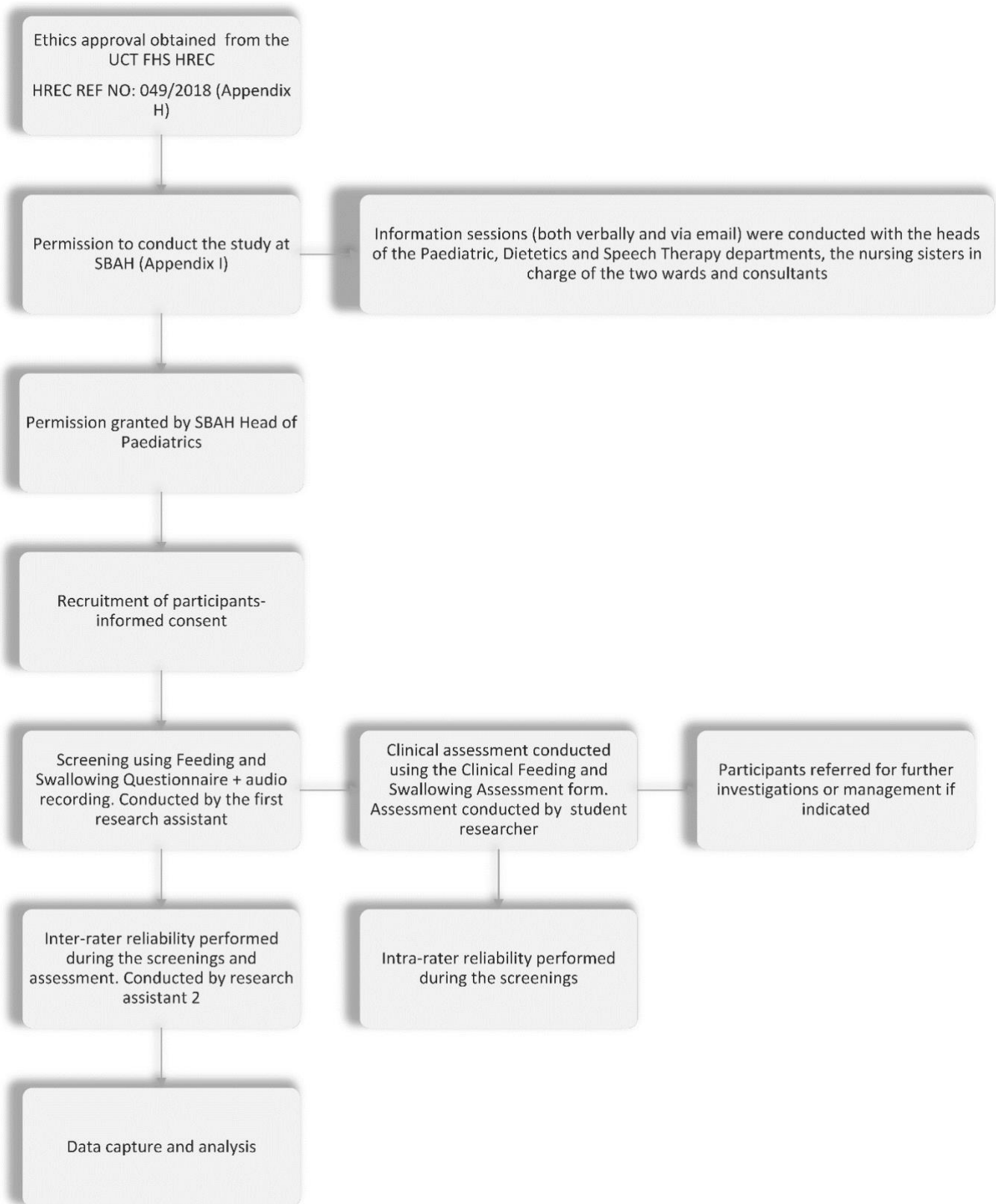


Figure 2-1: Procedure Algorithm

2.12 Data Analysis

Continuous variables were tested for normality and presented as mean (SD) or median (IQR), according to distribution. Descriptive statistics were used to describe the nature of FSD as well as the prevalence of FSD. The nature of FSD was described in terms of the oral phase, pharyngeal phase, oral and pharyngeal phase, behavioural feeding and swallowing difficulties and delayed feeding milestones. Furthermore, associations between the nature of FSD and underlying medical conditions were described.

The prevalence of FSD was determined by dividing the total number of children identified with FSD with the total number of children assessed. The Chi-square test was used to determine if any relationship existed between primary medical diagnosis and FSD. The Chi-square test was also used to determine associations between underlying medical diagnosis and FSD. With regards to criterion validity of the *FSQ*, sensitivity was determined by calculating the probability of the questionnaire correctly identifying participants with FSD (Bowers, House, Owens & Bewick, 2014), using a 4-box calculation method depicted in *Table 2-2*.

Table 2-2 Calculation methods for sensitivity, specificity, positive predictive value and negative predictive value

	Disorder	No Disorder
Positive Test Result	True Positive (TP)	False Positive (FP)
Negative Test Result	False Negative (FN)	True Negative (TN)
$Sensitivity = TP / (TP + FN)$ $Specificity = TN / (TN + FP)$ $PPV = TP / (TP + FP)$ $NVP = TN / (FN + TN)$		

Receiver Operating Characteristic (ROC) graphs were plotted to present the test sensitivity against the test specificity, which helped to show a mismatch between the true positives and false positives. The ROC graph was also used to plot the sensitivity and specificity against the screening questionnaire (*FSQ*) actual score. The construct validity was measured using factor analysis (Bowers et al., 2014). The positive predictive value (PPV) was established by calculating the probability that a participant tested positive whereby they truly did have FSD (Bowers et al., 2014).

The PPV was calculated by dividing the true positives by the sum of the true positives and false positives. The negative predictive values (NPV) was calculated by dividing the true negatives by the sum of the true negatives and false negatives see Table 2-2

The inter-rater and intra-rater reliability of the *FSQ* were calculated using the Cohen’s kappa statistic. Cohen’s kappa statistic was also used to calculate the inter-rater reliability of the *CFSAT*. A Kappa statistic above 0.8 classifies almost perfect agreement between two raters (May, Chance-Larsen, Littlewood, Lomas & Saad, 2010). The classification of Cohen’s kappa is described in Table 2-3. The level of agreement was set at 0.8 for this study.

Table 2-3: Classification of Cohen's Kappa

0.00- 0.20	Slight agreement
0.21- 0.41	Fair agreement
0.41- 0.60	Moderate agreement
0.61- 0.80	Substantial agreement
0.81- 0.99	Almost perfect agreement
1.0	Perfect agreement

(May et al., 2010)

The internal consistency of each item in the *FSQ* was calculated using Cronbach’s alpha. Acceptable Cronbach’s alpha values range between 0.70 to 0.95, for the purpose of this study a Cronbach’s alpha of 0.70 was considered acceptable (Connelly, 2011; Tavakol & Dennick, 2011). The statistical programmes that were used to calculate the internal consistency were the statistical package for the social sciences (SPSS) version 25 (IBM Corporation, 2017) and XLSATA (a statistical software and data analysis add-on for Microsoft Excel). The internal consistency was measured to determine whether the questionnaire was measuring what it was actually supposed to measure, that being *FSD*.

2.13 Ethical Considerations

Ethics approval was obtained from the University of Cape Town Faculty of Health Sciences’ Human Research Ethics Committee (HREC REF: 049/2018) (Appendix H) Permission to conduct the study at SBAH was granted by the hospital’s CEO (Appendix I).

The Declaration of Helsinki (2013) that was developed by the World Medical Association (WMA) provides the ethical principles that were used during this research study because the study involved human subjects. The ethical principles that were considered during this study were: autonomy (respect for persons), justice, privacy, confidentiality, beneficence and non-maleficence.

Autonomy refers to the right of an individual to decide what activities they will or will not engage in (World Medical Association, 2013). For a parent or legal guardian and their infant or child to participate in the study, written informed consent was needed. The parent/ legal guardian signed consent to be interviewed (and audio recorded), as well as consent for their infant or child to be assessed (*see Appendix A, C & D*).

The parent or legal guardian was informed about the aims, method, institutional affiliations of the student researcher and the potential benefits and risks of taking part in the study (World Medical Association, 2013). Additionally, parents and legal guardians were informed about their right to refuse for their infant or child to participate in the study and that their refusal would not impact on the current treatment of their child. Furthermore, they could withdraw from the study at any point (World Medical Association, 2013).

Privacy and Confidentiality was upheld during the research, with medical information kept confidential (World Medical Association, 2013). The participants' anonymity was ensured by allocating a code to each participant e.g. 001. Any information obtained about the participants remained anonymous and was not in any way linked to the participants.

A master list containing the participants' names and codes was kept separate from the information obtained and was stored on an external hard drive which was password protected. Only the student researcher, research assistants and the supervisors had access to this information. The data obtained will only be destroyed once the study has been published. The interview audio recordings were allocated a code so as to maintain anonymity. The recordings were stored on a separate external hard drive which was password protected. Once the study has been published the recordings will be erased from the external hard drive and it will be reformatted.

Justice stipulates that each participant in a study must have equivalent and fair opportunities to be selected for the research. To uphold justice, this study made use of consecutive convenience sampling method (Terre Blanche et al., 2006), which gave equal opportunities for participants to be recruited for the research. With regards to **distributive justice**, the results obtained from the study will be made available to SBAH and the UCT Faculty of Health Sciences. The participants who took part in the study will have access to the results through the UCT Faculty of Health Sciences or SBAH.

Since this research involved human subjects, **beneficence and non-maleficence** require that the benefits of participating in the study be more than the risks and burdens that could affect the participants (World Medical Association, 2013). The potential risk posed by this study was that participants could aspirate during the feeding and swallowing assessment. However, this risk was minimal because only small amounts of the different consistencies of food were given. It is a standard clinical practice to give small amounts of developmentally appropriate consistencies during feeding and swallowing assessments, therefore no additional research-related risk was placed on the participant above that of standard clinical practice.

Children with a known FSD diagnosis were included for the documentation of the prevalence of FSD and the description of medical conditions but were excluded from the main study in order to reduce the risk of study bias. Additionally, they were excluded because of the increased potential risk of aspiration during the clinical assessment, supporting the ethical principal of non-maleficence. The potential direct benefit of participating in the study, for those who did not have a known FSD diagnosis, was early identification of FSD, and immediate referral for appropriate intervention. In addition, the study provided generalizable knowledge, which could potentially benefit future hospitalized children in similar contexts.

This study included young children and infants admitted to hospital, this is a highly vulnerable population group. It was considered necessary to study this vulnerable group as they are anatomically and pathologically different to adults, and it may therefore not be appropriate to extrapolate adult studies of dysphagia to paediatric practice. Furthermore, this study was judged as affording minimal incremental risk above that of standard clinical practice. It was necessary to validate a paediatric feeding and swallowing screening tool in the population of interest, in order for the study to be clinically relevant to this population.

Consideration for the protection of minor participants included the requirement for parental/legal guardian informed consent and the low risk nature of the study. This study was therefore, focused on improving the identification of FSD in a particularly at-risk group of infants and children who may benefit from the research findings, either directly through referral and targeted management or indirectly through knowledge generation, with future benefit to hospitalized infants and children between the ages of 0 and 2 years.

3. Results

The flow diagram provides an overview of the results for the reader, including the different n-values relevant to each section of results.

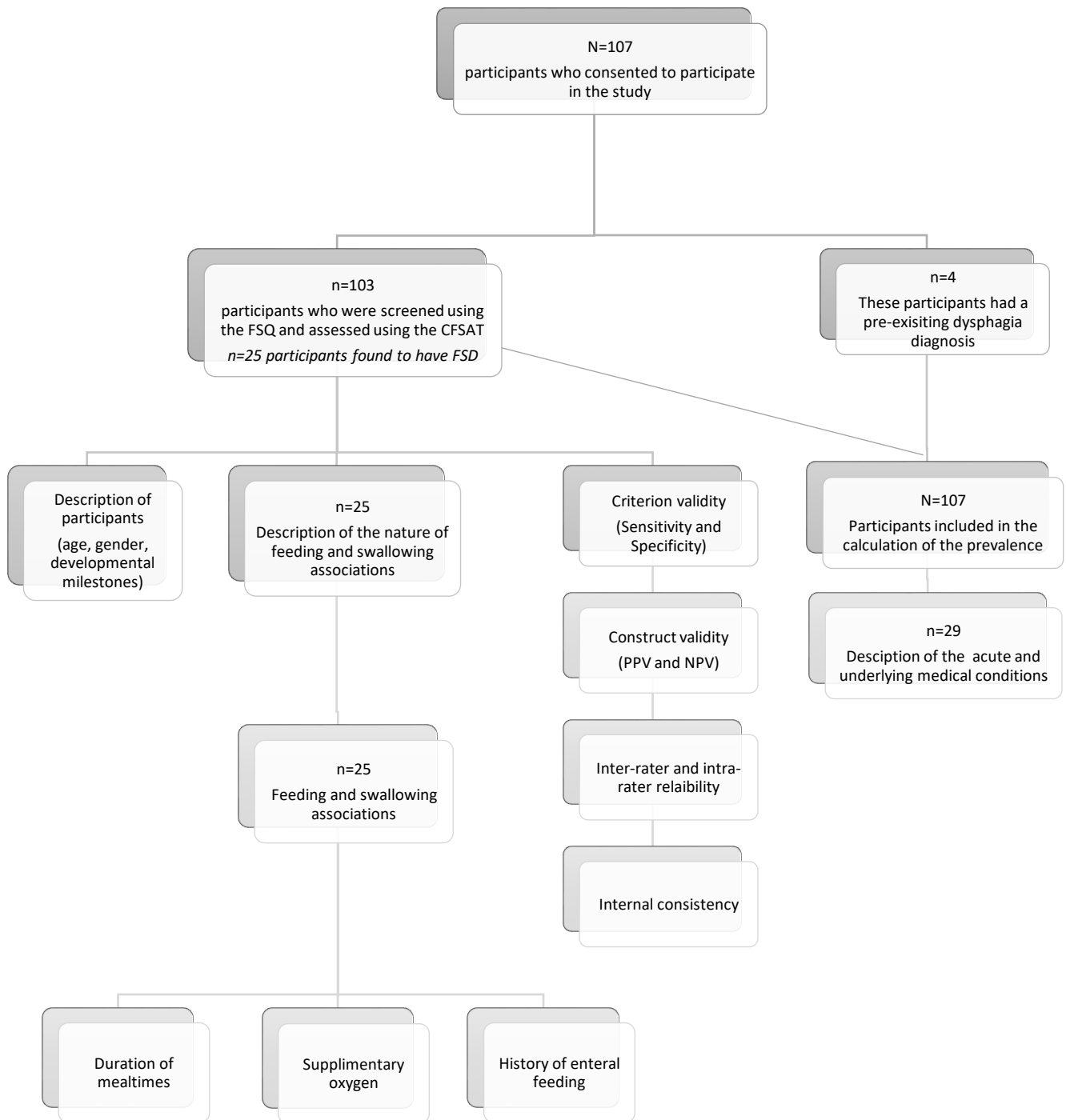


Figure 3-1: Results Flow Diagram

3.1 The criterion validity of the Feeding and Swallowing Questionnaire

3.1.1 Sensitivity and Specificity of the *Feeding and Swallowing Questionnaire*

The sensitivity of the *FSQ* was found to be 88%, and the specificity was 32%. The positive predictive value (PPV) was 29% and the negative predictive value (NPV) was 89% (Table 3-1). The test had a low percentage of false negatives, with only three participants (3%) incorrectly identified as not having FSD.

Table 3-1: Confusion matrix depicting the results of the *FSQ* as compared to the *CFSAT*

Feeding and Swallowing Questionnaire	Clinical Feeding and Swallowing Assessment		Total
	True Positive (+)	True Negative (-)	
Screening tool positive (+)	22	53	75
Screening tool negative (-)	3	25	28
Total	25	78	103

3.1.2 Relationships between the sensitivity and specificity, and the actual scores of the *Feeding and Swallowing Questionnaire*

The Receiver Operating Characteristic (ROC) curve graph in figure 3-2 presents the sensitivity, of the *FSQ*, plotted against the specificity. The sensitivity, the ability of the questionnaire to correctly identify those with FSD, being the true positive rate and the specificity is the ability of the questionnaire to correctly identify those without FSD, which is the true negative rate. The confidence level was set at 95% and the standard error was 0.075. The area under the curve (AUC) was calculated as 0.70 (95% CI 0.55 – 0.84). The high AUC of this study is indicative of the good test accuracy of the *FSQ*.

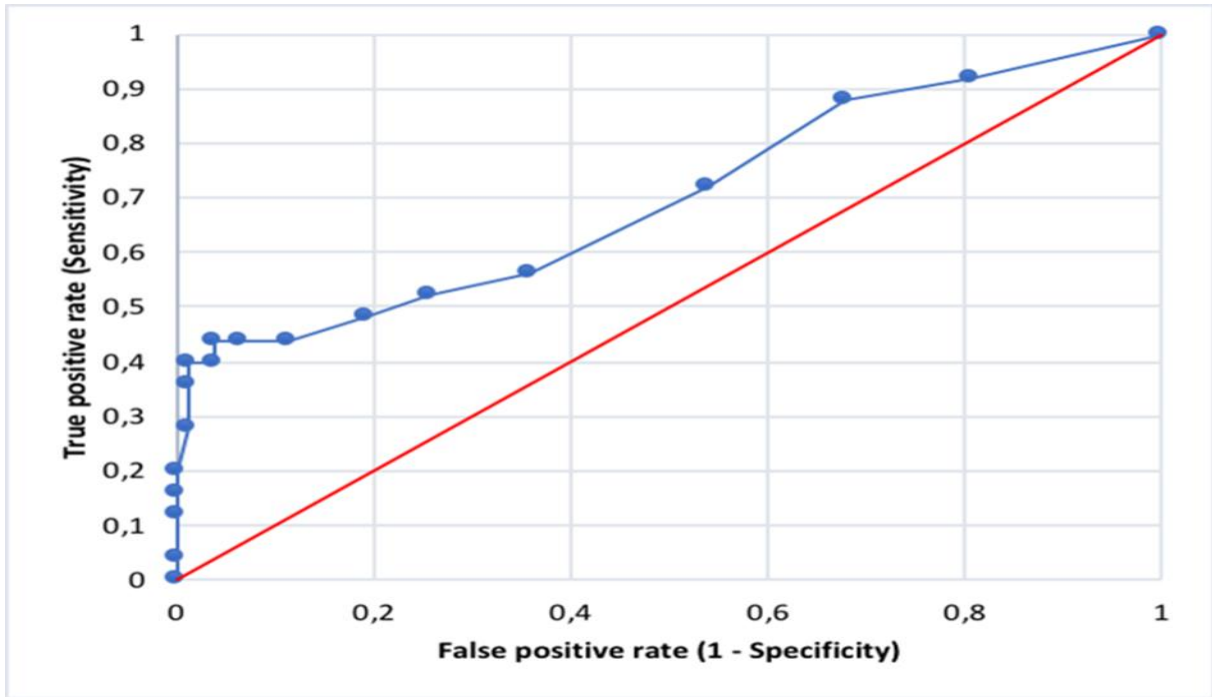


Figure 3-2: The relationship between sensitivity and specificity relative to the screening score

The sensitivity and specificity of the FSQ were best matched with a screening score of 2 (Figure 3-3). However, the ideal of a high sensitivity and a low specificity is achieved when the screening score is set at 1.5 (Table 3-2).

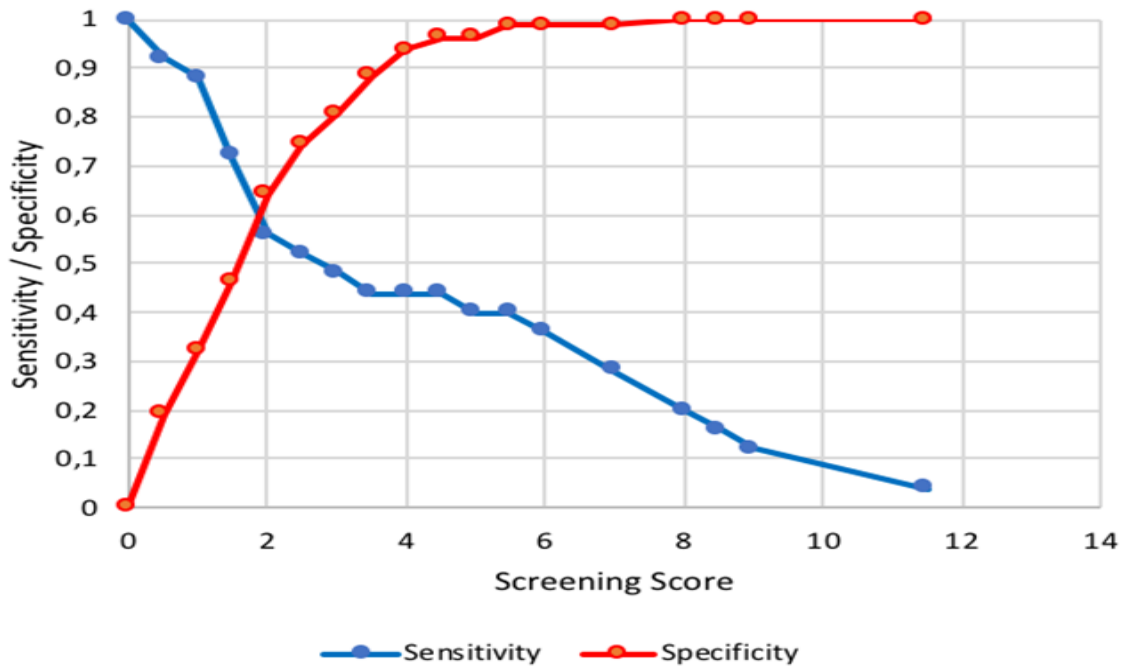


Figure 3-3: The relationship between sensitivity and specificity relative to the screening score

3.2 Construct validity of the Feeding and Swallowing Questionnaire

3.2.1 Predictive values (Negative and Positive Predictive Values)

The PPV of the *FSQ* was calculated as 29%, whereas the NPV was calculated as 89%. This means that when a participant tests positive during the screening, 29% of the time they truly have FSD. Whereas, when a participant tests negative during the screening, 89% of the time they truly do not have FSD.

Table 3-2: ROC analysis with actual screening scores

Screening Score	Sensitivity	Lower bound (95%)	Upper bound (95%)	Specificity	Lower bound (95%)	Upper bound (95%)	PPV	NPV	Sensitivity+ Specificity	Accuracy
0,000	1,000	0,839	1,000	0,000	0,000	0,058	0,243		1,000	0,243
0,500	0,920	0,737	0,988	0,192	0,120	0,295	0,267	0,882	1,112	0,369
1,000	0,880	0,690	0,965	0,321	0,228	0,431	0,293	0,893	1,201	0,456
1,500	0,720	0,521	0,858	0,462	0,355	0,571	0,300	0,837	1,182	0,524
2,000	0,560	0,371	0,733	0,641	0,530	0,738	0,333	0,820	1,201	0,621
2,500	0,520	0,335	0,699	0,744	0,636	0,828	0,394	0,829	1,264	0,689
3,000	0,480	0,301	0,665	0,808	0,705	0,880	0,444	0,829	1,288	0,728
3,500	0,440	0,267	0,629	0,885	0,792	0,940	0,550	0,831	1,325	0,777
4,000	0,440	0,267	0,629	0,936	0,854	0,975	0,688	0,839	1,376	0,816
4,500	0,440	0,267	0,629	0,962	0,887	0,991	0,786	0,843	1,402	0,835
5,000	0,400	0,235	0,593	0,962	0,887	0,991	0,769	0,833	1,362	0,825
5,500	0,400	0,235	0,593	0,987	0,923	1,000	0,909	0,837	1,387	0,845
6,000	0,360	0,203	0,556	0,987	0,923	1,000	0,900	0,828	1,347	0,835
7,000	0,280	0,142	0,479	0,987	0,923	1,000	0,875	0,811	1,267	0,816
8,000	0,200	0,086	0,397	1,000	0,942	1,000	1,000	0,796	1,200	0,806
8,500	0,160	0,059	0,354	1,000	0,942	1,000	1,000	0,788	1,160	0,796
9,000	0,120	0,035	0,310	1,000	0,942	1,000	1,000	0,780	1,120	0,786
11,500	0,040	0,000	0,214	1,000	0,942	1,000	1,000	0,765	1,040	0,767
<i>Test is positive if Actual Screening Score >= threshold value</i>										

3.3 Inter-rater and intra-rater reliability of the *Feeding and Swallowing Questionnaire* and the Clinical Feeding and Swallowing Assessment Tool

The inter-rater reliability was calculated so as to ensure that the method in which data was collected was correct and consistent. The Kappa statistic was used to calculate the inter-rater and intra-rater reliability. The interpretation of Kappa values is provided in Table 3-3.

Table 3-3: Interpretation of Kappa values

Interpretation of Kappa						
	Poor	Slight	Fair	Moderate	Substantial	Almost perfect
Kappa	0.0	0.20	0.40	0.60	0.80	1.0
Kappa	Agreement					
< 0	Less than chance agreement					
0.01- 0.20	Slight agreement					
0.21- 0.40	Fair agreement					
0.41- 0.60	Moderate agreement					
0.61- 0.80	Substantial agreement					
0.81- 0.99	Almost perfect agreement					

With regards to the *FSQ*, a Kappa static of 0.8 was achieved which indicates substantial agreement between the two raters (Table 3-3). In terms of the *CFSAT* a kappa statistic of 0.93 was obtained which indicates an almost perfect agreement between the two raters.

The intra-rater reliability of the *FSQ* was calculated as 0.87, which means that the research assistant was almost perfectly consistent in the manner in which she screened the participants using the questionnaire (Table 3-4).

Table 3-4: Inter and Intra-rater results

	Feeding and swallowing questionnaire (n=15)	Clinical feeding and swallowing assessment (n=15)
Inter-rater reliability (Kappa)	0.8	0.93
Intra-rater reliability (Kappa)	0.87	Not completed for the assessment

3.4 Internal consistency of the Feeding and Swallowing Questionnaire

Factor analysis was used to calculate the internal consistency of the *FSQ*. The internal consistency of the *FSQ* was calculated using the twenty-eight items of the questionnaire. A Cronbach's alpha of 0.79 was obtained, which indicates that the *FSQ* has an acceptable consistency (Table 3-5).

Table 3-5: Interpretation of Cronbach's alpha values

Cronbach's alpha	Internal consistency
$\alpha \geq 0.9$	Excellent
$0.9 > \alpha \geq 0.8$	Good
$0.8 > \alpha \geq 0.7$	Acceptable
$0.7 > \alpha \geq 0.6$	Questionable
$0.6 > \alpha \geq 0.5$	Poor
$0.5 > \alpha$	Unacceptable

3.5 Prevalence of feeding and swallowing difficulties

The prevalence of FSD in the study population was calculated as 27%. The total number of participants included in the prevalence study was 107; four of these participants had a known FSD diagnosis.

3.6 Participant Description

3.6.1 Gender and Age

A total of 103 infants and children (n=65 (63%) male; n=38 (37%) female) participated in this study. The participants' ages ranged from three days to twenty-four months old (median (interquartile range, IQR) age 5.23 (2.10 – 12.83) months). The majority of FSD were found in children under the age of one year (n=23; 92%), with 60% of those children being under the age of four months.

3.6.2 Development

Eighty-three (81%) participants were developing age appropriately as reported by their parents/ legal guardians; 16 (15%) were reported to have delayed communication milestones, and four (4%) participants were reported to have global developmental delays.

3.6.3 Acute diagnosis (N=29)

On admission, participants presented with a range of medical conditions, however in some participants a final diagnosis had not been made at the time this study was conducted (Table 3-6). The acute diagnosis and underlying medical conditions were obtained from the participants' medical files and were recorded during the clinical feeding and swallowing assessment. The acute and underlying medical diagnoses on admission for the four participants with a known FSD diagnosis were also included. The majority of FSD were identified in infants and children with medical conditions in the following categories: cardiorespiratory (n=9, 31%), neurological (n=6, 21%), GIT (n=4, 14%) as well as GIT conditions that affect the liver such as jaundice and biliary atresia (n=5, 17%). Feeding and swallowing difficulties were not found in the following categories of medical conditions; renal and those with metabolic conditions.

3.6.4 Underlying medical conditions (N=29)

Some of the participants had underlying medical conditions (Table 3-7) that may have been precipitated their presenting acute medical condition. Feeding and swallowing difficulties were found in infants and children with underlying medical conditions in the following categories: neurological (n=5, 17%), genetic (n=3, 12%), GIT conditions that affect the liver (n=2, 8%), prematurity (n=2, 8%) and a combination of genetic and cardiorespiratory conditions (n=2, 8%). However, other participants who had FSD did not have any diagnosed underlying medical conditions (n=13, 45%)

Table 3-6: Association between acute diagnosis and dysphagia

Medical condition categories	Dysphagia positive n =29	Dysphagia negative n =78
GIT	4 (14%)	11 (14%)
GIT (Liver)	5 (17%)	11 (14%)
Cardiorespiratory	9 (31%)	28 (36%)
Sepsis	1 (3%)	7 (9%)
Neurological	6 (21%)	9 (12%)
Growth faltering	2 (7%)	3 (4%)
ENT	1 (3%)	1 (1.2%)
Renal	0	1 (1.2%)
Genetic	1 (3%)	0
Metabolic	0	5 (7%)
Unknown at the time of admission	0	2 (3%)

Data are presented as n (%)

Table 3-7: Association between underlying medical conditions and dysphagia

Medical condition categories	Dysphagia positive n=29	Dysphagia negative n=78
Cardiorespiratory	1 (4%)	6 (8%)
Congenital bone disease	0	1 (1.2%)
ENT	0	1 (1.2%)
Genetic	3 (12%)	3 (4%)
GIT	1 (4%)	3 (4%)
GIT (Liver)	2 (8%)	2 (3%)
Metabolic	0	1 (1.2%)
Neurological	5 (17%)	4 (5%)
Prematurity	2 (8%)	3 (4%)
Sepsis	0	3 (4%)
Syndrome (renal related)	0	1 (1.2%)
No underlying condition	13 (45%)	48 (62%)
Unknown	0	1 (1.2%)
<i>Combination of medical conditions</i>		
Genetic and cardiorespiratory	2 (8%)	0
Neurological and ENT	0	1 (1.2%)

Data are presented as n (%)

3.6.5 The nature of feeding and swallowing difficulties (n=25)

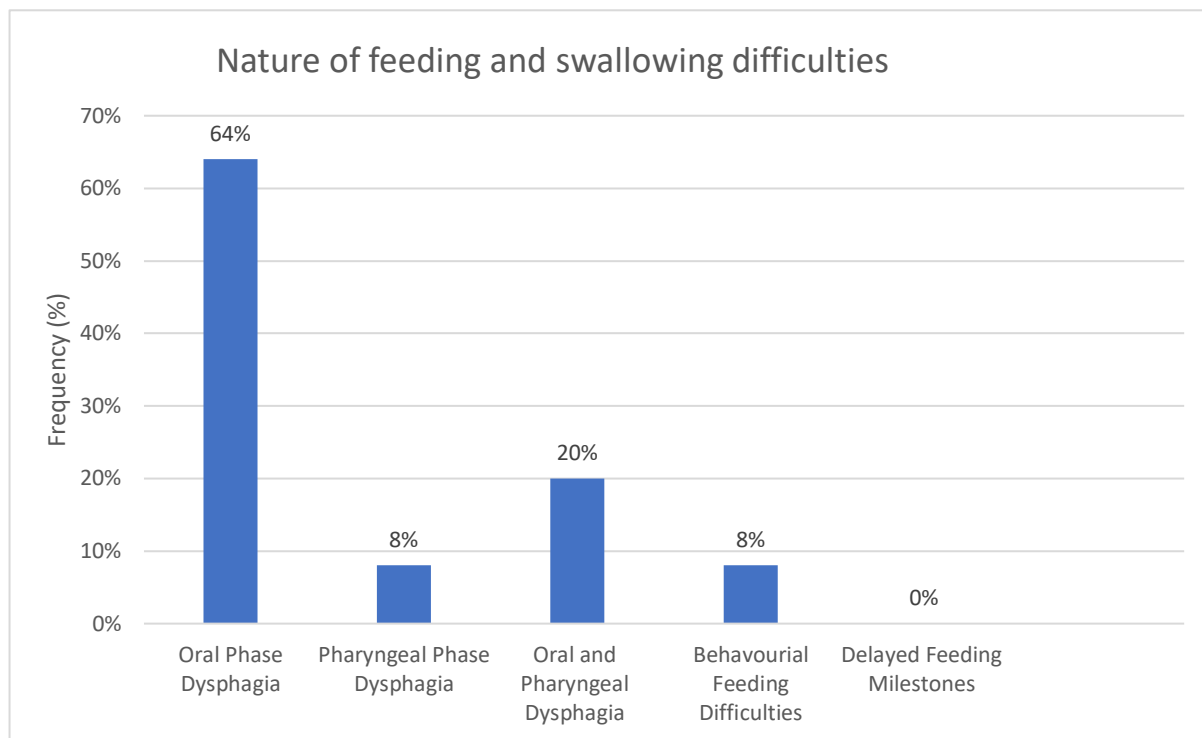


Figure 3-4: Nature of feeding and swallowing difficulties in the study population

Twenty-five participants were found to have FSD when assessed using the CFSAT. Figure 3-4 depicts the nature of FSD that participants presented with. Most of the participants (64%) were diagnosed with oral phase dysphagia, while a combination of oral phase and pharyngeal dysphagia was present in 20% of the participants. None of the participants presented with FSD as a result of delayed feeding milestones.

3.7 Feeding and swallowing associations

Inferential statistics were used to determine the relationships, if any, that exist between FSD and underlying medical conditions, acute medical conditions and associative factors such as length of feeding.

3.7.1 The association between medical conditions and feeding and swallowing difficulties

Acute medical diagnosis

In this study the majority of the participants who had FSD presented with cardiorespiratory conditions (31%) *see Table 3-6*, while others presented with GIT conditions (14%), neurological conditions (21%) and GIT conditions that affect the liver (17%). No associations were found between the acute medical diagnosis and the presence of FSD ($p = 0.36$).

Underlying medical conditions

Some participants who had FSD presented with both acute medical conditions and underlying medical conditions (Table 3-7). However, many participants did not have any underlying medical conditions (45%). The most common underlying medical conditions were neurological impairments (17%) and genetic medical conditions (12%). No associations were found between the underlying medical diagnosis and the presence of FSD ($p = 0.25$)

3.7.2 Factors that may be associated with feeding and swallowing difficulties

The third objective was to describe any association between underlying medical conditions and the nature of FSD. However, due to the small number of participants with FSD in each underlying medical category (table 3-7), this analysis was not possible. Hence, some factors that may be associated with FSD were analyzed as indicated in table 3-8. The findings were as follows:

3.7.2.1 Duration of feeding

Fifty-five (53%) participants reportedly took less than 20 minutes to complete feeds; 13 (24%) of those participants were found to have FSD. Thirty-nine (38%) participants reportedly took between 20-40 minutes to complete feeds, six (15%) of those participants were found to have FSD (Table 3-8). Lastly, nine (9%) participants reportedly took longer than 40 minutes to complete feeds, six (67%) were found to have FSD. The association between duration of feeding and presence of FSD was significant ($p= 0.005$), with infants and children who took longer (>40 minutes) to feed more likely to be diagnosed with FSD.

3.7.2.2 Respiratory difficulties

Eighty (78%) participants were breathing on room air, fifteen (18%) of whom were found to have FSD. Twenty (19%) participants were oxygen dependent, eight (40%) of whom had FSD (Table 3-8). Three (3%) participants presented with stridor, with two (67%; $n=3$) of those participants having FSD. There was a significant association between supplementary oxygen support and FSD ($p= 0.03$).

3.7.2.3 History of enteral feeding

Fifty-two participants (50%; $n=103$) had a history of nasogastric tube (NGT) feeding; 17 (33%; $n=52$) of those participants were found to have FSD (Table 3-8). However, there was no significant association between a history of enteral feeding and FSD ($p= 0.13$).

Table 3-8: Comparison between participants with and without feeding and swallowing difficulties (n=103)

Variable		All participants (n=103)	With dysphagia (n=25)	Without dysphagia (n=78)	P
Supplementary oxygen	Receiving supplementary oxygen	23 (22.3%)	10 (40%)	13 (17%)	0.027
	Not receiving supplementary oxygen	80 (78%)	15 (60%)	65 (63%)	
Duration of feeds	20 mins	55 (53.3%)	13 (52%)	42 (54%)	0.005
	20- 40 mins	39 (38%)	6 (24%)	33 (42.3%)	
	> 40 mins	9 (9%)	6 (24%)	3 (4%)	
Method of feeding	NGT	52 (50.4%)	17 (68%)	35 (45%)	0.132
	OGT	1 (1%)	0	1 (1.2%)	
	Eating orally	50 (50%)	8 (32%)	42 (54%)	

Continuous data are presented as median (IQR); categorical data as n (%). * comparison analysed using Mann Whitney U test

4. Discussion

This prospective observational study was the first to investigate the utility of the *FSQ* in identifying FSD in a general hospitalised paediatric population in South Africa.

4.1 Criterion validity

4.1.1 Sensitivity and Specificity

The sensitivity of the *FSQ* was 88%, indicating that the screening questionnaire was able to correctly identify the majority of participants with FSD (true positives). The specificity of the *FSQ* was 32%, meaning that as compared to the CFSAT, the *FSQ* was able to correctly identify approximately one third of participants without FSD.

It has been suggested that, for conditions which are potentially serious yet treatable, high sensitivity in a screening tool is more important than specificity (Lalkhen & McCluskey, 2008). Low specificity of the *FSQ* would lead to a number of children being referred for comprehensive clinical assessment, who do not in fact have FSD. However, as long as the clinical assessment is highly specific as a diagnostic test, the vast majority of children with FSD would ultimately be appropriately identified and managed (Lalkhen & McCluskey, 2008).

Receiver operator characteristic curves (ROC curves)

The test accuracy of the *FSQ* was calculated using ROC curves. The test accuracy for the *FSQ* was calculated as 0.70. This indicates that it is able to correctly identify participants with FSD 70% of the time. According to Lalkhen & McCluskey (2008), these findings are similar to those typically seen in screening tools. Accuracy (sensitivity and specificity) of the screening tools is not affected by population disease prevalence.

4.2 Construct validity

4.2.1 Positive and negative predictive values

Positive predictive value (PPV) and negative predictive value (NPV) are important to clinicians as they assist in considering the value of a screening tool (Trevethan, 2017).

The PPV of the *FSQ* was calculated as 29%, indicating that many infants and children identified as having FSD would ultimately test negative on clinical assessment. If a false positive is obtained, the infant or child will be referred for a comprehensive clinical assessment for further evaluation. The comprehensive clinical assessment is safe, easy and quick to administer provided that the infant or child is cooperative e.g. not crying or refusing to eat/swallow (Lalkhen & McCluskey, 2008; Trevethan, 2017). However, a low PPV may lead to caregiver stress after being told that their infant or child potentially has FSD. It is however, felt that this risk is outweighed by the potential benefit to the child of early identification and treatment of FSD, with associated reduction in the health-related consequences of this condition.

The low PPV in this study may be attributed to the low prevalence of FSD in the general paediatric study population. According to Ranganathan and Aggarwal (2018) PPV and NPV are heavily influenced by the prevalence of a disease in the population, such that the PPV increases with an increase in prevalence while the NPV decreases with an increase in prevalence, if other factors such as sensitivity and specificity remain constant (Ranganathan & Aggarwal, 2018).

The NPV was calculated as 89%, which implies that the number of false negatives are minimal when using the *FSQ*. Since the prevalence of FSD was low in the study population, the NPV was high (Ranganathan & Aggarwal, 2018). A high NPV of a screening test is desirable as this helps to avoid unnecessary further examinations and treatments (Umberger, Hatfield & Speck, 2017). The high NPV of the *FSQ* is reassuring for both the clinician and parents, that when the screening test result is negative, it almost certainly means that the infant or child does not have FSD and that further assessment or intervention is not indicated (Umberger et al., 2017). This will ensure that resources are effectively allocated to infants and children who in fact have FSD.

4.3 Inter-rater and Intra-rater reliability

The inter-rater reliability of the *FSQ* was calculated as 0.8. This indicated substantial screening agreement and consistency between the student researcher and the research assistant (Viera & Garret, 2005). The inter-rater reliability was established between SLTs; hence the finding cannot be extended to other health professionals such as nurses, doctors or other allied health professionals.

The intra-rater reliability of the *FSQ* was calculated as 0.87, indicating near perfect agreement and a consistent method of screening. The inter-rater reliability of the *CFSAT* was calculated as 0.93, indicating almost perfect agreement between the student researcher and the research assistant. Like the *FSQ*, the inter-rater reliability was established between SLTs, hence the results cannot be extended to other health professionals.

4.4 Internal consistency

Factor analysis was used to calculate the internal consistency of the *FSQ*, and Cronbach's alpha was calculated as 0.79. Determining alpha is essential as it adds to the validity and accuracy of a tool (Tavakol & Dennick, 2011). As outlined in Table 3-5, Cronbach's alpha was 0.79, indicating an acceptable internal consistency. It can therefore be concluded that items on the *FSQ* are unidimensional and measure the same construct of FSD.

Due to the complex nature of FSD, it may be difficult to achieve a higher Cronbach's alpha, as each item in the *FSQ* addresses a different aspect of FSD, which may not be interrelated. Moreover, participants may not present with all the signs and symptoms addressed by the individual items yet still have FSD.

4.5 Prevalence of feeding and swallowing difficulties

The prevalence of FSD in the study population was 27%. This finding is in accordance with previous estimates of 25% FSD prevalence in the general paediatric population (Orenstein, 2006). In other studies, the prevalence of FSD in typically developing children was described as ranging between 25% and 45% (Linscheid, Budd & Rasnake, 2003; Silverman, 2015).

There is a paucity of research on the prevalence of FSD in the general paediatric population, with most prevalence studies conducted in specific medical conditions such as children with neurological impairment in which the prevalence is estimated between 55% and 89% (Benfer et al., 2017; Prasse & Kikano, 2009, Sullivan et al., 2000). Hence, from a clinical perspective the *FSQ* would be a useful tool to screen patients in the general ward to identify those who require referral for further assessment by the SLT. Additionally, SLTs can spend more attention in wards where the prevalence of FSD is known to be high for instance in neurology wards.

4.6 Nature of feeding and swallowing difficulties

The findings of this study indicate that participants with FSD presented most commonly with difficulties in the oral phase (64%); participants also presented with difficulties in the pharyngeal phase (8%), both oral and pharyngeal phase (20%) and behavioural difficulties (8%). Oral phase difficulties were characterized by primitive oral reflexes such as tongue thrusting which resulted in anterior spillage. Participants also presented with disorganized tongue movements which resulted in poor bolus formation, poor bolus control and difficulty with bolus propulsion.

Some participants also presented with reduced endurance during feeding. Similar difficulties have been described in children with various medical conditions for instance Benfer et al. (2017) found that children with neurological impairments presented with oral phase difficulties such as reduced tongue movements, poor lip closure, tongue thrusting and difficulty with bolus manipulation. In children with congenital heart defects, oral phase difficulties present as a weak suck, poor endurance during feeding and also difficulty with bolus manipulation (Costello et al., 2014; Hehir et al., 2016)

Premature infants usually present with oral difficulties which are characterized by difficulty latching, immature oral motor skills which may affect sucking as well as reduced endurance during feeding (Lau et al., 2003; Mizuno et al., 2007). Oral phase difficulties in children with gastrointestinal disorders present as food refusal and fussiness during mealtimes which can consist of crying (Coppens et al., 2016).

The effects of oral phase difficulties consist of poor weight gain, increased meal duration times and a compromised nutritional status all of which further compromise the health of an already ill infant or child (Borowitz & Borowitz, 2018; Tutor & Gosa, 2012).

Clinical signs of pharyngeal phase swallowing difficulties included delayed triggering of the swallow, a disrupted suck-swallow-breathe coordination, coughing with swallowing and a gurgly voice quality after swallowing. These signs are all suggestive of possible aspiration or place the participants at risk of aspiration (Arvedson & Brodsky, 2002; Bejiqi et al, 2017; Borowitz & Borowitz, 2018; Costello et al., 2014; Lefton-Greif, 2008). Similar difficulties are extensively described in children with various medical conditions such as neurological impairments, cardiorespiratory disease and prematurity (Bejiqi et al, 2017; Borowitz & Borowitz, 2018; Costello et al., 2014; Lefton-Greif, 2008).

Pharyngeal phase difficulties in children with neurological impairments present as coughing and/ or choking during feeding as well as chronic aspiration (Srivastava et al., 2010). It is important to note that children with neurological impairments may also aspirate silently, and silent aspiration is difficult to detect in a clinical examination (Lagos-Guimaraes et al., 2016). However, in some cases an experienced SLT can infer silent aspiration by observing signs such as desaturations and teary eyes (Lagos-Guimaraes et al., 2016). In premature infants, pharyngeal phase difficulties present as difficulty with the suck-swallow-breathe coordination which is influenced by an immature respiratory system (Lefton-Greif, 2008; Mizuno et al, 2007).

Children with congenital heart defects may also present with pharyngeal phase difficulties that occur as a result of the iatrogenic injury of the laryngeal nerve post-surgical repair (Clement et al., 2008). The pharyngeal phase difficulties that have been described often indicate aspiration or place the children at risk of aspiration (Borowitz & Borowitz, 2018; Lefton-Greif, 2008). Chronic aspiration has been associated with recurrent lower respiratory infections and pneumonia which result in either recurrent hospital admissions or prolonged hospital stays (Seddon & Khan, 2003; Srivastava et al., 2010).

Moreover, pneumonia is also associated with significant morbidity and mortality (Borowitz & Borowitz, 2018; Lefton-Greif, 2008; Seddon & Khan, 2003; Srivastava et al., 2010). Pharyngeal phase difficulties also impact nutritional intake which compromise weight gain and the general health of children (Borowitz & Borowitz, 2018; Lefton-Greif, 2008; Seddon & Khan, 2003; Srivastava et al., 2010).

Some participants presented with difficulties that affected both the oral phase and pharyngeal phase. For instance, a participant could present with disorganized tongue movements with a delay in the triggering of the swallow. While other participants may have difficulty with bolus manipulation and coughing during the swallow. These findings are consistent with the available literature on the oropharyngeal difficulties that present in infants and children with various medical conditions. Lefton-Greif (2008) found that premature infants presented with immature oral motor skills and underdeveloped lungs which affected the infant's abilities to suck, as well as to coordinate sucking, swallowing and breathing.

A study on children with neurological impairments such as children with cerebral palsy found that oropharyngeal difficulties are common in this population (Benfer et al., 2017). As indicated in figure 3-4, two participants presented with isolated behavioural responses to feeding, such as fussiness and crying during feeding, and food refusal. Behavioural feeding difficulties are common in typically developing children and in children with medical conditions such as gastrointestinal disorders and developmental disorders (Kerzner et al., 2015).

Studies have found that children who exhibit behavioural feeding difficulties do not consume nutritious diets therefore they are at risk of impaired growth (Galloway et al., 2005; Garg, Williams & Satyavarat, 2015; Lindberg, Ostberg, Isacson & Danaeus, 2006). This is an area of concern especially in children who are hospitalized and are chronically ill, for instance children with chronic liver disease (Field et al, 2003). Moreover, behavioural feeding difficulties have been associated with lengthy mealtimes and parents have often described mealtimes as being stressful (Marshall, Ware, Ziviani, Hill & Dodrill, 2015).

In conclusion, the majority of participants with FSD presented with oral phase difficulties and a combination of oral and pharyngeal phase difficulties. The consequences of these difficulties include reduced oral intake which may negatively impact weight gain, and an increased risk on respiratory health (Bejiqi et al, 2017; Bingham, 2009; Costello et al., 2014; Field et al, 2003; Srivastava et al., 2010)

4.7 Medical conditions

The participants presented with acute medical conditions while others also had underlying medical conditions as expected in a general paediatric hospital ward (Table 3-6 & Table 3-7). The medical conditions that presented in those participants with FSD were similar to the medical conditions discussed in FSD literature namely, cardiorespiratory, neurological, GIT and prematurity (Bejiqi et al., 2017; Benfer et al., 2017; Benninga et al., 2018; Bingham et al., 2009; Borowitz & Borowitz et a., 2018; Coppens et al., 2016; Costello et al., 2014; Lefton-Greif et al., 2008; Lima, 2015; Sassi et al., 2018; Seddon et al., 2010).

Cardiorespiratory conditions were most prominent in participants with FSD. Cardiac conditions included congenital heart defects such as ventricular septal defect (VSD), patent ductus arteriosus (PDA), atrial septal defect (ASD) as well as the transposition of the great arteries. They affect both the oral and pharyngeal phases of the swallow as described above (Bejiqi et al, 2017; Costello et al., 2014).

Respiratory difficulties were also common in children with FSD, which included respiratory distress, pneumonia, bronchiolitis, chronic lung disease, upper and lower respiratory tract infections and cystic fibrosis. Respiratory difficulties affect the suck-swallow-breathe coordination, this may affect laryngeal airway protection (Sassi et al., 2018). Respiratory difficulties affect the pharyngeal phase of the swallow potentially leading to aspiration, which is associated with pneumonia and increased hospital stay (Borowitz & Borowitz, 2018; Mizuno et al, 2007; Sassi et al., 2018).

Neurological difficulties in children with FSD included hydrocephalus, cerebral palsy and epilepsy, with some participants presenting with a combination of neurological difficulties such as cerebral palsy and seizures. Children with neurological impairments typically present with oral and pharyngeal difficulties and they are also at risk of aspiration.

A study by Benfer et al (2017) found that children who were under the age of 2 years and had neurological impairments presented with both oral and pharyngeal dysphagia which resulted in increased feeding times as well as aspiration.

Pharyngeal phase difficulties are common in children with neurological impairments due to the immaturity of the neuromuscular coordination that is essential during the swallowing process (Sheikh et al., 2001). Feeding and swallowing difficulties in this population negatively affects their oral intake and nutritional status, therefore some children with neurological impairment may eventually require a long-term feeding method such as the insertion of a percutaneous gastrostomy tube (Benfer et al., 2017; Sheikh, 2001).

The GIT conditions that presented in the participants with FSD were chronic liver disease and acute gastroenteritis (AGE). Gastro-oesophageal reflux disease is the most common GIT disorder associated with FSD (Benninga et al., 2016; Coppens et al., 2016) however this was not documented in the current study. This may be because GORD may have not been the primary presenting medical condition.

Feeding difficulties, particularly those that are behavioural in nature, are common in children with chronic liver disease because of decreased stomach volume, discomfort from ascites as well as increased pro-inflammatory cytokines which result in nausea and vomiting (Yang, Perumpail, Yoo, Ahmed & Kerner, 2017). Acute gastroenteritis is common in South Africa, where it has been found that it is the second leading cause of death in children under five (Awotiwon et al., 2016). Globally, AGE has been found to be responsible for approximately 40% of hospital admissions in children under the age of five (Awotiwon et al., 2016). Acute gastroenteritis is not typically associated with FSD; it is likely that those children admitted with AGE who presented with FSD may have had pre-existing undiagnosed FSD , as it is most common in children under two years (Kakodkar & Schroeder, 2013).

Feeding and swallowing difficulties have been associated with premature infants (Mizuno et al, 2007). In this study only five participants presented with a history of prematurity and only two (8%) of them presented with FSD. This was surprising as the rate of preterm births (<37 weeks gestational age) and low birth weight (<2500g) is estimated at 14.7% in South Africa, this rate is double than that of high income countries where the rate is estimated at 7% (Fouche, Kritzinger & le Roux, 2018).

This small number may have been attributed to the fact that participants were recruited from a general paediatric medical ward as opposed to a neonatal high care ward or kangaroo mother care unit.

Feeding and swallowing difficulties in preterm infants often occur in the oral phase and pharyngeal phase, with difficulties latching or sucking (immature oral motor skills) as well as difficulty coordinating sucking, swallowing and breathing (Bingham, 2009; Lefton-Greif, 2008; Mizuno et al, 2007). Moreover, due to underdeveloped lungs which affect their respiratory system, place premature infants at risk of aspirating and developing aspiration induced chronic lung disease (Bingham, 2009; Lefton-Greif, 2008; Mizuno et al, 2007).

In addition to medical conditions, other factors were also considered as possible indicators for FSD. Participants who were reported to take longer than 40 minutes to complete feeds were likely to be diagnosed with FSD ($p=0.005$). This finding is supported by Arvedson (2013) who reported that infants and children with FSD had mealtimes longer than 30 minutes, and that participants described mealtimes as being stressful. An increase in the duration of mealtimes may be due to poor oral motor skills such as difficulty with manipulating a bolus, difficulty sucking and/ or difficulty coordinating swallowing and breathing as well as reduced endurance (Bejiqi et al, 2017; Costello et al., 2014). This may affect the child's oral intake therefore result in poor weight gain and in some instances malnutrition (Bejiqi et al, 2017; Costello et al., 2014). Hence, one of the strengths of the *FSQ* is that it incorporates a question about the duration of feeding, which is a good indicator of whether an infant or child may have FSD requiring further assessment.

Although 33% of the participants with a history of enteral feeding presented with FSD, there was no statistically significant association between a history of tube feeding and the presence of feeding and swallowing difficulties ($p= 0.13$). This finding is not consistent with other studies which have reported that enteral feeding significantly impacts on early feeding development (Benoit et al., 2000). During enteral feeding children may miss critical feeding milestones which may result in the development of oral aversion to certain food textures (Bingham, 2009; Sullivan, 2014).

The lack of association in this study may be due to the small sample size or because the children did not have NGTs for extended periods of time; this may be due to the fact that admissions to general medical wards tend to be for children who present with acute illnesses that require short-term admission as compared to admissions to specialized wards (Westwood & Levin, 2012).

There was a statistically significant association between respiratory difficulties requiring supplementary oxygen and FSD ($p= 0.03$). This may be due to the fact that respiratory difficulties affect the efficacy of the swallow and therefore are often associated with FSD (Sassi et al., 2017). This is because during swallowing, laryngeal airway closure must occur with a respiratory pause, both of which are difficult to do when an infant or child has respiratory difficulties and tachypnoea (de Camargo, Ono, Park, Caruso & Carvalho, 2010). The findings obtained indicate that oxygen supplementation and an increased mealtime duration are factors that have an effect on the feeding and swallowing of a child. Therefore, the inclusion of questions about length of mealtimes and respiratory difficulties in the *FSQ* is indicative of a strength in the *FSQ*.

4.8 Limitations and future research

A limitation of this study was the low prevalence and therefore small sample size of participants with FSD. While the sample size was appropriate for the validation of the screening questionnaire, a larger sample size of infants and children with FSD would have provided more information for the description of FSD. Moreover, it would have provided more information for the student researcher to describe any relationships that existed between medical conditions and the prevalence of FSD as well as between medical conditions and the nature of FSD. Future research should focus on describing the nature of FSD and associations with medical conditions should be conducted with a larger sample.

The CFSAT was only inclusive of three consistencies and did not include other consistencies which have been described by the International Dysphagia Diet Standardization Initiative (IDDSI, 2016). This was a limitation of this study, therefore it is recommended that future research incorporates a variety of consistencies such as those described by IDDSI (2016).

Although the CFSAT was used a comparator during this study, the lack of a gold standard clinical assessment tool was a limitation. Therefore, it is recommended that future research focuses on developing and validating a clinical feeding and swallowing assessment tool that can be used as a gold standard in the general hospitalized paediatric population.

Another limitation of the study is the inter-rater and intra-rater reliability of the *FSQ* that was established by SLTs therefore it may not be assumed that the questionnaire can be used by other health professionals. This is because SLTs possess knowledge about feeding and swallowing difficulties that other health professionals may not have.

It is therefore recommended that both the inter- and intra-rater reliability of the *FSQ* be established with other health professionals. This will ensure that the usability of the *FSQ* is generalizable to all health professionals and not only SLTs, therefore ensuring that children can be screened in various health institutions, including those without access to SLTs. It is also recommended that future research focuses on the effectiveness of incorporating the *FSQ* as part of the initial admission consultation, for example by nursing staff.

Moreover, future research should focus on the usability of the *FSQ* in rural settings and at primary healthcare levels where there is limited access to health care and where the initial point of contact is usually at a local clinic. Hence, the *FSQ* should be translated into other official South African language so that it can be used in these various settings. With regards to clinical practice, future research can focus on the usability of the *FSQ* in the broader paediatric hospitalized population as currently the *FSQ* can only be used in general medical wards.

5. Conclusion

The study has shown promising results for the use of the FSQ as a screening tool to identify feeding and swallowing difficulties in general paediatric medical wards, particularly for infants and children who are under the age of two years. The study has also shown that the *FSQ* has acceptable criterion validity and construct validity. Moreover, it *FSQ* has acceptable inter-rater and intra-rater reliability.

The participants presented with various medical conditions, as described in literature some conditions were common in infants and children with FSD. However, other medical conditions such as acute gastroenteritis were not common in infants and children with FSD. There were various factors that were associated with the presence of FSD, for instance children and infants who received supplemental oxygen were highly likely to have FSD. Moreover, those who took longer than forty minutes to complete meals were also found to have FSD.

It is recommended that future research uses a larger sample size that has substantial representation of the various medical conditions, so it can be analysed whether any relationships exist between medical conditions and the prevalence of FSD. Further research needs to be conducted in other various settings so as to increase the robustness of the screening tool. Furthermore, it is recommended that the inter-rater reliability of the *FSQ* be conducted using other health professionals as currently it has only been established with SLTs.

6. References

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Appendices

Appendix A: Feeding and Swallowing Questionnaire (English)

Feeding and Swallowing Questionnaire

Participant number: _____ Date of birth: _____

Date of assessment: _____ Primary language of caregiver: _____

I am going to ask you some questions about how your baby / child drinks and eats.

<i>Complete all sections and indicate responses clearly with comments if necessary</i>					
					Comments
1. Please indicate which type of feeds XXX has everyday: Breast feeding only ____ Bottle feeding only ____ Breast feeding & Bottle feeding ____ Breast feeding & solids ____ Breast feeding, bottle feeding & solids ____ Bottle feeding & solids ____ Liquids & solids ____ Other: _____					
2 Does XXX have any problems with eating or drinking	YES	NO			
3. Is it difficult for you, or anyone else, to feed XXX?	YES	NO	Over 2 years: N/A		
4. Does it take longer than 30 minutes for XXX to finish feeding / eating a meal?	YES	NO			
5. Does XXX get tired when s/he is drinking or eating?	YES	NO			
6. Is XXX picking up weight?	Well <input type="checkbox"/> Slowly <input type="checkbox"/> Not at all <input type="checkbox"/> Losing weight <input type="checkbox"/>			If objective evidence for weight loss or crossing centiles (RTHC)	

7. Does XXX have problems breathing during feeding or after feeding? For example does breathing become faster, noisy, difficult?	YES	NO		
8. Does XXX finish his / her feeds / meals most of the time?	YES	NO		


9. Does XXX become upset or fussy e.g. cry, wriggle, turn face away, with feeding? <i>(demonstrate these behaviours with physical cue)</i>	YES	NO	N/A	
10. Does XXX vomit with feeds?	YES	NO		During feed <input type="checkbox"/> After feed <input type="checkbox"/> After medication <input type="checkbox"/> Anytime <input type="checkbox"/>
11. Is XXX's voice hoarse, scratchy or has it changed?	YES	NO	>2 weeks	Refer ENT
12. Does XXX's voice sound gurgly (wet) after drinking?	YES	NO		
13. Does XXX drool (does spit run out of XXX's mouth)? <i>(demonstrate with hand gesture)</i>	YES All the time ___ More during eating / drinking ___ Only when teething ___	NO		<i>Observe during session: if child older than 3 years and wearing a bib or has noticeable drooling:</i> Yes ___ No ___


	0 – 6 months		6 – 12 months		12 + months	
14. Does XXX drink liquids such as milk and water?	YES	NO	YES	NO	YES	NO
15. Does XXX eat semi-solids such as cereal?			YES	NO	YES	NO
16. Does XXX eat solids such as bread or biscuits?					YES	NO
17. Does XXX drink well from a bottle / breast?	YES	NO	YES	NO		
18. Can XXX drink from a cup?			YES	NO	YES	NO
19. Does XXX mess / spill a lot from the mouth during feeding?	YES	NO	YES	NO	YES	NO
20. Does liquid or food ever come out of XXX's nose while drinking or eating?	YES	NO	YES	NO	YES	NO
21. Does XXX gag (want to vomit – demonstrate) with liquids?	YES	NO	YES	NO	YES	NO
22. Does XXX gag (want to vomit – demonstrate) with food?	N/A		YES	NO	YES	NO
23. Does XXX refuse to drink liquids such as milk or water?	YES Always — Daily —	NO	YES Always — Daily —	NO	YES Always — Daily —	NO

	Weekly — Once or twice —		Weekly — Once or twice —		Weekly — Once or twice —	
24. Does XXX refuse to eat food?	YES Always — Daily — Weekly — Once or twice —	NO	YES Always — Daily — Weekly — Once or twice —	NO	YES Always — Daily — Weekly — Once or twice —	NO
25. Does XXX spit out liquids such as milk?	YES Always — Daily — Weekly — Once or twice —	NO	YES Always — Daily — Weekly — Once or twice —	NO	YES Always — Daily — Weekly — Once or twice —	NO
26. Does XXX spit out food?	YES Always — Daily — Weekly — Once or twice —	NO	YES Always — Daily — Weekly — Once or twice —	NO	YES Always — Daily — Weekly — Once or twice —	NO

27. Does XXX cough with drinking?	YES	NO	YES	NO	YES	NO
28. Does XXX cough with eating?			YES	NO	YES	NO
29. Does XXX choke with drinking (does liquid go down the wrong pipe)?	YES	NO	YES	NO	YES	NO
30. Does XXX choke with eating (does food go down the wrong pipe)?			YES	NO	YES	NO

Referral criteria to SLT for clinical feeding and swallowing assessment:

Any response shaded 

More than one response shaded 

INDICATE (Please tick):

PASS 

FAIL 

Additional comments:

Appendix B: Clinical Feeding and Swallowing Assessment Tool

Participant number: _____ Date of birth: _____

Date of assessment: _____

Primary language of caregiver: _____

History:

Family

1. Primary caregivers:

.....

2. Who feeds participant:

.....

3. History of any of the following:

	Yes / No	Dates / Year (if available)
Oral Candida		
Pharyngeal Candida		
Oesophageal Candida		
Middle ear infections		
Allergies		
Mouth Breathing		
Seizures		
CMV		
Snoring		
Upper Respiratory Tract Infections		
Other illnesses		

4. Previous medical investigations and results:

Barium swallow:

.....

Milk Scan:

.....

GI Scope:

.....

Other:.....

.....

5. Developmental history:

	Age (where applicable)
Smiled	
Sat	
Crawled	
Cruised along furniture	
Walked	
Said first words	
2 words together	

Feeding history:

6. Tube feeding Type Duration

7. Breastfed Duration

8. Bottle fed Duration

9. Cup fed Duration

10. Position during feeding:

Held in arms Held on lap Infant seat / car seat High chair

Chair at table Wheelchair Lying down Other

11. Duration of meal times: <20 minutes 20 – 40 minutes 40+ minutes

12. Completion of feeds: Never Seldom Sometimes Often Always

13. Feeding Routine: 2 hours 3 hours 4 hours

Regular mealtimes e.g. breakfast, lunch & supper with snacks

.....

Other:

14. Describe a typical daily diet (24 hours):

.....

.....

.....

.....

.....

.....

15. Textures in diet

Texture	Examples	Age introduced	Difficult for participant
Liquid			
Puree			
Lumpy puree			
Solid			

16. Utensils used

Utensil	Age introduced	Caregiver/Self	Utensil	Age introduced	Caregiver/Self
Bottle			Spoon		
Sippy Cup			Fork		
Open Cup			Straw		
Fingers			Sports bottle		
Other					

Signs & Symptoms reported by caregiver

17. Consistency-specific information

	All	Liquid	Puree	Lumpy Puree	Solid
Spillage	Always	Always	Always	Always	Always
	Daily	Daily	Daily	Daily	Daily
	Weekly	Weekly	Weekly	Weekly	Weekly
	Once or Twice	Once or Twice	Once or Twice	Once or Twice	Once or Twice
Refusal	Always	Always	Always	Always	Always
	Daily	Daily	Daily	Daily	Daily
	Weekly	Weekly	Weekly	Weekly	Weekly
	Once or Twice	Once or Twice	Once or Twice	Once or Twice	Once or Twice
Spits	Always	Always	Always	Always	Always
	Daily	Daily	Daily	Daily	Daily
	Weekly	Weekly	Weekly	Weekly	Weekly
	Once or Twice	Once or Twice	Once or Twice	Once or Twice	Once or Twice
Gags	Always	Always	Always	Always	Always
	Daily	Daily	Daily	Daily	Daily
	Weekly	Weekly	Weekly	Weekly	Weekly
	Once or Twice	Once or Twice	Once or Twice	Once or Twice	Once or Twice
Coughs	Always	Always	Always	Always	Always
	Daily	Daily	Daily	Daily	Daily
	Weekly	Weekly	Weekly	Weekly	Weekly
	Once or Twice	Once or Twice	Once or Twice	Once or Twice	Once or Twice
Chokes	Always	Always	Always	Always	Always
	Daily	Daily	Daily	Daily	Daily
	Weekly	Weekly	Weekly	Weekly	Weekly
	Once or Twice	Once or Twice	Once or Twice	Once or Twice	Once or Twice
Vomits	Always	Always	Always	Always	Always

	Daily Weekly Once or Twice	Daily Weekly Once or Twice	Daily Weekly Once or Twice	Daily Weekly Once or Twice	Daily Weekly Once or Twice
--	----------------------------------	----------------------------------	----------------------------------	----------------------------------	----------------------------------

- 18. Fussy/cries during feeding
- 19. Reports pain with swallowing (caregiver/self)
- 20. Keeps food in mouth for a long time before swallowing
- 21. Gurgly voice: No Always During feeding After feeding
- 22. Noisy breathing: NoAlwaysDuring feeding After feeding
- 23. Postural changes during feeding (e.g. hyperextension)
.....
- 24. Falls asleep during feeding
.....
- 25. Colour changes with feeding
- 26. Sensitive to touch around mouth
- 27. Drools: All the time More during eating/drinkingOnly when teething
.....

Pre-feeding assessment

- 28. State: Drowsy Awake Agitated Crying
- 29. Physiological status:

	Heart rate	Respiratory rate	Oxygen saturation level (%)
Before feeding			
During feeding			
After feeding			

- 30. General posture and tone: Normal Hypotonic Hypertonic Fluctuating
.....
- 31. Airway: Normal Stridor Stertor TracheostomyVentilated
..... Oxygen dependent
- 32. Wet voice

- 33. Audible pooling of secretions in pharynx
- 34. Bubbling of secretions at mouth
- 35. Pooling of secretions in mouth
- 36. Drools: No Mild (around lips) Moderate (on chin)
 Severe (onto clothes) Profound (onto table / objects)

Oral motor structure examination

- 37. Face: normal symmetrical asymmetrical
- 38. Cheeks: normal reduced tone
- 39. Lips: symmetrical weakness L / R
 closure maintained no closure
 normal retracted reduced tone
- 40. Tongue: symmetrical asymmetrical
 protrusion in midline deviates L / R
 hypotonic hypertonic
 at rest: retracted protrudes
 short frenulum
- 41. Hard palate: normal high arched narrow cleft
- 42. Soft palate: normal cleft
- 43. Jaw: normal small retracted protruded
 clenched
 stable uncontrolled movement
 occlusion
- 44. Dentition:

Feeding & Swallowing Assessment

Non-nutritive sucking (up to 9 months)

45. Present Absent
46. Rate: normal (2/sec) slow fast
47. Strength: normal weak
48. Rhythm: normal no rhythm disorganized
49. Tongue cupping: present absent weak
50. Sucking bursts and pauses:
51. Suck : swallow ratio:
52. Abnormal responses: gag tonic bite

Feeding and swallowing

Liquids:

53. Position:
54. Mode: Breast Bottle Spout cup Cup Sports bottle
Straw Other
55. Breast feeding: latch normal poor latch
56. Lip closure: normal poor seal
57. Anterior spillage: none minimal moderate
significant
58. Sucking:

Applicable to infant
bottle /breast
feeding only

- Rate
- Strength (flow rate)
- Rhythm
- Bursts: normal short sucking burst and long pause long sucking burst and short /
no pause Suck: swallow ratio
- Suck, swallow and breathing co-ordination: normal inco-ordinated
.....
59. Swallow and breathe co-ordination: normal inco-ordinated
.....

60. Pooling of liquid in mouth: none anterior lateral
61. Tongue movement: normal reduced thrusting poor bolus control
62. Anticipatory mouth opening yes no
63. Jaw movement: normal thrust tonic bite bites utensil
64. Trigger of swallow: normal delayed absent inconsistent
65. Swallows per bolus:
66. Oral residue after swallowing: none anterior sulcus lateral sulci tongue floor of mouth
67. Nasal regurgitation: yes no
68. Signs of aspiration

	None	Before Swallow	During Swallow	After Swallow
Coughing				
Eye Tearing				
Gurgle voice quality				
Desaturation				
Increased RR				
Colour Changes				

Signs of discomfort / aversion

69. Gags with liquids
70. Averts face / refuses
71. Cries
72. Complains of painful swallowing
73. Does not complete feed
74. Vomits: none during feed after feed.....
75. Other comments / observations during liquid feed:
.....

Signs of discomfort / aversion

- 87. Gags with semi-solid
- 88. Averts face / refuses
- 89. Cries
- 90. Does not complete feed
- 91. Vomits: none during feed after feed
- 92. Other comments / observations during semi-solid feed:

.....
.....
.....
.....
.....
.....

Solids - biscuit (from 10 – 12 months depending on introduction)

- 93. Anticipatory mouth opening: yes no
- 94. Lip closure: normal poor seal
- 95. Lip movement: none active movement retracted pursed
- 96. Anterior spillage: none minimal moderate significant
- 97. Tongue movement: normal reduced thrusting
poor bolus control poor bolus formation cleans lips lateralization
- 98. Jaw movement: normal / graded bite..... thrust tonic bite
- 99. Trigger of swallow: normal delayed absentinconsistent
- 100. Swallows per bolus:
.....
- 101. Nasal regurgitation: yes no
- 102. Residue after swallow: none anterior sulcus lateral sulci
tongue floor of mouth palate
- 103. Signs of aspiration

	None	Before Swallow	During Swallow	After Swallow
Coughing				
Eye Tearing				
Gurgle voice quality				
Desaturation				
Increased RR				
Colour Changes				

Signs of discomfort / aversion

104. Gags with solids

105. Averts face / refuses

106. Cries

107. Does not complete feed

108. Vomits: none during feed after feed

109. Other comments / observations during solid feed:

.....
.....
.....
.....
.....
.....

Recommendations

110. No intervention required

.....

111. Caregiver training (specify)

.....

112. No oral feeds

.....

113. Normal age appropriate diet

.....

114. Combined tube and oral feeds

.....

115. Consistency modification: thickened liquids custard /
nectar

..... yoghurt / pudding cereal /
porridge
purees only

..... soft diet, no pieces

..... purees and solids

116. Utensils: spoon spoon bottle squeeze bottle

..... Other

117. Develop sucking: NNS NS

118. Provide oral control for lip closure

119. Positioning:

120. Graded sensory programme:

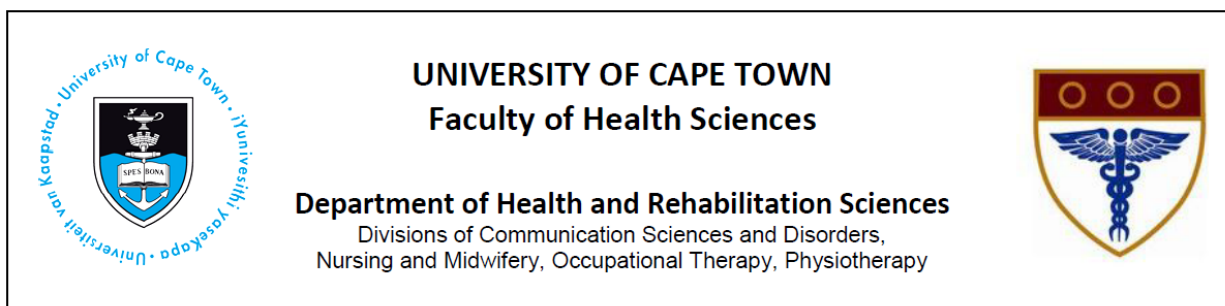
121. Dry swallows to clear residue :

122. Smaller meals

123. Keep upright after feeds:

124. Other

Appendix C: Participant information and consent form (English)



TITLE OF THE RESEARCH STUDY: The validation of a screening tool for the identification of feeding and swallowing difficulties in the paediatric population aged 0 - 2 years admitted to general medical wards

This study has been approved by the Human Research Ethics Committee at University of Cape Town and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research. (HREC reference number: 049/2018).

Dear Parent or Legal Guardian

My name is Cynthia Sibanda and I am a masters student from the University of Cape Town. I am a speech therapist and I work with babies and children who have problems with drinking and / or eating. I am doing a research study to see if a questionnaire can help to identify eating and drinking problems in children who have been admitted to hospital and are between 0 and 2 years of age. This research study will contribute towards my Master of Science Degree in Speech-Language Pathology. You and your child are being invited to take part in this research study.

More information about this study will be given in this letter, do take time to read it or someone can read it for you. Should you have any questions or need further explanations feel free to ask the researcher.

The purpose of the study?

Infants and toddlers who are sick and have been hospitalized may have eating and drinking problems. This research study will be conducted to test whether a screening questionnaire is able to identify eating and drinking difficulties in infants and toddlers.

Why has your child been invited to participate in this study?

Your child has been asked to participate in this study for any of the reasons below:

- He or she has been admitted in the general paediatric ward and is between 0 and 2 years of age.

What happens after consent is given?

If you give permission for you and your child to take part in this study, we will ask you and your child to do the following:

1. The *research assistant* (also a speech therapist) will ask you some questions, using a screening questionnaire, about your child's eating and drinking and get some information about his/her health from the medical folder, e.g. chest infections, medications. The interview will take about 10-15 minutes.
2. If your child has already been seen by a speech therapist and you know s/he has difficulties with eating or drinking, then the research assistant will only write down some information from your child's file, like his age, dates of hospital admissions, weight and medical conditions, so that we can try to understand how many children under 2 years old have problems with eating and drinking.
3. Then the student researcher will do the clinical feeding and swallowing assessment which will take about 20-30 minutes. The clinical assessment will occur immediately after you answer questions from the screening questionnaire. If not immediately after, it will happen within 24 hours after the screening has been completed. Before conducting the clinical assessment, the researcher will ask you detailed questions about your child's medical history and feeding history; the researcher will look in your child's mouth to examine the oral structures such as teeth, tongue, palate and then she will watch your child swallow liquid (milk), cereal / yoghurt (if it is suitable for your child's age) and a biscuit (if it is suitable for

your child's age). The student researcher will then make notes about how your child swallows the different foods.

4. If it seems that your child does have a problem feeding and/ or swallowing, we will refer your child to the speech therapist at this hospital for further management. The doctors who are attending to your child will also be informed about the referral to the speech therapist.

You and your child's participation is **entirely voluntary** and you are free to say that you do not want to participate. If you say no, this will not affect you negatively in any way, and it will not affect the standard of your child's health care. You are also free to stop participating in the study at any point, even if you do initially agree to take part.

Will you be recorded during this study?

Yes, audio recordings will be made when answering the questions from the screening questionnaire. This will be done so that the research assistant can check that all the information is collected correctly on the forms. Your name will not be included in the recording, only a number for example 001 will be used on the audio recordings. Research records will be kept safe on an external hard drive, all the information on this hard drive will be accessed with a password. The password will be known only by the researcher, research assistant and the research supervisor. The external hard drive will only be used by the student researcher, research assistant and the research supervisor. When it is not being used, it will be locked safely in a cupboard in a secure office. Once the research is published the audio recordings will be deleted.

Will your child benefit from taking part in this research?

There may be no direct benefit for your child when participating in the study if he/she does not have any problems with eating or drinking. If your child is found to have a feeding or swallowing difficulty, he or she will be referred to the speech therapist for further management which will be an immediate benefit.

Are there in risks involved in your child taking part in this research?

If your child does have a feeding or swallowing problem, there may be a small risk that he/she might choke on some of the food or liquid given to swallow. If we think that the food or liquid is going down the wrong way, we will immediately stop giving your child that food. After this your child will be given thicker food for example yoghurt, so as to make sure that he or she does not have any other feeding or swallowing problems.

Who will have access to the results of the study?

The results of the study will be published, and they will be available to everyone. However, your personal information will only be known by the student researcher, research assistant and the supervisors.

Will you or your child be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study. There will be no additional costs involved for you if you do take part, as the assessment will take place while your child is still in hospital.

Is there anything else that you should know or do?

- Your child's doctor will be informed that your child is taking part in a research study.
- The results of the assessment will be written in your child's file so that the doctor and other health professionals who are attending to your child, know about the results obtained and the referrals made.
- The results of the study will be published in journals so that other doctors, speech therapists and other health professionals know what we found which will hopefully help them when working with children with feeding and swallowing problems.
- At no time will your identity nor your child's identity be made known.
- The University of Cape Town (UCT) will be liable for any loss, injuries and/or harm that you may sustain during this research.

Yours sincerely,

Cynthia Sibanda

Msc Speech-Language Pathology student (SBNCYN001)

Email: sbncyn001@myuct.ac.za

Cellphone number: 083 559 7478

Research Supervisors

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Professor Brenda Morrow

Department of Paediatrics

Red Cross Children's Hospital

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Should you have a complaint or questions about your rights and welfare, please contact the Chair of the Human Research Ethics Committee below:

Professor Marc Blockman

Chair of Human Research Ethics Committee

021 406 6492

By signing below, I (name of parent/legal guardian)..... agree to:

Answer questions from the screening questionnaire

To be audio recorded when answering questions from the screening questionnaire

By signing below, I (name of parent/legal guardian) agree to allow my child (Name of Child) to:

Participate in the clinical feeding and swallowing assessment

Infant or child already has a feeding or swallowing problem

I (name of parent/legal guardian)..... understand that my child cannot participate in the screening questionnaire and clinical assessment because we already know that s/he has problems with eating and drinking, but I agree that you can include my child’s information from their folder to count the number of children with feeding and swallowing problems.By signing below, I agree to:

The use of my child’s diagnosis for the documentation of the prevalence of dysphagia

I declare that:

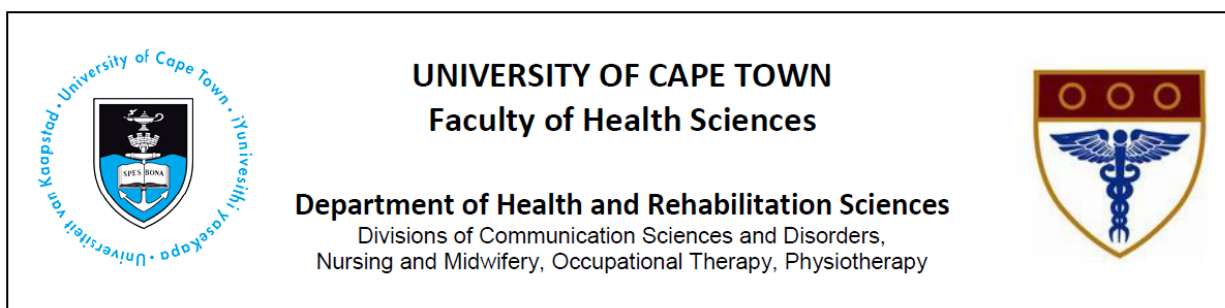
- The study has been explained to me in a language I understand
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and have not been forced to take part.
- I may choose to leave the study at any time and not have any negative consequences.
- My child’s clinical care will not be affected by taking part in this study

Signed at (*place*) on (*date*)

.....

Signature of Parent/Legal Guardian Signature of Witness

Appendix D: Participants Information and Consent Form (Afrikaans)



Deelnemer informasie en toestemmings vorm

TITEL VAN DIE ONDERSOEK: Die validasie van die vrealys vir die indentifiseering van voer en sluk probleme in die kinder populasie vanaf 0 tot 2 jaar ouderdom wat opgeneem is in die algemene mediese saal.

Die studie is goedgekeur deur die Human Research Ethics Committee van die Universiteit van Kaapstad en sal uitgevoer word volgens die etiese riglyne en beginsels van die international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research. (HREC reference number: 049/2018).

Liewe Ouer of Wettige Voog

My naam is Cynthia Sibanda en ek is 'n meesters student vanaf die Universiteit van Kaapstad. Ek is 'n spraakterapeut en ek werk met babas en kinders wie probleme met drink en/of eet het. Ek doen 'n ondersoek om te sien of die vrealys kan help met die indentifiseering van drink en eet probleme in kinders wie opgeneem is by die hospital en tussen die ouderdomme van 0 en 2 is. Die ondersoek sal bydra lewer vir my Meestersgraad in die Wetenskap in Spraak en Taal Patologie. U en u kind word uitgenooi om deel te neem in die ondersoek.

Meer informasie omtent die studie sal gegee word in die brief, vat tyd om dit te lees of iemand kan dit vir u lees. As u enige ander vrae het of 'n dieper verduidelikking wil he, vra asseblief die ondersoeker.

Wat is die doel van die studie?

Babas en kleuters wie siek is en wie al gehospitaliseer was mag dalk eet en drink probleme he. Die ondersoek sal uitgevoer word om te toets of 'n vraelys die potensiaal het om eet of drink probleme te identifiseer in babas en kleuters.

Hoekom word u kind uitgenooi om deel te neem in die studie?

U kind is gevra om deel te neem in die studie vir enige van die redes wat gelys word:

- Hy of sy was al opgeneem in die algemene kindersaal en is tussen 0 en 2 jaar oud.

Wat gebeur nadat u toestemming gee?

As u toestemming gee vir u en u kind om deel te neem in die studie gaan ons vir julle vra om die volgende te doen:

1. Die ondersoek assistent (ook 'n spraakterapeut) gaan 'n paar vrae vra met die gebruik van die vraelys, die vra handel oor hoe u kind eet en drink, en om informasie oor sy/haar gesondheid te kry vanaf die mediese lêer, byvoorbeeld borsinfeksies, medikasies. Die onderhoud sal omtrent 10-15 minute lank vat.
2. As u kind alreeds deur 'n spraakterapeut gesien word en u weet hy/sy het probleme met eet of drink, dan sal die ondersoek assistent van die informasie vanuit die kind se lêer neerskryf soos byvoorbeeld sy ouderdom, datums van hospitalisering, gewig en mediese omstandighede, sodat ons kan probeer om te verstaan hoeveel kinders onder 2 jarige ouderdom probleme het met eet en drink.
3. Die navorser sal die kliniese eet en sluk assessering doen wat omtrent 20-30 minute sal vat. Die kliniese assessering sal plaasvind net nadat u all die vrae van die vraelys geantwoord het. As die assessering nie direk daarna plaasvind nie sal dit binne die volgende 24 uur na die vraelys gedoen word. Voordat die kliniese assessering plaasvind, sal die navorser vir u vrae vra oor u kind se mediese geskiedenis en eet en drink geskiedenis; die navorser sal in u kind se mond kyk om ondersoek in te stel oor die mondelinge strukture soos die tande, die tong, verheemelte. Sy sal dan kyk hoe u kind vloeistof (melk), pap/jogurt (as dit van toepassing is)

en n koekie (as dit van toepassing is vir die kind se ouderdom) eet en drink. Die navorser sal dan notas maak oor hoe u kind die verskillende kosse sluk.

4. As dit lyk asof u kind 'n probleem daarmee het om te sluk, sal ons u kind verwys na die spraakterapeut by die hospital om verder daarmee te help. Die dokters wat u kind help sal ook in kennis gestel word oor die verwysing na die spraakterapeut. U en u kind se deelname is **heeltemal vrywillig** en u is vry om te se as u nie wil deelneem nie. As u nee se sal dit u nie negatief beïnvloed nie, dit sal ook nie die standaard van mediese sorg vir u kind beïnvloed nie. U kan ophou om deel te neem enige tyd gedurende die studie, al het u aan die begin gese dat u sal deelneem.

Sal u opgeneem word gedurende die studie?

Ja, wat u se sal opgeneem word wanneer u die vraelys beantwoord. Dit sal gedoen word sodat die navorser die informasie kan nagaan wat sy op die vorms neergeskryf het. U naam sal nie opgeneem word nie, net 'n nommer, byvoorbeeld 001 sal gebruik word in die opname. Die informasie sal veilig gehou word op 'n eksterne hardeskyf, al die informasie op die hardeskyf sal veilig gehou word deur 'n toegangskode (password). Die navorser, die navorser se assistent en die navorser se toesighouer is die enigste persone wat die toegangskode sal weet. Die eksterne hardeskyf sal net gebruik word deur die bogenoemde drie persone. Wanneer dit nie gebruik word nie, sal dit toegesluit word in a kas binne in 'n veilige kantoor.

Sal u kind baat vind daarby om deel te neem in die ondersoek?

Daar sal nie 'n direkte voordeel vir u kind wees as hulle deelneem sonder enige eet of drink probleme nie. As u kind 'n eet of sluk probleem het sal hy/sy verwys word na 'n spraakterapeut vir verdere behandeling wat n dadelikke voordeel vir u kind sal bewys.

Is daar enige risiko's betrokke as u kind deelneem in die ondersoek?

As u kind n eet of sluk probleem het, mag daar dalk 'n klein risiko wees dat hy/sy verstuk met van die kos of vloeistof wat vir hulle gegee word om te sluk. As ons dink dat die kos of vloeistof verkeerd afgaan, sal ons onmiddelik stop om vir u kind daardie kos te gee. Na dit sal daar vir u kind dikker kos gegee word byvoorbeeld joghurt, om seker te maak dat hy of sy nie enige ander eet of sluk probleme het nie.

Wie sal toegang he tot die uitslae van die studie?

Die uitslae van die ondersoek sal gepubliseer word en sal dus beskikbaar wees vir almal. Alhoewel u persoonlike informasie net aan die navorser, navorser se assistent en toesighouer bekend sal wees.

Sal u of u kind betaal word om deel te neem in die ondersoek of is daar enige kostes verbonde?

Nee, u sal nie betaal word om deel te neem aan die ondersoek nie. Daar sal geen addisionele kostes betrokke wees as u deelneem nie omdat die assessering plaas sal vind gedurende die tyd wat u kind by die hospital is.

Is daar enige iets anders wat u moet weet of doen?

- U kind se dokter sal ingelig word omtrent die feit dat u kind gaan deelneem in die studie.
- Die uitslae van die assessering sal in u kind se leer geskryf word sodat die dokter en ander gesondheidswerkers wat u kind behandel die uitslae en ander verwysings kan sien.
- Die uitslae van die ondersoek sal gepubliseer word in joernale sodat ander dokters, spraakterapeute en ander gesondheidswerkers sal weet wat ons bevind en hopelik hulle help wanneer hulle met kinders werk wat eet en sluk probleme het.
- Nie u identiteit of u kind se identiteit sal bekend gemaak word nie.
- Die Universiteit van Kaapstad sal verantwoordelik wees vir enige verliese, beserings en/of skade wat u mag opdoen gedurende die ondersoek

Vriendelike groete,

Cynthia Sibanda

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Ondersoek toesighouer

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Mag u enige klagtes of vrae oor u regte of welsyn he, kontak die Chair of the Human Research Ethics Committee hieronder:

Professor Marc Blockman

Chair of Human Research Ethics Committee

021 406 6492

Deur hieronder te teken gee ek (naam van ouer/wettige voog).....
toestemming tot die volgende:

Vrae te beantwoord vanaf die vraelys:

Om opgeneem te word tydens ek die vraelys se vrae beantwoord

Deur hieronder te teken gee ek (naam van ouer/wettige voog).....
toestemming vir my kind (naam van kind).....om deel te neem aan
die volgende:

Deelname aan die kliniese sluk en eet assessering

Ek (naam van ouer/wettige voog)..... verstaan dat my kind nie kan
deelneem aan die vraelys of kliniese assessering nie, want hy/sy het alklare probleme met eet
en drink, maar ek gee my toestemming dat my kind se informasie vanuit sy/haar lêer getel
kan word saam met die kinders wat eet en sluk probleme het. Deur hieronder te teken gee
ek toestemming tot die volgende:

Om my kind se diagnose te gebruik vir die opname van die voorkoms van eet en sluk proble

Ek verklaar dat:

- Die ondersoek verduidelik is in 'n taal wat ek verstaan.
- Ek het 'n kans gehad om vrae te vra en al my vrae is beantwoord.
- Ek verstaan dat my deelname in die ondersoek vrywillig is en ek is nie gevorseer om deel te neem nie.
- Ek mag kies om my deelname te staak sonder enige nagevolge op enige gegewe tyd gedurende die ondersoek.
- My kind se gesondheidsorg sal gladnie beïnvloed word deur sy/haar deelname in die studie nie.

Geteken by (*plek*) op (*datum*)

.....

.....

Handtekening van Ouer/Wettige voog

Handtekening van getuie

Appendix E: Participants Information and Consent Form (Setswana)



Tshedimosetso ya motsayakaroto le loromo ya go fa tetla

TITLE OF THE RESEARCH STUDY: The validation of a screening tool for the identification of feeding and swallowing difficulties in the paediatric population aged 0 - 2 years admitted to general medical wards.

This study has been approved by the Human Research Ethics Committee at University of Cape Town and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research. (HREC reference number: 049/2018).

Leina la me le Cynthia Sibanda me ke mothuti wa Masters ko Yunivesithing ya Moste Kapa. Ke dira jaka Speech Therapist, ebile ke thusa masea le bana ba ba anele bothata jwa go nwa le go ja . Ke dira dipatlisiso go bana fa sethipa sa dipotso tse di riling a di tla re thusa go supa mathata a go nwa le go jam o baneng ba dingwaga tse o go fitha go tse 2 ba leng mo bookelong. Dipatlisiso tsa di tla nthusa go bona gerata ya Masters no Speech-Language Pathology. Wena le ngwana wa gago lo balediwa go tsaya karata mo dipatlisisong tse.

Tshedimosetso mobapi le dipatlisiso tse e mo lekwalong le. O kapiwa go bala lekwalo le ka kelathloko, kgotsa o ka kopa motho mongwe go balela. O rotlesetswa go botsa mmatlisisi dipotso fa go na le sengwe se o sa se tthaloganyeng kgotsa fa e tlhoka tlhalozo ya tshedimosetso e mo lekwalong le.

Maikaelelo a dipatlisiso

Masea le bana ba lwalang ebile ba le mo bookelong ba ka nna ba nna le mathata a jo ja le a go nwa. Dipatlisiso tse di tla tlhatlhoba gore a setlhopa sa dipotso tse di rileng di tla kgona go thusa go bona go re a masea b aba lwalang ban a le mathata a go ja le go nwa.

Goreng ngwana wag ago a baleditswe go tsaya karoto?

Ngwana wa gago o baleditswe go tsaya karoto mo dipatlisisong tse ka gone: O mo bookeleng ko General ward ya bana, ebile o magareng ga dingwaga di le 0 le 2.

Go diragalang morago ga gore ke fe tetla?

Fa o tla fa tetla ya gore wena le ngwana wa gago lo tseye karoto mo dipatlisisong tse, bo tla kopiwa go dira dolo tse di latelang:

1. Mothusi wa mmatlisisi (le ene o dira jaaka Speech Therapist) o tla go botsa dipotso di le mmalwa. Dipotso tse di mabapi le mokgwa yo ngwana wag ago a jang le go nwa ka one. Go na le tshedimasetso e tla bonwang mo faeleng ya ngwana ya bookelo go leba boitekarelo jwa gagwe (seka, ditlohare tse ngwana a di nwang le gore o tshewerwe ke eng). Dipotso tse o tla di bodiwang di tla tsaya metsotso e le 10 go fitha 15.
2. Mothusi wa mmatlisisi o tla kwala tsedimoserso e e rileng go tswa faeleng ya ngwana wag ago fa e le gore o ngwana tlile a bonwa ke Speech Therapist ebile o a itse gore o na le mathata a go ja le go nwa. Tshedimosetso e e tla bonwang go tswa mo faeleng e akaretsa dingwaga tsa ngwana, letlha le ngwana a ileng bookelong ka lona, “weight” ya ngwana le bothloko gore ngwana o tshwere ke eng. Se se tla dirwa go leka go bona gore ke bana ba le ba kae ba ba motlaase ga dingwaga di le pedi baba nang le mathata a go ja le go nwa.
3. Morago ga gore o arabe dipotso, mmatlisisi o tla thlatlhola ngwana wa gago go bona gore o ja jang, o nwa jang, ebile o metsa jang. Tlhatlholo e e tla tsaya metsotso se ;e 20 go fitha go 30. Ngwana wa gago o tla tlhatlholwa ke mmatlisisi morago ga gore o arabe setlhopa sa dipotso tse di rileng. Fa se se sa kgonagale, ngwana wa gago o tla tlhatlholiwa pele diura di le 24 di fera morago ga gore o arabe dipotso. Pele ga tlhatlholo ya go bona gore ngwana wa gago o ja jang, ebile o metsa janang; mmatlisisi

o tla go botsa dipotso tse di mmalwa maleba le batekanelo jwa ngwana wa gago le mokgwa yo a ntseng a ja ka one mo dikgweding tse di fetileng. Morago ga se, mmatlisisi o tla leba mo gore ga molomo wa ngwana go leba dilo tse di tshwanang le ideme, meno, le magalapa. Morago ga go dira se, ngwana wa gago o tla fiwa lebese, motogo kgotse yogate(fe fa e le gore o tshimoletse go ja dijo) le bisikiti (se se tla dirwa fela fa e le gore ngwana o a ja). Mmatlisisi o tla nna a ntse a kwala fa ngwana a ntse a ja se se tla dirwa fela go tshalosa gore go diragalang fa ngwana a nste a ja dijo tsa mofita e e farologaneng.

4. Ngwana wa gago o tla romeliwa go Speech Therapist ya a dirang mo bookelong jo, fa le gore mmatlisisi o bona a na le mathata. Dingaka tse di okang ngwana wa gago le bone bat la itsisiwe fa e le gore ngwana w agago o na le bothata jwa go ja le go metsa.

Go tsaya karoto gag ago le ngwana wa gago go dirwa jalo ka go itharopa, ebile o lokolosegile go bua fa o sa batle go tsaya karoto. Thuso e ngwana wag a go a e bonang mo bookelong ga e kitla e amega. Le fa o sa tseye karoto mo dipatlisisong tse. Le wena ga kitla o amega ka gape. O lokolosagile go emisa go tsaya karoto fa o dumetse, mme o fetotse monagano wa gago.

A o tla rekhodiwa dipatlisisong tse?

Fa o bodiwa dipetso ke Mothusi wa mmatlisisi le mmatlisisi, dikarabo tse gago di tla rekhodiwa mo founong. Se tla dirwa gore mmatlisisi a kgone go leba gore a o bone tshedimisetso yotlhle fa a tlatsa diforomo tsa dipotso tse o tla di bodiwang. Leina la gago ga le kitla le dirisiwa mo dikarabong tse o tla di arabang; mmatlisisi o tla dirisa nomore go netefatsa gore leina la gago le tlhagelele. Tshedimisetso gotlhe go tswa mo dipatlisisang tse e tlile go bewa mo khomphutoreng mo faeleng e leng gore e tlhoka leina la sephira gore e bulwe. Leina le la sephira le tla itsiwe fela ke mmatlisisi, Mothusi wa mmatlisisi le motlhokomede wa mmatlisisi. Fa khomphuthara e e tla tshwarang tshedimisetso ya dipatlisiso se sa dirisiwe , e tla bewa sentle mo nakeng e e botlelwang.

A ngwana wa gago tla ungwelwa fa a tsaya karoto mo dipatlisisong tse?

Ngwana wag ago ga nkitla a ungwela (kgotsa go beelwa ke sepe) fa a sena mathata a go ja le go nwa. Fa ngwana wa gago a fitlhelwa a na le mathata a go ja le go metsa, o tla romelwa ga Speech Therapist go bona thuso.

A go na le kotsi fa ngwana waga tsaya karoto ma dipatlisisong tse?

Fa e le gore ngwa wa gago o na le bothata jwa go ja, go nwa, le go metsa, a ka nna a kangwa ke dijo kgotsa metsi tse a ka di fiwang ke mmatslisis fa a tlhatlhoifiwa. Fa go balelwa gore ngwana o kgongwana ke dijo, mmatlisis o tla emisa ditlhatlholo. Morago ga se ngwana o tla fiwa yoghurt (ga e le gore o semoletse go ja dijo) go netefatsa gore ga gona mathata mangwe a go ja le go metsa.

Fe mang a tla bonang tsa dipatliso?

Diphithoko tsa dipatlisiso tse di thle go kwalwa ebile mongwe le monwe o tla kgona go di bona fa a batla . Tshedimisetso ya gogo e e botlhokwa (jaaka leina la gago le ngwana) ga nkitla e itsiwe ke ope fela, ntle ga mmatlisisi, Mothusi wa mmatlisisi le motlhokomedede wa mmatlisisi.

A ngwana wa gago le wena lo tla kopiwa go patela kgotsa lo tsa patelwa?

Ga lo nkitla lo patelwa go tsaya karoto mo dipatlisisong tse. O a ithapa ga tsaya karoto. Ngwana wa gago o tla tlhatlhoikiwa fa a saintse a le mo bookelong mme go lo nkitla lo kopiwa go patela ga lo tsaya karoto.

Ke eng gape se o tlhokang go se itse kgotsa go se dira?

- Ngaka ya ngwana wa gago o tla itsesiwa gore ngwana o tsaya karoto mo dipatlisisong tse.
- Diphithlelelo tsa ditlhatlholo di tla kwalwa mo faeleng ya ngwana ya bookelo gore badiri botlhe ba ba thusang ngwana ba itse ka ditlhatlholo tse le fa e le gore ngwana a rometse gongwe go bona thuso (jaaka Speech Therapist).
- Diphithlelelo tsa dipatlisiso di thle go kwalwa mo dibakeng gore dingaka tse di thusang bana, di Speech Therapist le badiri ba bangwe ba ba thusang ban aba itse gore mmatlisis o bone eng. Se se tla ba thusa go tlhaloganya gore ba direng fa ba thusa bana ba ba nang le mathata a go ja le go metsa.
- Leina la gago le ngwana wa gago ga nkitla le tlhagelela gope, ebile ga nkitla le itsewe ke ope.

- Yunibesithi ya Motse Kapa e tsaya maikarabelo fa ngwana wa gago a ka tlhagelwa ke mathata fa a tlhatlolelwa dipatlisiso tse.

Weno

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Batlhokomedi ba mmatlisisi

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Fa o na le ditletlolo kgotsa dipotso mobapi le ditokolo tsa gago le tsa nwana, oka lelitsa Modulasetilo wa Komiti Meladlohomo ya Dipatlisiso tsa Batho. Ene ke Professor Marc Blockman mme dinomore ta gagwe tse moyala ke

021 406 6492

Nna (leina la motsadi kgotsa motlhokomedi wa nwanga) ke dumela go:

Araba setlhopa sa dipotso tse ke tla di bodiwang

Rekhodiwa mo motshining fa ke araba dipotso tse tla di botswang

Nna (leina la motsadi kgotsa motlhokomedi wa nwanga), ke fa titla ya gore wana wa me (leina la ngwana)

Tseye karoto mo dipatlisong go tthatlhabiwa gore o ja le go mesta jang

Nna (leina la motsadi kgotsa motlhokomedi wa nwanga) ke tthaloganya gore ngwana wa me ga a kgore ga tsaya karoto mo dipotsong tse di ne di tshwanetse go bodiwa, le go tthatlhabiwa go bona fore o ja jang, ebile o metsa jang. Se se dirwa ka gore re itse fa ngwana a na le bothata jwa go ja le go metsa. Mme ke a dumela gore o tseye tshedimose tse e o e tlhokang go tswa mo faeleng ya ngwana ya bookelo gore o kgone go mo balelo mo palong ya bana ba ban ang le mattha a go ja le go metsa.

Ke dumela gore:

- Ke tthaloseditswe ya dipatlisiso tse ka puo e ke tthaloganyang
- Ke filwe tshono ya go botso dipotso, ebile dipotso tse me tsotlhe di arabilwe ka mokgwa o o kgotsofatsang.
- Ke tthalogana gore ke ithaopa go tsaya karoto
- Fa ke fetola monagano ka yo tsaya karoo, ken a le tokelo ya go bua ntle le go tthalo setse ope.
- Thuso e ngwana wa me a e bonang mo bookelong ga e kitla e fetoga fa ngwana a tsaya karoto kgotsa a sa tseye karato

E saenilwe ko ka litsatsi

.....

Saena (Motswadi/Motlokomedi) Seana (mopaki)

Appendix F: Feeding and Swallowing Questionnaire (Setswana)

Dipotso mabapi le go ja le go nwa ga ngwana

Nomoro ya motsayakarolo : _____

Letlha la tsalo _____

Letlha la tlhatlhobo: _____ **Puo ya motlhokomedi:** _____

Ke tlile go go botsa dipotso tse di mmalwa ka ngwana wa gago le ka mokgwa ô a jang le go nwa ka ône.

<i>O kopiwa go araba dipotso tsotlhe, ebile o kwale fa go na le tshedimosetso ê e fetang ê e kopiwang mo foromong ê</i>				
				Ditshwaelo
<p>1. O Kopiwa o kwale fa gore ngwana wagago oja ing :</p> <p>O anya letsele fela ____ O nwa go tswa mo botloleng hela ____ O anya letsele le botlole ____</p> <p>O anya letsele ebile o ja dijo ____ O anya letsele le botlole, ebile o ja dijo ____</p> <p>O anya botlole ebile o ja dijo ____ DiNnyaa le dijo) ____ Tse dingwe: _____</p>				
2. A ngwana o na le mathata a go ja kgotsa go nwa?	E	Nnyaa		
3. A go na le bothatanyana fa wena kgotsa mongwe a jesa ngwana?	EE	NNYAA		

<p>4. A go tsaya nako ê e telele (go feta metsotso e le 30) gore ngwana a fetse go ja dijo?</p>	EE	NNYAA		
<p>5. A go lebega fa ngwana a lapa fa a ja?</p>	EE	NNYAA		
<p>6. A go lebega fa ngwana a gold sentle? A weight ya gagwe e ya ko godimo?</p>	<p>Sentle____ Ga nyenyane____ Le eseng____ Weight e ya ko tlase____</p>			
<p>7. A go lebega fa ngwana a nna le mathata a go hema fa a ja? Sekao: a o simolola go hemêla ko godimo, a o hema ka bonako kgotsa go lebega okare o palelwa ke go hema?</p>	EE	NNYAA		
<p>8. A ngwana o feta dijo tsa gagwe ka dinako tsotlhe</p>	EE	NNYAA		

(kgotsa ka dinako di le dintsi)				
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9. A go lebega fa ngwana a simolola go selekega kgotsa o a lela fa a ja kgotsa a nwa?	EE	NNYAA	N/A	
10. A ngwana o a tlhatsa fa a ja kgotsa a feta go ja?	EE	NNYAA		Fa a ntse a ja__ (Morago ga a ja__ Morago ga a nwa ditlhare/melemo__ Nako nngwe le nngwe__
11. A le ntswe la ngwana le a fetoga fa a fêtsa go ja?	EE	NNYAA	Go feta dibeke tse pedi	Ngwana abonwe ke ngaka ya nko tsebe le 'metso
12. A lentswe la ngwana ga le a tlhapa ebile okare o na le segotlholo fa o rEetsa?	EE	NNYAA		

13. A ngwana wa gago o na le go êlêla mathe?	EE Mihla yohle (Ka dinako tsotlhe)___ — Thata fa a ja kgotsa a nwa___ Fela fa a midisa; fa a tswa meNnyaa_—	NNYAA				
	Dikwedi go tswa 0 – 6	Dikwedi go tswa 6 – 12	12 + kgwedi			
14. A ngwana o nwa dinô, jaaka lebese kgotsa metsi?	EE	NNYAA	EE	NNYAA	EE	NNYAA
15. A ngwana o ja dijo tse di borethe jaaka motôgô?			EE	NNYAA	EE	NNYAA
16. A ngwana o ja dijo tsa go tshwana le borôthô kgotsa dikuku?					EE	NNYAA

17. A ngwana o nwa sentle fa a anya letsêlê kgotsa botlole?	EE	NNYAA	EE	NNYAA		
18. A ngwana o kgona go nwa go tswa mo kôping/bikiring?			EE	NNYAA	EE	NNYAA
19. A ngwana o a tsholola thata fa a ja kgotsa a nwa?	EE	NNYAA	EE	NNYAA	EE	NNYAA
20. A dijo le diNnyaa di na le go tswa ka dinko fa ngwana a ja?	EE	NNYAA	EE	NNYAA	EE	NNYAA
21. A go lebega fa ngwana a batla go tlhatsa fa a nwa?	EE	NNYAA	EE	NNYAA	EE	NNYAA
22. A go lebega fa ngwana a batla go tlhatsa fa a ja?	N/A		EE	NNYAA	EE	NNYAA

<p>23. A go na le dinako tse ngwana a lebegang okare ga a batle go go nwa metsi kgotsa lebese?</p>	<p>EE</p> <p>Mihla yohlemet na/ dinako tsotlhe) Letsatsi le letsatsi</p> <p>—</p> <p>Bekê nngwê le nngwê</p> <p>—</p> <p>Ga ngwe kgotsa ga bedi</p>	<p>NNYAA</p>	<p>EE</p> <p>Mihla yohle Lestatsi le letsatsi</p> <p>—</p> <p>Beke nngwe le nngwe</p> <p>—</p> <p>Ga ngwe kgotsa ga bedi</p> <p>—</p>	<p>NNYAA</p>	<p>EE</p> <p>Mihla yohle Lestatsi le letsatsi</p> <p>—</p> <p>Beke nngwe le nngwe</p> <p>—</p> <p>Ga ngwe kgotsa ga bedi</p> <p>—</p>	<p>NNYAA</p>
<p>24. A go na le dinako tse ngwana a lebegang okare ga a batle go ja dijo?</p>	<p>N/A</p>		<p>NNYAA</p>	<p>EE</p> <p>Mihla yohle Lestatsi le letsatsi</p> <p>—</p> <p>Beke nngwe le</p>	<p>NNYAA</p>	

					nngwe — Ga nngwe kgotsa ga bedi —	
25. A go na le dinako tse ngwana a kgwang diNnyaa (jaaka lebese) ka tsone?	EE Mihla yohle — Lestatsi le letsatsi — Beke nngwe le nngwe — Ga nngwe kgotsa ga bedi —	NNYAA	EE Mihla yohle — Lestatsi le letsatsi — Beke nngwe le nngwe — Ga nngwe kgotsa ga bedi —	NNYAA	EE Mihla yohle — Lestatsi le letsatsi — Beke nngwe le nngwe — Ga nngwe kgotsa ga bedi —	NNYAA


<p>26. A go na le dinako tse ngwana a kgwang dijo ka tsone?</p>	N/A	<p>EE</p> <p>Mihla yohle</p> <p>—</p> <p>Lestatsi le letsatsi</p> <p>—</p> <p>Beke nngwe le nngwe</p> <p>—</p> <p>Ga ngwe kgotsa ga bedi</p> <p>—</p>	NNYAA	<p>EE</p> <p>Mihla yohle</p> <p>—</p> <p>Lestatsi le letsatsi</p> <p>—</p> <p>Beke nngwe le nngwe</p> <p>—</p> <p>Ga ngwe kgotsa ga bedi</p> <p>—</p>	NNYAA
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<p>27. A ngwana o na le go gôtlhola fa a nwa?</p>	EE	NNYAA	EE	NNYAA	EE	NNYAA
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<p>28. A ngwana o na le go gôtlhola fa a ja?</p>		EE	NNYA A	EE	NNYAA
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29. A ngwana o na le go kgangwa/kgamiwa (balêlwa) ke diNnyaa?	EE	NNYAA	EE	NNYA A	EE	NNYAA
30. A ngwana o na le go kgangwa/kgamiwa (balêlwa) ke dijo?			EE	NNYA A	EE	NNYAA

Romela ngwana go Speech Therapist gore a mo tthatlhobe go bona gore o ja le go nwa jang fa o bona:

Dikarabo tsotlhe tse di mmala ô 

Fa dikarabo tsê pedi kgotsa go feta di le mmala ô 

O kopiwa go tshwaya dikarabo tsa gago:

O falotse  Ga a falola 

Additional comments:

Appendix G: Feeding and Swallowing Questionnaire (Afrikaans)

Deelnemer nommer: _____ Geboortedatum: _____

Datum van aanslag: _____ Primêre taal van versorger: _____

Ek gaan vir U vrae oor hoe u baba/kind drink en eet vra. Indien dit lyk asof daar probleme is, sal ek hom/haar na 'n spraakterapeut vir 'n deeglike evaluasie stuur.)

Voltooi al die afdelings and dui aan die antwoorde duidelik met kommentaar indien nodig				
				Kommentaar
1. Dui asseblief aan watter tipe voedings XXX elke dag eet: Slegs borsvoeding _____ Slegs bottelvoeding _____ Borsvoeding and bottelvoeding _____ Borsvoeding en vastekos _____ Borsvoeding, bottelvoeding en vastekos _____ Borsvoeding en vastekos _____ Vloeistowwe en vastekos _____ Ander: _____				
2. Het XXX enige problem met eet of drink?	JA	NEE		
3. Is dit moeilik vir jou of enigiemand anders om XXX te voed?	JA	NEE		
4. Neem dit langer as 30 minute vir XXX om klaar te eet of voed?	JA	NEE		
5. Word XXX moeg as hy/sy drink of eet?	JA	NEE		
6. Tel XXX gewig op?	Goed <input type="checkbox"/> Stadig <input type="checkbox"/> Glad nie <input type="checkbox"/> Verloor gewig <input type="checkbox"/>			Indien objektiewe bewyse vir gewigswelies of sentiele te kruis (RTHCC)
7. Het XXX probleme met asemhaling tydens of na voedings? Byvoorbeeld, word die asemhaling vinniger, raserig, of moeilik?	JA	NEE		

8. Maak XXX sy/haar voedings meeste van die tyd klaar?	JA	NEE				
9. Word XXX onsteld of knieserig (bv huil, draai gesig weg) tydens voeding?	JA	NEE	N/A			
10. Gooi XXX op met voedings?	JA	NEE		Tydens voer <input type="checkbox"/> Na voer <input type="checkbox"/> Na medikasie <input type="checkbox"/> Enige tyd <input type="checkbox"/>		
11. Is XXX se stem hees of het dit verander?	JA	NEE	>2 weeks	Verwys ONK		
12. Klink XXX se stem nat nadat hy/sy gedrink het?	JA	NEE				
13. Kwyl XXX?	JA Alyda _____ Meer _____ tydens die eet / drink _____ Slegs as u tande kry _____	NEE				
	0 – 6 maande		6 – 12 maande		12 + maande	
14. Drink XXX vloeistowwe soos melk en water?	JA	NEE	JA	NEE	JA	NEE
15. Eet XXX semi-vaste kos soos graan?			JA	NEE	JA	NEE
16. Eet XXX vastekos soos brood of beskuitjies?					JA	NEE
17. Drink XXX goed aan die bors of uit 'n bottel uit?	JA	NEE	JA	NEE		
18. Kan XXX uit 'n koppie uit drink?			JA	NEE	JA	NEE
19. Mors XXX baie kos uit sy/haar mond uit tydens voeding?	JA	NEE	JA	NEE	JA	NEE

20. Kom vloei-stowwe of kos ooit uit XXX se neus uit terwyl hy/sy drink?	JA	NEE	JA	NEE	JA	NEE
21. Word XXX ooit naar (wil hy braak – demonstreer) met vloei-stowwe?	JA	NEE	JA	NEE	JA	NEE
22. Word XXX ooit naar (wil hy braak – demonstreer) met vastekos?	N/A		JA	NEE	JA	NEE
23. Weier XXX om vloei-stowwe soos melk en water te drink?	JA Altyd ____ Daaglikse ____ Weeklikse ____ Een of twee keer ____	NEE	JA Altyd ____ Daaglikse ____ Weeklikse ____ Een of twee keer ____	NEE	JA Altyd ____ Daaglikse ____ Weeklikse ____ Een of twee keer ____	NEE
24. Weier XXX om vastekos te eet?	N/A		JA Altyd ____ Daaglikse ____ Weeklikse ____ Een of twee keer ____	NEE	JA Altyd ____ Daaglikse ____ Weeklikse ____ Een of twee keer ____	NEE
25. Spoeg XXX vloei-stowwe soos melk uit?	JA Altyd ____ Daaglikse ____ Weeklikse ____ Een of twee keer ____	NEE	JA Altyd ____ Daaglikse ____ Weeklikse ____ Een of twee keer ____	NEE	JA Altyd ____ Daaglikse ____ Weeklikse ____ Een of twee keer ____	NEE

26. Spoeg vastekos uit?	XXX	N/A		JA Altyd Daaglikse Weeklikse ____ Een of twee keer ____	NEE	JA Altyd Daaglikse Weeklikse ____ Een of twee keer ____	NEE
27. Hoes XXX terwyl hy/sy drink?		JA	NEE	JA	NEE	JA	NEE
28. Hoes XXX terwyl hy/sy eet?				JA	NEE	JA	NEE
29. Verstik XXX wanneer hy/sy drink?	XXX	JA	NEE	JA	NEE	JA	NEE
30. Verstik XXX wanneer hy/sy eet?	XXX			JA	NEE	JA	NEE

Verwysing kriteria na SLT vir kliniese voeding en slukassessering:

Enige reaksie geskakeer



Meer as een reaksie is geskakeer



Merk asseblief:

Slaag



Misluk



Bykomende kommentaar:



UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee



Room E52-24 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone (021) 404 7682
Email: nositsama@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

10 April 2018

HREC REF: 049/2018

Ms V Norman
Communication Sciences & Disorders
Health & Rehab Sciences
F45, Old Main Building

Dear Ms Norman

PROJECT TITLE: THE VALIDATION OF A SCREENING TOOL FOR THE IDENTIFICATION OF FEEDING AND SWALLOWING DIFFICULTIES IN THE PAEDIATRIC POPULATION AGED 0-2 YEARS ADMITTED TO GENERAL MEDICAL WARDS (MSc-CANDIDATE-C Sibanda)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 April 2019.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the following student will be involved in this study: Ms Cynthia Sibanda.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate Institutional approval before the research may occur.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Yours sincerely

signature removed to avoid exposure online
PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637
Institutional Review Board (IRB) number: IRB00001938

Appendix I: Letter of approval from Steve Biko Academic Hospital

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

TO:
The [CEO] Chief Executive Officer of Steve Biko Hospital

Re: Permission to do research at Steve Biko Hospital

TITLE OF STUDY: The validation of a screening tool for the identification of feeding and swallowing difficulties in the paediatric population aged 0 - 2years admitted to general medical wards

This study is approved by the relevant Head of Department [HOD]: ...[Print Name and Surname] Signature.....

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

I am a lecturer at the Department of Health and Rehabilitation Sciences (Division of Communication Sciences) at the University of Cape Town. I am supervising Ms Cynthia Sibanda's masters research. Ms Aletta Ntlatleng (research assistant) and Ms Dimakatso Dikgweli (research assistant) are assisting Ms Sibanda as research assistants. I herewith request permission on behalf of all of us to conduct a study on the above topic on the hospital / clinic grounds.

This study involves clinical research – please see the attached proposal for details.
We intend to publish the findings of the study in a professional journal and/ or to present them at professional meetings like symposia, congresses, or other meetings of such a nature.

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

We undertake not to proceed with the study until we have received approval from the hospital. The study has already received ethics approval from the University of Cape Town Faculty of Health Sciences' Human Research Ethics Committee (HREC reference number 049/2018 – see attached).

Yours sincerely

Print Name: Vivienne Norman
Principal Investigator

Signature signature removed to avoid exposure online

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

Title and name of Chief Executive Officer: Dr S Mangwana

Name of hospital / clinic: Steve Biko Academic Hospital

signature removed to avoid

Signature: exposure online

Date: 2018/07/17

