A Profile of a Paediatric Population with Feeding and Swallowing Difficulties at a Tertiary Hospital in the Western Cape

By *Ms* ***Nicolene Oosthuizen***

Student number: OSTNIC 002

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MSc. in Speech-Language Pathology

Faculty of Health Sciences

University of Cape Town

Supervisors:

Ms Vivienne Norman

A/Prof Shajila Singh

University of Cape Town

Division of Communication Sciences and Disorders

School of Health and Rehabilitation Sciences

F45 Old Main Building

Groote Schuur Hospital

Observatory

7925

Declaration

I, *Nicolene Oosthuizen*, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and have used the American Psychological Association, 6th edition (2010) system of referencing. I declare that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Abstract

Background: Feeding and/or swallowing difficulties (FSD) have been associated with some of the leading causes of infant and child mortality in South Africa. Preventable conditions such as lower respiratory tract infections (LRTI) and under-nutrition may be caused by FSD. FSD are frequently reported in paediatric populations and may occur with various medical co-morbidities. The nature of FSD is however under described and information specific to developing countries is scarce. Furthermore, limited information regarding the service delivery requirements of the paediatric population with FSD is available.

Research Aims: To describe in a paediatric population: the nature and frequency of FSD, the nature of FSD in different medical conditions or participant characteristics, and the nature of the services and interventions received by infants and children with FSD.

Method: A descriptive, retrospective survey design was used to examine the medical records of 446 infants and children aged less than 13 years who accessed services for FSD at a paediatric tertiary hospital from January 2007 to December 2009. Seventy percent of participants were under the age of 2 years at the time of first assessment. The nature of participants' FSD, the medical conditions present, and services/interventions received were recorded. The data were described and associations were analysed statistically.

Results: Participants presented with difficulties in all phases of swallowing, with poor oral skills reported most frequently. Infants and children with FSD often presented with various medical co-morbidities affecting multiple organ systems with neurologic and gastro-intestinal tract conditions occurring most frequently. A third (34%) of the participants had confirmed aspiration on instrumental assessment. Participants with confirmed aspiration presented with statistically significantly more aspiration pneumonia (x^2 = 26.4314, p < .001) and unspecified LRTI (x^2 = 21.2757, p < .001) than those without aspiration. Participants required a range of services for FSD from Speech-Language Therapists (SLT) as well as medical intervention, and surgical procedures. Most participants (91%) received intervention for FSD for an average of 6 months with a mean of 6 SLT consultations. Forty-three percent of participants completed intervention while 20% continued to receive intervention.

Conclusions: The present study profiled paediatric FSD in the Western Cape, South Africa. Infants and children with FSD presented with varied and multiple underlying medical conditions. The safety of swallowing was often (34%) compromised in this population which may have affected respiratory health negatively. Infants and children with FSD frequently presented with LRTI and growth faltering/under-nutrition, two of the leading causes of death in children under the age of 5 years. There is a need for dysphagia services at primary and district levels of health care in the Western Cape to detect and prevent paediatric FSD. While the management of FSD requires the collaboration of many health care professionals, the inclusion of SLTs and dieticians into primary and district level teams may assist with the identification of FSD for early intervention and may prevent FSD-related LRTI and under-nutrition in infants and children with FSD.

Author's Note

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Referencing Style:

The present dissertation has utilized the referencing style as per the American Psychological Association, 6th edition (2010).

Glossary – Selected Terms

Aspiration:

The entry of food particles, liquid or secretions below the level of the true vocal folds which may occur before, during or after swallowing (Arvedson & Brodsky, 2002; Giambra & Meinzen-Derr, 2010; Hall, 2001).

Dysphagia:

Dysfunction in one or more of the phases of swallowing (Arvedson, 2008).

Feeding:

May be regarded as an umbrella term including the child's capacity/skill set to feed, emotional and physiological state as well as the mealtime environment. This includes the consumption of food as well as any external stimuli within the mealtime environment affecting the intake of food. Examples may include appetite, sucking, chewing, and swallowing along with meal preparation, the anticipation of the meal, and the feeder's interaction with the child (Arvedson & Brodsky, 2002; Rudolph & Link, 2002; Winstock, 2006).

Feeding difficulties:

Difficulties such as food refusal and selectivity, disruptive mealtimes, developmentally delayed self-feeding skills, and dysfunctional swallowing (Arvedson, 2008; Arvedson & Brodsky, 2002). These difficulties are not mutually exclusive (Arvedson, 2008). Examples of general signs of feeding difficulties include: prolonged feeding times (>30 minutes), decreased endurance/fatigue, or crying with feeds.

Gastro-oesophageal reflux (GOR):

Backflow of the acidic contents of the stomach into the oesophagus which is commonly associated with feeding difficulties (Hall, 2001; Rommel, De Meyer, Feenstra, & Veereman-Wauters, 2003).

Odynophagia:

Painful or uncomfortable sensation experienced during the act of swallowing (Arvedson & Brodsky, 2002; Hall, 2001).

Prematurity:

Birth at a gestational age of 37 weeks or less is considered premature; birth at a gestational age of 38 weeks or more is considered as term (Hall, 2001).

Swallowing:

The movement of food or secretions from the oral cavity into the stomach (Hall, 2001). The four phases of swallowing are: oral preparatory, oral, pharyngeal, and oesophageal (Arvedson & Brodsky, 2002; Groher, 1997;

Hall, 2001; Rodgers & Arvedson, 2005; Winstock, 2006). The function of swallowing is to achieve adequate nutrition, hydration, and protection of the airway (Arvedson & Brodsky, 2002).

1. Oral Preparatory Phase: the voluntary intake of food followed by oral manipulation in order to form a manageable bolus for later posterior propulsion (Arvedson & Brodsky, 2002). The length of this phase varies according to the viscosity of the bolus. The oral preparatory phase is limited in young infants to latching, achieving a lip seal, grooving, and elevating the tongue to hold the liquid bolus to the hard palate (Arvedson & Brodsky, 2002). In older infants and children this phase includes chewing of solid food and bolus formation, involving the lateral movement of the tongue to collect the bolus medially and holding it whilst forming a seal against the alveolar ridge (Arvedson & Brodsky, 2002).

2. Oral Phase: the posterior propulsion of the bolus into the pharynx. Negative pressure in the oral cavity created by the inward movement of the buccal muscles (Logemann, 1998) and the posterior movement of the tongue whilst maintaining the palatal seal, transports the bolus until the pharyngeal swallow is initiated. This propulsion is still under voluntary control (Arvedson & Brodsky, 2002).

3.a. Pharyngeal Phase Initiation: the pharyngeal swallow may be initiated as the bolus reaches any of the following points: the anterior tonsillar pillars, base of tongue or valleculae (Arvedson, 2007).

3.b. Pharyngeal Phase: Following the initiation of the swallow, a sequence of actions can be observed: velopharyngeal closure; elevation and anterior movement of the hyoid and larynx; laryngeal closure and protection of the airway; opening of the upper oesophageal sphincter; and propulsion of the bolus into the oesophagus through base of tongue retraction and pharyngeal wall contraction (Arvedson & Brodsky, 2002; Groher, 1997).

4. Oesophageal Phase: begins with the head of the bolus moving through the upper oesophageal sphincter (Arvedson & Brodsky, 2002). The bolus is then transported through a series of peristaltic movements within the oesophagus until it enters the stomach via the lower oesophageal sphincter (Arvedson & Brodsky, 2002).

Abbreviations

AVSD	atrioventricular septal defect
CHD	congenital heart disease
CLD	chronic lung disease
CNS	central nervous system
CP	cerebral palsy
d-TGA	d-transposition of great arteries
EGID	eosinopilic gastrointestinal disease
ENT	ear nose and throat
FSD	feeding and/or swallowing difficulties
GA	gestational age
GIT	gastro-intestinal tract
GOR/D	gastro-oesophageal reflux/disease
LBW	low birth weight
LRTI	lower respiratory tract infections
MBS	modified barium swallow
NPO	nil per oral
PHC	primary health care
RDS	respiratory distress syndrome
RSV	respiratory syncytal virus
SA	South Africa
SD	standard deviation
SLT	speech-language therapist
TB	tuberculosis
TBI	traumatic brain injury
PEG	percutaneous endoscopic gastrostomy
UAO	upper airway obstruction
UOS	upper oesophageal sphincter
VFSS	videofluoroscopic swallow study

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1. Introduction

Preventable conditions such as HIV/AIDS, lower respiratory tract infections and under-nutrition are some of the leading causes of up to 8 million infant and child deaths globally (Ki-Moon, 2010), with developing countries such as South Africa most vulnerable (Groenewald et al., 2003; United Nations, 2010; World Health Organization, 2010a). To address the global impact of preventable conditions, the United Nations established a set of measurable targets, the Millennium Developmental Goals, at the United Nations Millennium Summit (UN, 2000). As a UN member state, South Africa committed to reducing the country's high infant and child mortality rates in order to attain one of the Millennium Developmental Goals (South Africa & UNDP, 2010). Even though South Africa has implemented a number of national health policies aimed at reducing the mortality rates of infants and children by 2015, social, health, and economic challenges led to an increase in child mortality from 1998 to 2008 (South Africa & UNDP, 2010). The impact of preventable morbidities, such as HIV/AIDS, lower respiratory tract infections (LRTI), and under-nutrition, on infant and child mortality rates in South Africa is high (South African Department of Health, 2007). Even though feeding and/or swallowing difficulties (FSD) are associated with a range of preventable respiratory morbidities (Baudon et al., 2009; Kirsch & Sanders, 1988; Lodha, Puranik, Natchu, & Kabra, 2002; Loughlin, 1989; Mizuno & Ueda, 2005; Owayed, Campbell, & Wang, 2000; Weir et al., 2007) and under-nutrition (Arvedson, Brodsky & Claxton, 2002), there is only limited information available regarding the nature of FSD. The possible impact of FSD on infant and child mortality rates in South Africa and globally is unknown.

FSD may lead to insufficient airway protection and the resulting aspiration has been associated with life threatening respiratory sequelae in some instances (Arvedson & Brodsky, 2002). Aspiration-related respiratory sequelae reported in the literature include: chronic lung disease (Loughlin, 1989), recurrent pneumonia (Arvedson & Brodsky, 2002; Kirsch & Sanders, 1988; Lodha et al., 2002; Owayed et al., 2000; Weir et al., 2007), pulmonary oedema, necrotizing infections, empyema (Kirsch & Sanders, 1988), bronchiectasis, granuloma formation or stenosis within the respiratory tract (Arvedson & Brodsky, 2002). Some studies have reported fatalities directly related to aspiration-events (Baudon et al., 2009; Mizuno & Ueda, 2005). Literature also suggests that aspiration may be the underlying cause in

infants and children presenting with respiratory symptoms with an unspecified cause (Bossley, Hogg, Stoneham, Jacques, & Bush, 2010; Lefton-Greif, Carroll, & Loughlin, 2006). The early identification and management of aspiration in infants and children may resolve respiratory symptoms (Sheikh et al., 2001), prevent further pulmonary morbidities (Khooshoo, Ross, Kelly, Edell & Brown, 2001) and reduce associated hospitalizations (MacIntyre, McIntyre & Cagney, 2003). In South Africa where LRTIs are among the leading causes of infant and child mortality (Groenewald et al., 2003), there is a need for the development and implementation of strategies to address the impact of aspiration early and effectively in infants and children with FSD.

The presence of FSD may also impede adequate nutritional intake in infants and children (Arvedson, Brodsky & Claxton, 2002; Biniwale & Ehrenkranz, 2006). The prevalence of under nourished infants and children in South Africa is high and has increased from 9.3% (1994) to 10.2% (2005) (South Africa & UNDP, 2010). Although this high prevalence rate is suggested to relate directly to the high ratio of economically disadvantaged families within South Africa (South Africa & UNDP, 2010), one UK survey study concluded that the impact of economic/demographic features on under-nutrition may be over stated (Wright & Birks, 2000). Wright and Birks (2000) found that under nourished infants and children presented with similar economic/demographic features when compared to matched controls with age appropriate weight gain. For example, the caregivers in both groups presented with comparable frequencies of unemployment where families did not own a house/car. The infants and children with under-nutrition however presented with significantly more reported FSD (Wright & Birks, 2000), suggesting that FSD in infants and children in developing nations may contribute largely to the prevalence of under-nutrition. While the prevalence rates of under-nutrition and poverty in the UK cannot be compared to that of South Africa, the findings of Wright and Birks (2000) suggest that the contribution of FSD to the high prevalence of under-nutrition in SA needs to be investigated. Other sources have indicated that the early identification and management of FSD effectively reduces the presence of under-nutrition (not related to the unavailability of food sources) in infants and children (Arvedson, Brodsky & Claxton, 2002; Craig et al., 2006; Townsend, Craig, Lawson, Reilly & Spitz, 2008).

Prevalence rates for FSD are commonly reported to be between 25 - 45% in normally developing children (Arvedson, 2008; Arvedson & Brodsky, 2002; Bentovim, 1970; Burklow, Phelps, Schultz,

McConnell, & Rudolph, 1998; Lefton-Greif & Arvedson, 2007; Lincheid, Budd, & Rasnake, 2003; Manikam & Perman, 2000; O'Brien, Repp, Williams, & Christophersen, 1991). There is some uncertainty as to the reliability of this prevalence information, as many studies utilized secondary referencing which has been traced back to five decades ago (Sears, Maccoby & Levin, 1957). The incidence of dysphagia specifically, is reportedly unknown (Lefton-Greif & Arvedson, 2007). Furthermore, there seems to be no epidemiological studies on the incidence or prevalence of paediatric FSD. Limited prevalence information for FSD is available in populations with specific medical conditions and varies greatly among different conditions. The reported prevalence of FSD varies from 21% in participants with HIV (Pressman, 1992) to 75% in infants with a history of prematurity or low birth weight (Howe, Hsu, & Tsai, 2010) and up to 99% in those with severe cerebral palsy or intellectual disability (Calis et al., 2008). Even though the prevalence and incidence of paediatric FSD in South Africa is unknown, factors relating to the county's developing status such as poverty, inadequate access to healthcare and education as well as the high burden of disease (South Africa & UNDP, 2010) may predispose the country to higher prevalence rates for FSD. The global incidence of prematurity was recently established at 10% in 2005, with the highest rate of premature births identified in Southern Africa at 18% (Beck et al., 2010). The high rate of prematurity and associated morbidities in South Africa (Beck et al., 2010) may also contribute to the prevalence rates for FSD.

Research on paediatric FSD is limited, specifically within the context of a developing country (Barrat & Ogle, 2010; Cooke et al., 2009; Lodha et al., 2002; Norman, Louw, & Kritzinger, 2007). There are very few comparative studies among the existing research on paediatric FSD. Studies make use of diverse study samples and usually focused on only one type of medical condition associated with FSD (Fung et al., 2002; Limperopoulos et al., 1999; Ng, McCarthy, Tarby, & Bodensteiner, 2004; Sullivan et al., 2000). Studies also utilize a variety of different or unspecified methods of data collection (Barkat-Masih et al., 2010; Calis et al., 2008; Duca, Dantas, Rodrigues, & Sawamura, 2008; Masarei et al., 2007; Reilly et al., 1996; Sullivan et al., 2000) where the conflicting terminology in others creates further challenges when comparing results (Fung et al., 2002; Howe et al., 2010). These methodological differences limit the number of studies available for the comparison of the nature of FSD in different populations. While classification systems for the universal description of FSD have been suggested as a

solution (Field, Garland, & Williams, 2003; Rommel et al., 2003), no specific classification system has been widely accepted.

Attempts to categorize FSD have evolved from simple dichotomies to more complex biopsychosocial classification systems. The classification system regarding FSD as organic or non-organic has been deemed inadequate due to its' rigidity and over simplification (Bithoney et al., 1989; Budd et al., 1992; Burklow et al., 1998; Ramsay, Gisel, & Boutry, 1993; Wittenberg, 1990). Other classification attempts which rely solely on medical categories to describe difficulties with feeding and/or swallowing (Kosko, Moser, Erhart, & Tunkel, 1998) offer no explanation for the population of children without medical conditions underlying their FSD (Lefton-Greif et al., 2006; Sheikh et al., 2001). Behaviour based classifications fail to consider physiological causes for swallowing difficulties (or dysphagia) as the focus is more on feeding behaviours (for example food refusal, aversion or selectivity) and mealtime environments (Bryant-Waugh, Markham, Kreipe, & Walsh, 2010). Burklow et al. (1998) attempted a description of FSD which included behavioural along with structural, neurologic, cardiopulmonary, and metabolic categories. This description allowed for overlap between categories, but offered no category for children with gastro-oesophageal conditions. Rommel et al. (2003) attempted to divide FSD into categories guided by etiologies and the labels "medical, behavioural and oral" were suggested. These labels may however lead to confusion as pharyngeal difficulties were grouped under *Oral*.

A classification system that does not include the physiology of FSD may be unclear, misleading and oversimplify a complex disorder. Research has also clearly indicated the presence of co-morbidities underlying difficulties with feeding and/or swallowing (Burklow et al., 1998; Field et al., 2003; Rommel et al., 2003; Weir et al., 2007) and many classification systems struggle to adapt to the need for non-mutually exclusive categories. Such a classification system is further in danger of losing descriptions aimed at guiding intervention. These dangers may be overcome when the clinician or researcher utilizes a descriptive method based on the physiology of the feeding and/or swallowing process whilst still acknowledging the impact of underlying medical conditions.

Although a wide variety of medical conditions have been associated with FSD, the nature of the difficulties within the different medical conditions is under described. The nature of FSD in different medical conditions reported in the literature is summarized in Table 1, where the *FSD/Dysphagia*

undefined-columns represent studies where only the presence of FSD or dysphagia was mentioned without describing its' characteristics. The medical conditions affecting the following systems are often associated with FSD: gastrointestinal tract (GIT), neurologic, cardiac, and respiratory, as well as genetic conditions/syndromes, developmental delays, and craniofacial abnormalities (Arvedson, 2008; Arvedson & Brodsky, 2002; Barkat-Masih, Saha, Hamby, Ofner, & Golomb, 2010; Baudon et al., 2009; Bauer & Lyrene, 1999; Burklow et al., 1998; Calis et al., 2008; Clemente, Barnes, Shinebourne, & Stein, 2001; Cooper-Brown et al., 2008; Duca, Dantas, Rodrigues, & Sawamura, 2008; Einarson & Arthur, 2003; Eischer et al., 2000; Field et al., 2003; Fung et al., 2002; Hall, 2001; Hawdon, Beauregard, Slatetry, & Kennedy, 2000; Hernandez, Khoshoo, Thoppil, Edell, & Ross, 2002; Howe et al., 2010; Khoshoo & Edell, 1999; Leder, Baker, & Goodman, 2010; Lee, Beattie, Meadows, & Walker-Smith, 1999; Limperopoulos et al., 1999; Mathisen, Worral, Masel, Wall, & Shepherd, 1999; Melvin, Wright, & Goddard, 1997; Midulla et al., 2004; Nelson, Chen, Syniar, & Christoffel, 2000; Reilly, Skuse, & Plobete, 1996; Rommel et al., 2003; Sachdeva et al., 2007; Schädler, Süss-Burghart, Toschke, Von Voss, & Von Kries, 2007; Sheikh et al., 2001; Sullivan et al., 2000; Truong et al., 2007; Winstock, 2006).

Sub-Saharan Africa has the highest prevalence of HIV/AIDS globally (UNAIDS, 2010a, 2010b) and in 2009 South Africa had the 4th highest percentage of people living with HIV/AIDS (UNAIDS, 2010b). HIV/AIDS is the leading cause death in children under the age of 5 years in South Africa (WHO, 2010a) where the South African mortality rate for children in this age bracket has increased since the 1990's (South Africa & UNDP, 2010; WHO, 2010a) and has been recorded as up to 35% (WHO, 2011). Even though the worldwide prevalence of HIV/AIDS is high (UN, 2010; UNAIDS, 2010a, 2010b; WHO, 2010a), little research has been published about its' effects on paediatric feeding and swallowing (Pressman, 1992). The prevalence of FSD in infants and children with HIV/AIDS has been reported to range from 21% (Pressman, 1992) to 50% (Melvin et al., 1997), where difficulties were found in all of the phases of swallowing (Table 1). The nature of FSD in this South African population is under described and requires further investigation in order to identify populations at risk for FSD in the South African context for early identification and effective management. Table 1 also provides an over view of the different studies' country of origin, methods utilized, along with sample sizes in order to illustrate methodological differences and to allow for easier comparisons.

Table 1

The Nature of FSD in Different Medical Conditions as Described in Current Literature

Area / Medical Condition	Diagnoses/Description	Study	Signs of Feeding and/or Swallowing Difficulties [a]																						Country	N	Age range [b]	Methodology
			FSD undefined	Dysphagia undefined	Oral preparatory phase difficulties	Oral motor difficulties	Sucking difficulties	Poor lip closure	Abnormal lingual movement	Abnormal jaw movement	Oral sensory difficulties	Food refusal	Food selectivity	Oral phase difficulties	Pharyngeal phase difficulties	Nasopharyngeal backflow	Laryngeal penetration	Aspiration	Coughing with swallowing	Silent Aspiration	Desaturation during feeding	Choking	Oesophageal phase difficulties	Odynophagia				
Prematurity	Gestational age <37 weeks	Burklow et al. (1998)	X																						USA	103	4 m to 17 yrs	Retrospective record review
	-	Field et al. (2003)	X																						USA	349	1 m to 12 yrs	Retrospective record review
	Gestational age <37 weeks	Hawdon et al. (2000)					X																		UK	35	1 to 291 days	Prospective study in neonates
	Birth weight < 2500 g	Howe et al. (2010)	X																						Taiwan	2118	< 5 yrs	Retrospective cross-sectional study
	Gestational age <38 weeks	Reilly et al. (1996)	X																						UK	49	1 to 6 yrs	Parent survey and clinical Ax
	Gestational age <38 weeks	Rommel et al. (2003)																X							Belgium	700	< 10 yrs	Prospective study. Participants referred for feeding Ax
	Gestational age <37 weeks	Schadler et al. (2007)	X																						Germany	86	< 10 yrs	Case series
Neurologic	CP	Fung et al. (2002)		X																					USA & Canada	230	2 to 18 yrs	Parent interviews (feeding history) and clinical Ax
	CP	Reilly et al. (1996)		X		X	X																		UK	49	1 to 6 yrs	Parent survey and clinical Ax
	CP	Schadler et al. (2007)	X																						Germany	86	< 10 yrs	Case series
	CP (96%)	Sullivan et al. (2000)	X																						UK	343	4 to 13 yrs	Parent survey to participants with FSD
	Neonatal arterial ischemic stroke and/or CP	Barkat-Masih et al. (2010)	X			X												X							USA	84	< 17.9 yrs	Retrospective record review
	CP, TBI	Barratt & Ogle (2010)	X																						South Africa	100	2m to 14 yrs	Retrospective record review
	CP, sezures, others	Bauer & Lyrene (1999)																X							USA	113	< 15 yrs	Retrospective record review
	CP, PDD, CNS insults, muscular dystrophy	Burklow et al. (1998)	X																						USA	103	4 m to 17 yrs	Retrospective record review
	Severe CP and ID	Calis et al. (2008)			X										X										Netherlands	166	2 to 19 yrs	Longitudinal study with parent survey and clinical Ax
	CP, TBI, seizures, brain anomalies	Field et al. (2003)		X		X						X	X												USA	349	1 m to 12 yrs	Retrospective record review
	CP, neuromuscular disorder	Hawdon et al. (2000)					X																		UK	35	1 to 291 days	Prospective study in neonates
	Brain tumor	Bossley et al. (2010)													X										UK	1	13 yrs	Case study
	Agenesis of corpus callosum	Ng et al. (2004)		X			X				X			X											USA	7	1.2 to 6.1 yrs	Retrospective record review
	-	Rommel et al. (2003)				X																			Belgium	700	< 10 yrs	Prospective study. Participants referred for feeding Ax
Gastro-Intestinal Tract	GOR	Bauer & Lyrene (1999)																X							USA	113	< 15 yrs	Retrospective record review
	GOR	Field et al. (2003)		X		X						X	X												USA	349	1 m to 12 yrs	Retrospective record review
	GOR/D	Lee et al. (1999)	X																						UK	69	< 14 yrs	Retrospective record review
	GORD	Mathisen et al. (1999)			X			X	X	X	X	X		X	X					X	X	X	X		Australia	(20)40	5 to 7 m	Prospective study with control group. Clinical & Instrumental Ax
	GOR	Nelson et al. (2000)																						X	USA	1765	3 to 17 yrs	Cross-sectional survey in children and parents

Area / Medical Condition	Diagnoses/Description	Study	Signs of Feeding and/or Swallowing Difficulties [a]																						Country	N	Age range [b]	Methodology
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GIT (continued)	GOR or EE	Duca et al. (2008)	X									X					X					X			Brazil	(37)52	7 to 37 m	Prospective study with control group. Clinical & Instrumental Ax
	GOR, Food allergy, mucosal & anatomic abnormalities	Rommel et al. (2003)	X																						Belgium	700	< 10 yrs	Prospective study. Participants referred for feeding Ax
	EGID	Mukkada et al. (2010)	X	X							X	X													USA	200	14 m to 9.4 yrs	Retrospective record review
	-	Schadler et al. (2007)	X																						Germany	86	< 10 yrs	Case series
HIV/AIDS	HIV/AIDS, GIT conditions	Cooke et al. (2009)		X																			X	X	South Africa	26	< 12.5 yrs	Retrospective record review
	HIV/AIDS, GIT conditions and neurologic involvement	Pressman (1992)			X									X	X				X						USA	96	4 m to 17.3 yrs	Retrospective review of patients clinically managed
	-	Melvin et al. (1997)	X									X	X												UK	42	< 5 yrs	Prospective study with clinical Ax & parent interview
Cardio-pulmonary	BPD & congenital heart disease	Field et al. (2003)		X		X						X	X												USA	349	1 m to 12 yrs	Retrospective record review
	-	Burklow et al. (1998)	X																						USA	103	4 m to 17 yrs	Retrospective record review
Cardiovascular	CHD	Clemente et al. (2001)																			X	X			UK	151	< 20.4 m	Prospective, parent questionnaire
	CHD	Limperopoulos et al. (1999)	X				X																		Canada	56	neonates	Prospective study
	HLHS, d-TGA	Davis et al. (2008)	X																						US	53		Retrospective record review
	CHD, vocal fold dysfunction following surgery	Einarson & Arthur (2003)	X																						Canada	101	< 25 days	Retrospective record review
	-	Rommel et al. (2003)									X														Belgium	700	< 10 yrs	Prospective study. Participants referred for feeding Ax
	Vocal fold paralysis following cardiac surgery	Sachdeva et al. (2007)													X		X	X							USA	38	< 18 yrs	Retrospective record review
	-	Schadler et al. (2007)	X																						Germany	86	< 10 yrs	Case series
	Clinical sign of heart failure	Westerlind et al. (2004)	X																						Sweden	26	3 m to 16 yrs	Prospective study
Respiratory	CLD, RDS	Hawdon et al. (2000)					X																		UK	35	1 to 291 days	Prospective study in neonates
	CLD, tracheostomy, ventilation	Leder et al. (2010)					X																		USA	14	3 to 14 m	Prospective study
	Laryngomalacia	Midulla et al. (2004)																X							Italy	25	1 to 10 m	Retrospective record review
	Tracheostomy, UAO, GOR	Norman et al. (2007)			X	X					X				X	X	X	X					X		South Africa	80	< 3 yrs	Retrospective record review
	RSV Bronchiolitis	Hernandez et al. (2002)																X							USA	6	1 to 9 m	Prospective study
	RSV Bronchiolitis	Khoshoo & Edell (1999)	X														X	X							USA	12	3 to 12 m	Prospective study
	RSV Bronchiolitis	Khoshoo et al. (2001)															X	X							USA	15	3 to 12 m	Prospective study
	Respiratory symptoms, GOR	Lefton-Greif et al. (2006)									X	X			X	X	X	X	X	X					USA	19	< 5.75 yrs	Retrospective record review
	Respiratory symptoms, e.g. recurrent LRTI	Sheikh et al. (2001)													X	X	X	X	X	X		X			USA	13	< 9.3 m	Retrospective record review

Area / Medical Condition	Diagnoses/Description	Study	Signs of Feeding and/or Swallowing Difficulties [a]																							Country	N	Age range [b]	Methodology
			FSD undefined	Dysphagia undefined	Oral preparatory phase difficulties	Oral motor difficulties	Sucking difficulties	Poor lip closure	Abnormal lingual movement	Abnormal jaw movement	Oral sensory difficulties	Food refusal	Food selectivity	Oral phase difficulties	Pharyngeal phase difficulties	Nasopharyngeal backflow	Laryngeal penetration	Aspiration	Coughing with swallowing	Silent Aspiration	Desaturation during feeding	Choking	Oesophageal phase difficulties	Odynophagia				
Respiratory (continued)	Recurrent LRTI, GOR	Lodha et al. (2002)																X					X		India	70	< 14 yrs	Retrospective record review
	Recurrent LRTI, GOR, CP (variety of medical conditions)	Owayed et al. (2000)																X							USA	238	2.5 m to 15.6 yrs	Retrospective record review
	-	Rommel et al. (2003)	X																						Belgium	700	< 10 yrs	Prospective study. Participants referred for feeding Ax
	Pneumonia (variety of medical conditions)	Weir et al. (2007)													X		X	X							Australia	150	< 20 yrs	Retrospective record review
Genetic	22q11.2 deletion, GOR	Eischer et al. (2000)					X					X	X		X	X						X	X		USA	75	<17 yrs	Prospective study. Participants referred for feeding Ax (clinical or instrumental)
	22q11.2 deletion, GOR	Hopkin et al.(2000)	X				X																		USA	12	< 12 m	Retrospective record review
	-	Barratt & Ogle (2010)	X																						South Africa	100	2m to 14 yrs	Retrospective record review
	T21	Field et al. (2003)		X		X						X	X												USA	349	1 m to 12 yrs	Retrospective record review
	-	Rommel et al. (2003)	X																						Belgium	700	< 10 yrs	Prospective study. Participants referred for feeding Ax
	-	Schadler et al. (2007)	X																						Germany	86	< 10 yrs	Case series
Craniofacial/ structural	Micrognathia, cleft conditions, glossoptosis, stridor, different syndromes with orofacial malformations	Baudon et al. (2009)					X		X						X						X	X	X		France	42	< 10 yrs	Retrospective record review
	Cleft conditions, PRS, tracheostomy, oesophageal strictures	Burklow et al. (1998)	X																						USA	103	4 m to 17 yrs	Retrospective record review
	Cleft conditions, TOF, microgastria	Field et al. (2003)		X		X						X													USA	349	1 m to 12 yrs	Retrospective record review
	Cleft conditions	Masarei et al. (2007)					X																		UK	(69)49	neonates	Prospective study with control group. Clinical Ax & parent interview
	Cleft conditions, PRS	Reid et al. (2006)	X			X																			Australia	62	9 to 25 days	Prospective, logitudinal study
	-	Rommel et al. (2003)	X																						Belgium	700	< 10 yrs	Prospective study. Participants referred for feeding Ax
Developmental delay	-	Barratt & Ogle (2010)	X																						South Africa	100	2m to 14 yrs	Retrospective record review
	-	Burklow et al. (1998)	X																						USA	103	4 m to 17 yrs	Retrospective record review

Note. FSD = feeding and/or swallowing difficulties; Ax = assessment; CP = cerebral palsy; ID = intellectual disability; TBI = traumatic brain injury; PDD = pervasive developmental disorder; CNS = central nervous system; GOR/D = gastro-oesophageal reflux/disease; EOE = eosinophilic oesophagitis; EGID = eosinopilic gastrointestinal disease; GIT = gastro-intestinal tract; CHD = congenital heart disease; d-TGA = d-transposition of great arteries; HLHS = hypoplastic left heart syndrome; CLD = chronic lung disease; RDS = respiratory distress syndrome; UAO = upper airway obstruction; RSV = respiratory syncytal virus; LRTI = lower respiratory tract infection; T21 = Down syndrome; PRS = Piere Robin sequence; TOF = trache-oesophageal fistula

[a] The presence of a specific sign of FSD is indicated with *X*.

[b] The age ranges reported reflect the age used in the source article.

FSD or dysphagia (with the nature undefined) are reported across all types of medical conditions (Table 1). Some medical conditions however presented more frequently with certain types of FSD. *Oral preparatory phase difficulties* appear to be characteristic of the FSD in infants and children with neurologic conditions (Barkat-Masih et al., 2010; Calis et al., 2008; Field et al., 2003; Hawdon et al., 2000; Ng, et al., 2004; Reilly et al., 1996; Rommel et al., 2003). Research on neurologic conditions has focused on FSD in infants and children with cerebral palsy (CP) (Barkat-Masih et al., 2010; Barratt & Ogle, 2010; Bauer & Lyrene, 1999; Burklow et al., 1998; Calis et al., 2008; Field et al., 2003; Fung et al., 2002; Hawdon et al., 2000; Reilly et al., 1996; Schadler, et al., 2007; Sullivan et al., 2000). O*ral phase difficulties* were reported by only three of the articles reviewed (Mathisen et al., 1999; Ng et al., 2004; Pressman, 1992). These studies' samples included infants and children with neurologic and GIT conditions, as well as HIV. While Ng et al. (2004) refer to the presence of *oral phase difficulties* in their participants with agenesis of the Corpus Callosum, it is unclear whether the distinction between bolus formation (oral preparatory phase) versus oral transit (oral phase) was made in their study.

FSD associated with respiratory conditions are primarily characterized by *pharyngeal phase difficulties and aspiration* (Table 1). Many studies have reported a link between the aspiration of foods or fluids during swallowing and respiratory conditions (Hernandez et al., 2002; Khoshoo & Edell, 1999; Khoshoo et al., 2001; Lefton-Greif et al., 2006; Sheikh et al., 2001; Lodha et al., 2002; Owayed et al., 2000; Weir et al., 2007). Respiratory conditions may however have a reciprocal relationship with aspiration as each may be a sign or symptom of the other (Arvedson & Brodsky, 2002). Aspiration may therefore not only cause respiratory conditions, but may present as a result of respiratory conditions. Aspiration was reported in the absence of other medical conditions or a history of FSD in infants with RSV bronchiolitis (Hernandez et al., 2002; Khooshoo & Edell, 1999). Hernandez et al. (2002) argued that the presence of aspiration during swallowing in clinically stable infants with RSV bronchiolitis was the most likely reason for the deterioration of their respiratory health. Some infants and children with respiratory conditions may therefore be at risk for aspiration during feeding which may result in further lung damage.

Oesophageal phase difficulties were reported to occur in infants and children with a variety of medical conditions (Table 1) and included structural abnormalities and dysmotility of the oesophagus. Oesophageal phase difficulties were not associated with a single medical condition and were reported in GIT (Mathisen et al., 1999) and genetic conditions (Eischer et

al., 2000), HIV/AIDS (Cooke et al., 2009), and in infants and children with tracheostomies (Norman et al., 2007).

GIT conditions and specifically gastro-oesophageal reflux/gastro-oesophageal reflux disease (GOR/D) (a sign of a GIT condition) was one of the most frequently reported conditions underlying FSD in infants and children (Bauer & Lyrene, 1999; Field et al., 2003; Giambra & Meinzen-Derr, 2010; Lee et al., 1999; Mathisen et al., 1999; Rommel et al., 2003). Although GOR/D has been associated with difficulties in multiple phases of swallowing (Duca et al., 2008; Mathisen et al., 1999), no causal relation between GOR/D and FSD has been established (Vandenplas et al., 2009). Mathisen et al. (1999) specifically highlighted a lack of developmentally appropriate oral feeding skills in infants with GOR between 5 to 7 months of age and considered a possible cause. They suggested that these infants may receive less oral exposure due to the negative stimuli related to GOR and may therefore experience a delay in acquiring feeding skills. Thus, by missing the critical period for the development of oral feeding skills (Illingworth & Lister, 1964), aversive behaviours or the refusal of solid food may arise (Arvedson and Brodsky, 2002).

The presence of developmental delays (in the absence of other underlying medical conditions) may also be associated with FSD (Barrat & Ogle, 2010; Burklow et al., 1998). Arvedson and Brodsky (2002) suggested that children with developmental delays may be prone to FSD when solid and textured foods are introduced during a period when the child is not developmentally ready. In the study by Burklow et al. (1998), 74% of the participants with FSD had developmental delays and intellectual disability; it is unclear whether developmental delays included conditions such as CP. In a recent South African study, 29% of children with neurodevelopmental conditions presented with FSD, of whom 14% had isolated developmental delays (Barratt & Ogle, 2010). Neither of the studies however described the nature of the FSD associated with developmental delays.

Although only a few studies have reported on the nature of FSD in infants with cardiovascular conditions (Table 1), some have reported sucking (Limperopoulos et al., 1999) and oral sensory difficulties (Rommel et al., 2003). Parents of children with congenital heart disease often report problems such as breathlessness, vomiting, and growth faltering (Clemente et al., 2001), which may be related to the presence of FSD. Arvedson and Brodsky (2002) suggest that FSD in infants and children with cardiac conditions are related to increased effort and fatigue during oral feeding.

Pharyngeal phase difficulties and aspiration in infants with cardiovascular conditions related to vocal fold paralysis following cardiac surgery have also been reported (Sachdeva et al., 2007). Davis et al. (2008) found that infants with cardiac anomalies who required more surgical intervention (hypoplastic left heart syndrome) presented with more FSD (48%) than infants who required only one repair (4%). Findings by Limperopoulos et al. (1999) however suggest that the FSD in infants and children with congenital cardiac anomalies may not be solely related to the surgical procedures as almost a third of their participants presented with FSD prior to surgical repairs. Limperopoulos et al. identified signs of neurologic conditions in 56% of their participants prior to surgery. The FSD reported in infants and children with congenital cardiovascular conditions may therefore be related to a variety of factors such as neurologic damage due to oxygen deprivation associated with underlying cardiac abnormalities, or complications of corrective surgery.

The nature of FSD in infants and children with genetic conditions/syndromes is also not well defined. A variety of genetic conditions and syndromes are associated with FSD and are described by multiple sources (Arvedson, 2008; Arvedson & Brodsky, 2002; Cooper-Brown et al., 2008; Hall, 2001; Rommel et al., 2003; Winstock, 2006). The nature of FSD in genetic conditions/syndromes may be directly dependent on the specific characteristics or set of conditions defined by the syndrome, whether structural, muscular or neurologic. For instance, over 80% of infants and children with Down syndrome (a condition often associated with hypotonia) may present with oral motor difficulties (Field et al., 2003). As a syndrome complex is often associated with a variety of conditions, it is not surprising that infants and children with genetic conditions/syndromes may present with difficulties in multiple phases of swallowing. For example, infants and children with 22q11.2 deletion may present with oral preparatory, pharyngeal, and oesophageal phase difficulties (Table 1). Even though a great number of genetic conditions and syndromes are reported to present with FSD (Arvedson, 2008; Arvedson & Brodsky, 2002; Cooper-Brown et al., 2008; Hall, 2001; Rommel et al., 2003; Winstock, 2006), little has been reported on the nature of these difficulties.

A history of prematurity and/or low birth weight has also been described as a risk factor for FSD (Arvedson & Brodsky, 2002; Burklow et al., 1998; Giambra & Meinzen-Derr, 2010; Hall, 2001; Leifton-Greif & Arvedson, 2007; Rommel et al., 2003; Sheikh et al., 2001). Approximately a third (32-38%) of infants and children with FSD have a history of prematurity (Burklow et al., 1998; Rommel et al., 2003; Schädler et al., 2007). However, most studies that

reported FSD associated with prematurity did not describe the nature of the difficulties in their population (*FSD undefined*, Table 1).

Infants and children with FSD often present with complex medical histories where the majority will present with two or more co-morbidities (Burklow et al., 1998; Weir et al., 2007). Furthermore, the presence of an increased number of medical conditions (affecting multiple organ systems) with FSD is associated with an increased risk for pneumonia (Weir et al., 2007). Cu and Sidman (2011) indicated that the rate of gastrostomy tube placements among infants with cleft lip and/or palate increased in the presence of co-morbidities from 3% in participants with no other medical conditions present to 94% in those with additional respiratory involvement. There is a need to further explore the effect that certain co-morbidities may have on FSD.

South Africa has a unique clinical environment. International literature on FSD may not always be applicable as SA presents with a different *burden of disease* profile when compared to developed countries (WHO, 2010a). Considering that FSD varies in different medical conditions, the nature of FSD in the South African paediatric population may present differently. Literature on FSD from developing countries is sparse and only three South African studies (see Table 1) have been published at the time of this review. The first study reported that 80% of infants with tracheostomy tubes presented with dysphagia with multiple phases of swallowing being affected (Norman et al., 2007). The second study provided frequency information for FSD in children with neurodevelopmental disorders or delays (Barrat & Ogle, 2010). Barrat and Ogle (2010) also provided some information on the multidisciplinary intervention required by participants and identified a lack of appropriate referrals in the management of FSD. The third study examined the endoscopy findings of children with HIV/AIDS and reported that 15% of this population had dysphagia (Cooke et al., 2009). However the reliability of this data may be influenced by the small sample size (*N* = 26). There is limited to no available information about current service delivery practices for paediatric FSD in South Africa (Barrat & Ogle, 2010). Information regarding service delivery requirements for FSD in South Africa is important as clinicians require this data to guide management and to allocate scarce resources efficiently. This information may further be utilized for the implementation of health care policies and may inform the South African government of the need for FSD services at various levels of care.

The infrastructure of the South African health care system aims to distribute services across 3 levels of care (primary/community-based, secondary, and tertiary) in order to

alleviate the high case load of tertiary levels and to provide better access to services (South African Department of Health & Provincial Government of the Western Cape, 2007; South African Department of Health, 1997, 2011). Where the focus of the SA health care system had historically been curative, a shift was made toward prevention advocated by the primary health care (PHC) approach (South African Department of Health, 1997, 2000). It was envisaged that tertiary level care would be preceded by health care at primary/district levels (South African Department of Health, 1997, 2000). However, community-based services and resources are scarce (South African Department of Health & Provincial Government of the Western Cape, 2007) and services are often only accessed at tertiary levels (Mojaki, Basu, Letskokgohka, & Govender, 2011). Therefore the prevention and promotion initiatives of the PHC approach have not been implemented throughout every province in South Africa.

The majority of SLTs working in the Western Cape are based at tertiary hospitals (National Speech Therapy/Audiology Forum, 2007). However, tertiary level services may not be accessible to all individuals in SA due to geographic distribution of such services and limited transport (South African Department of Health & Provincial Government of the Western Cape, 2007), resulting in late identification of FSD or aspiration which may compromise an infant or child's health. The South African Department of Health (2011) has proposed a re-engineered PHC model with restructuring of services that will be provided through 3 streams: District level clinical specialist support teams, School-based health care services, and Municipal ward-based primary health care agents (South African Department of Health, 2011). The aim of this re-engineering of primary health care is to be cost effective and to increase access to services (South African Department of Health, 2011). However it is uncertain how the proposed policy plans to address the need for dysphagia services these levels. Information regarding the service delivery requirements of infants and children with FSD may be utilized to inform relevant stakeholders in health care management regarding the need for dysphagia services and therefore SLT posts at all levels of care. Providing community-based dysphagia services may improve the health outcomes of infants and children (Khooshoo et al., 2001; Sheikh et al., 2001) and decrease the cost burden of paediatric FSD (MacIntyre et al., 2003; Pinelli & Symington, 2005) on the South African health care system. There is a need for information regarding the services provided for paediatric FSD at tertiary levels of care in order to inform current primary health care initiatives.

The management of paediatric FSD requires a biopsychosocial approach where clinicians not only consider oral feeding skills but also the adequacy of nutritional intake, the

impact of underlying medical conditions and the safety of the swallow with regard to the presence and severity of aspiration (Arvedson, Brodsky, & Reigstad, 2002). Infants and children with FSD often present with complex medical histories with multiple co-morbidities; the management of FSD therefore requires the collaboration of an interdisciplinary team where the primary caregiver/parent of an infant or child with FSD is included as a leading member of the team (Arvedson & Brodsky, 2002; Ayoob & Barresi, 2007; Barratt & Ogle, 2010; Craig, Scambler, & Spitz, 2003; Field, et al., 2003; Hall, 2001; Lefton-Greiff & Arvedson, 2008; Rommel et al., 2003; Silverman, 2011). As a part of the team, the SLT in South Africa (Health Professions Council of South Africa (HPCSA), 2008; South African Speech Language and Hearing Association (SASLHA) Ethics and Standards Committee, 2011) is responsible for clinical feeding and swallowing assessments, the interpretation of instrumental swallow studies, and implementation of individualized oral sensorimotor treatment programmes where appropriate (American Speech Language and Hearing Association, 2001; Arvedson & Brodsky, 2002; Arvedson, Brodsky, & Christensen, 2002; DeMatteo, Matovich, & Hjartarson, 2005).

The management of FSD often include a range of services from Speech-Language Therapists (SLT) as well as medical intervention, and surgical procedures. Infants and children with FSD who cannot achieve adequate nutrition and hydration safely may require enteral modes of feeding in the form of naso- or orogastric tube feeding. When these short-term feeding methods are required for a period greater than 1-3 months, the use of a Percutaneous Endoscopic Gastrostomy (PEG)/Gastrostomy tube should be considered (Rossi, Brodsky, & Arvedson, 2002). The candidacy of long-term enteral feeding should always be decided in collaboration with an interdisciplinary team. Team members will often consider multiple factors relating to each individual case in order to decide whether a PEG/gastrostomy tube is appropriate. The following indications for PEG/gastrostomy tube placement have been described: dysphagia, aspiration, and growth faltering (Fortunato, et al., 2010; Norman et al., 2011; Novotny, Jester, & Ladd, 2009; Van der Merwe et al., 2003). The presence and nature of underlying medical conditions may also influence the decision regarding the need for long-term enteral feeding (Norman et al., 2011). Special care and consideration should be given to counselling of parents/caregivers of infants and children who are candidates for long-term enteral feeding (Craig et al., 2003).

FSD can have a significant impact on a child and the family in terms of the child's growth, health, and development, as well as early social skills such as interaction-attachment

(Craig, et al., 2006; Lucarelli, Ambruzzi, Cimino, D'Olimpio, & Finistrella, 2003; Mathisen et al., 1999; Petersen, Kedia, Davis, Newman, & Temple, 2006; Rommel et al., 2003; Sheikh, et al., 2001). It is therefore essential to identify and manage these difficulties early. Research suggests that identifying and managing paediatric FSD early may result in reduced length of hospital stay (MacIntyre et al., 2003; Pinelli & Symington, 2005) and prevention of associated respiratory morbidities thereby reducing hospital admissions (Khoshoo et al., 2001; Petersen et al., 2006; Sheikh et al., 2001). The early identification and management of FSD may have positive implications for the child and the family, as well as cost benefit implications (Townsend et al., 2008) for the South African health care system trying to address the high burden of disease.

The current study arose from a need to describe the nature of FSD in a heterogeneous population of infants and children presenting with different types of medical conditions. This information may assist health care professionals in South Africa to identify FSD in at risk populations earlier, and refer for appropriate assessment and management. Furthermore, information regarding the nature of FSD in different medical conditions may assist health care professionals in the management of FSD. Information regarding current service delivery for FSD at tertiary levels of care will also be described. Information regarding current service delivery practices may increase efficacy and distribution of services as well as inform current health policies of the need for the prevention, promotion, and early identification of FSD. Two research questions have been identified: What is the nature of FSD in infants and children who presented to a tertiary hospital in the Western Cape from January 2007 through December 2009? What is the nature of service delivery that the infants and children with FSD received?

2. Methodology

2.1. Aims and Objectives

In the sample of infants and children who were referred for a feeding and swallowing assessment at a tertiary hospital in the Western Cape from January 2007 through December 2009 the following will be described:

Aim 1: To describe the nature and frequency of feeding and swallowing difficulties (FSD)

Objectives:

To describe:

a. The general signs of feeding difficulties
b. The signs and disorders in the different phases of swallowing
    - Oral Preparatory Phase
    - Oral Phase
    - Pharyngeal Phase
    - Oesophageal Phase
c. The medical conditions prevalent in participants with FSD
d. The nature and frequency of FSD in the different medical conditions
    - The frequency of difficulties in the phases of swallowing in different medical conditions
    - The age at initial feeding and swallowing assessment in the different medical conditions
e. A comparison of FSD in participants with a history of term versus premature birth
    - The age at initial feeding and swallowing assessment in participants with a history of term versus premature birth
    - A comparison of swallowing difficulties in participants with a history of term versus premature birth
f. Aspiration in infants and children with FSD
    - The frequency of aspiration
    - The frequency of aspiration in the different medical conditions
    - The association between aspiration and lower respiratory tract infections
    - The association between aspiration and gastro-oesophageal reflux
    - The presence of aspiration in participants with isolated versus multiple medical conditions

Aim 2: To describe the nature of service delivery for FSD

Objectives:

To describe:

a. The referral sources for feeding and swallowing assessments

b. The management of FSD

   i. The professionals consulted in the management of FSD
   ii. The frequency of clinical and instrumental assessments for FSD
   iii. The surgical interventions related to FSD
   iv. Speech-Language Therapy services
      - Management recommendations during the intervention period for FSD
      - Intervention strategies
      - Duration and frequency of services
      - Duration of services in participants with different medical conditions
   v. Mode of intake
      - During the SLT intervention period
      - Upon completion of SLT treatment

2.2. Research Design

The research project utilized a descriptive, retrospective survey design (Irwin, Pannbacker & Lass, 2008).

A descriptive design systematically describes a phenomenon as it occurs, allowing variables to be observed and recorded (Du Plooy, 2009; Leedy & Ormrod, 2004). This design allowed the researcher to highlight any possible associations between the phenomenon (i.e. feeding and/or swallowing difficulties) and possible external influences (i.e. medical conditions) (Leedy & Ormrod, 2004). Another advantage of this design is that it allows for the description of variables and groups of variables with statistical procedures, whereby feeding and/or swallowing difficulties (FSD) could not only be quantified, but could also be described a function of variables such as participants' gestational age or presenting medical conditions (Du Plooy, 2009). Even though the descriptive design prevents the researcher from reporting on causality (Jackson, 2009; Leedy & Ormrod, 2004), it allowed for the comprehensive description of the characteristics of FSD, making it ideal for achieving the study aims.

A retrospective survey design is ideal for the collection of historical data (Bowling, 1997; Creswell, 2008; Irwin, Pannbacker, & Lass, 2008). The review of medical records allowed for the collection of data without the need for direct observation (Creswell, 2008), implying that neither the participants nor the data could be affected by the researcher as an observer. Data from a longer period of intervention (36 months) could be collected in a shorter period of time, resulting in a larger sample size. This design has fewer financial and time constraints as data collection involved the review of the participants' medical records without the need for additional human resources or expensive instrumentation (Irwin et al., 2008).

A challenge of the retrospective survey design was that the researcher had no control over the quality or reliability of the data (Irwin et al., 2008). The researcher attempted to address this obstacle by selecting a period during which participants received management for FSD that would provide the most consistency for the documented data. During the chosen period there were only 3 speech-language therapists providing paediatric dysphagia services at the research site. All had received similar training in paediatric dysphagia.

The retrospective survey design also does not permit any cause and effect conclusions due to the lack of variable manipulation (Bowling, 1997; Irwin et al., 2008; Leedy & Ormrod, 2004). Nevertheless, it allowed the researcher to report on the results of Videofluoroscopic Swallow Studies without requiring participants to be exposed to any additional radiation. Although no causal relations could be established, associations and differences between variables could be described as a result of the frequency information that was obtained (Bowling, 1997; Creswell, 2008; Irwin et al., 2008).

The descriptive, retrospective survey design that was employed in this study was best suited to describe FSD in the paediatric population without influencing the data or inflicting harm on participants. This design was effective as it utilized rich information sources (participants' medical records) for data collection of multiple relevant variables in a short period of time, allowing for the research questions to be addressed.

2.3. Participants

2.3.1. Selection Criteria

Inclusion criteria

Participant medical records were included in the research project if they adhered to the following criteria:

Age:

Services at the chosen research site, a tertiary paediatric hospital, are provided to children under the age of 13 years. Participants were therefore also required to be below the age of 13 years as the purpose of this study was to report on the FSD in infants and children.

Research setting:

Participants were included only if they had a feeding and swallowing assessment (on an in- or out-patient basis) at the chosen research site, a tertiary paediatric hospital in the Western Cape. The specific paediatric tertiary hospital was selected as there were speech-language therapists providing paediatric dysphagia services during the period of January 2007 through December 2009. The hospital was the most suitable research site as it is the largest paediatric tertiary hospital in Sub-Saharan Africa and is therefore a referral hospital for many infants and children with FSD.

Feeding and swallowing assessment:

All participants included in the study sample must have had their first feeding and swallowing assessment by a trained speech-language therapist between January 2007 and December 2009. Either clinical or instrumental assessments were accepted.

Presence of feeding and/or swallowing difficulties (FSD):

All participants had to have been identified as having FSD, as the purpose of the study was to document the nature of FSD in infants and children.

Exclusion criteria

Participants were excluded from this study if their medical records were unavailable during the 5-month data collection period.

2.3.2. Recruitment/Identification of Records

The Medical Superintendent and the Head of the Speech-Language Therapy Department of the paediatric hospital were contacted for permission to conduct research at the site (see Appendix A) after approval for the research project was granted by the University of Cape Town's Faculty of Health Sciences Human Research Ethics Committee (FHS HREC) (Appendix B). The Speech-Language Therapy Department's statistical records (which are maintained for hospital audit purposes) were then requested, and the records of all individuals between the ages of 0 – 12 years who had been referred for FSD during the 36-month period (from January 2007 through December 2009) were extracted and 1158 potential participants were identified. The potential participants' medical records were requested from the hospital's Records Department and these were reviewed at the research site to determine eligibility for inclusion in the study.

2.3.3. Sampling

The records of participants were selected using non-probability, purposive sampling (Creswell, 2008; Leedy & Ormrod, 2004). Non-probability, purposive sampling is non-random sampling, aimed at accessing participants representing specific characteristics, which in this case were the medical records of infants and children with FSD (Bowling, 1997; Creswell, 2008). Although this method of sampling does not allow results to be generalised to the wider paediatric population, it may be applied to similar populations.

2.3.4. Sample Size

A total of 1158 records of infants and children with FSD were identified. Of the 1158 potential participants, 30 records were reviewed for the purpose of piloting the study's data collection checklist (please refer to 2.6.2. *Checklist Pilot* for more detail). Following the pilot, 1128 potential participants remained of which 446 participants' medical records met the study inclusion criteria and were allocated a reference number that served as a code to protect participants' anonymity and confidentiality (MRC, 2000).

Five-hundred-and-fifty-six records were excluded from the study as they did not meet the inclusion criteria. The medical records for 126 participants could not be reviewed for the following reasons: the records or certain volumes of the records were unavailable or missing for the duration of data collection, records were being reviewed for other research or were in use by medical personnel, invalid or faulty patient information made it impossible to locate participants' medical records.

2.3.5. Participant Description

Participant characteristics are described in Table 2. Participants were nearly equally distributed in terms of sex. Data regarding gestational age was missing for 144 participants. Almost a third of participants (32%) had a history of prematurity. The mean gestational age for the sample was 36 weeks (*SD* = 2.93, range = 25 - 38). The mean birth weight of participants was recorded as 2758g (n = 336, SD = 806.12, range = 620 – 5000g). Growth faltering was reported by dieticians in 59% of the sample.

Table 2
Participant Characteristics (N = 446)

Participant Characteristics		Percent
Sex:	Male	51.1
	Female	48.9
Neonatal History:		
Gestational Age (n=302):		
	Term (38+weeks)	67.9
	34-37 weeks	16.6
	28-33 weeks	13.2
	<28 weeks	2.3

Figure 1 reflects the age distribution of participants at the first feeding and swallowing assessment. The average age of participants was 23 months ranging from 3 days to 12:4 years (*Mdn* = 10 months). The majority (70.4%, 314/446) of the participants were under 2 years of age when first assessed, with 53% (237/446) aged less than 1 year.

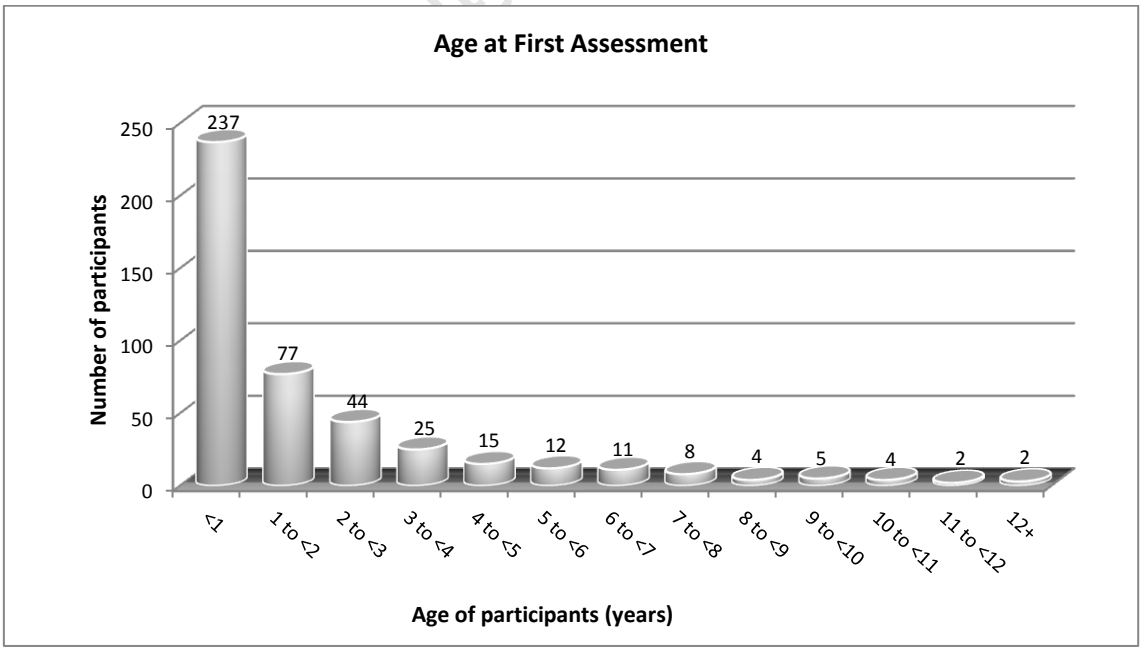

Figure 1. Age at First Assessment (N = 446)

Service delivery for FSD at the research site was not limited to individuals from one geographical area as participants were widely distributed within the Cape Metropole (as reflected in Figure 2). Only 38% of the sample were situated within the paediatric hospital's catchment area (Klipfontein and Mitchell's Plain) while 49% were from other sub-districts within the Cape Metropole. A further 8% were from other areas in the Western Cape, 5% from other provinces in South Africa (Eastern and Northern Cape) and 0.4% from other countries (East and Southern Africa).

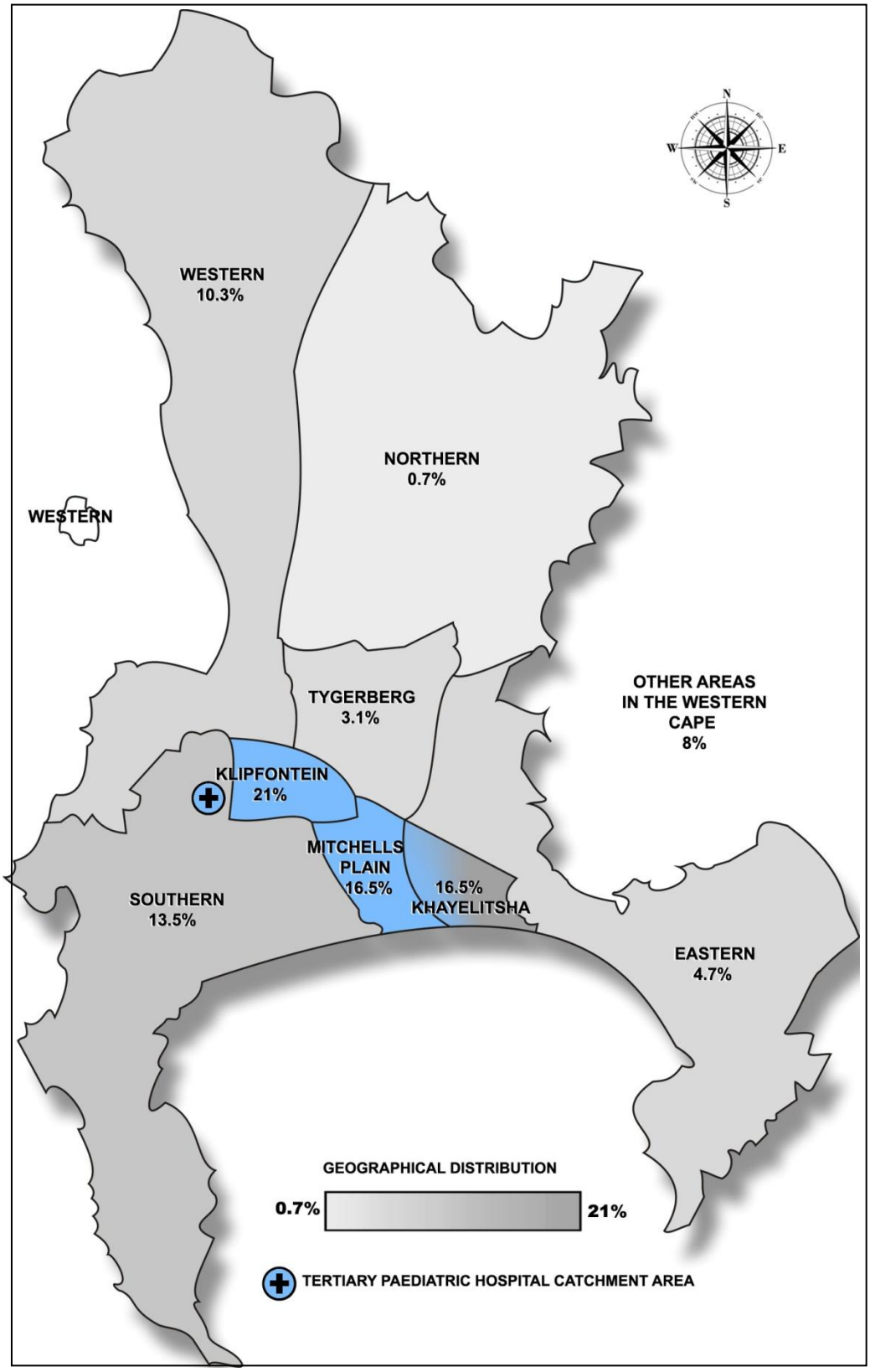

Figure 2. Geographical Distribution of the Sample within the Sub-Districts of the Cape Metropole

Adapted from the *Comprehensive Service Plan for the Implementation of Healthcare 2010 (*South African Department of Health & Provincial Government of the Western Cape, 2007).

2.4. Materials and Instrumentation

2.4.1. Checklist

A checklist was developed in order to structure the data collection procedure and facilitate consistency of the data collected across participants' medical records (refer to Appendix C for the checklist). The items which were included in the checklist were identified and supported by an in-depth literature review (Table 3). These items needed to cover a range of areas in order to provide the data required to answer the research questions and included: a reference number, participant information which includes biographic, demographic, and medical information, feeding and swallowing clinical and/or instrumental assessment results, services, and interventions received for FSD and the outcomes of feeding and swallowing intervention.

2.4.2. Validity

Validity pertains to the ability of a research tool to accurately measure what it set out to accomplish (Gomm, 2008; Irwin et al., 2008); in the case of the present study, the checklist items needed to provide sufficient information in order to address the aims and objectives of the project. Validity measures were used to ensure that all items included in the checklist would provide the researcher with information aimed at answering the research questions (Litwin, 1995).

Face validity requires the subjective assessment of the relevance of the items included in the checklist (Bowling, 1997). To satisfy face validity, the checklist was reviewed by untrained judges (Litwin, 1995), who included the researcher's peers (speech-language therapists).

Content validity needed to be addressed as it ensures that the complete scope of items needed to answer the research question were included in the checklist (Creswell, 2008). The researcher made use of a comprehensive literature review to support the inclusion of all items in the checklist in order to address content validity (Arvedson 2007; Arvedson, 2008; Arvedson & Brodsky, 2002; Baudon et al., 2009; Cooke et al., 2009; Cooper-Brown et al., 2008; Delaney & Arvedson, 2008; Einarson & Arthur, 2003; Field et al., 2003; Grimberg et al., 2009; Groenewald et al., 2003; Hall, 2001; Kirby & Noel, 2007; Lefton-Greif et al., 2006; Lefton-Greif & Arvedson, 2007; Logemann, 1998; Norman et al., 2007; Pressman, 1992; Rodgers & Arvedson, 2005; Rommel et al., 2003; Sachdeva et al., 2007; Sheikh et al., 2001; Stoner, Bailey, Angell, Robbins & Polewski, 2006; Sullivan et al., 2006; Truong et al., 2007;

Winstock, 2006; Wright & Goddard, 1997). Table 3 includes supporting literature as rationale for each item included in the checklist. Content validity was also addressed by submitting the checklist to the research supervisors for review, as they are professionals experienced in the field of dysphagia and provided guidelines to ensure that all relevant items were included in the checklist (Creswell, 2008; Litwin, 1995).

Construct validity includes testing whether the checklist can extract the necessary data to achieve the aims of the study and whether the items included can be deemed relevant to the phenomenon being examined (Creswell, 2008; Gomm, 2008). Construct validity was established during the pilot study as the practical usefulness of the checklist was reviewed (Creswell, 2008). Following the pilot study, the researcher adjusted the layout of the checklist in order to increase the efficiency of data collection.

Criterion validity relates to whether the checklist results correlate with the results of another valid and standardised test accepted as the "gold-standard" (Creswell, 2008). Although specifically comparable checklists are not available, the researcher has made use of a comprehensive literature review to support the inclusion of all items in the checklist.

Table 3
Checklist for Feeding and Swallowing Data Collection with Supporting Literature

Information	Rationale	Reference
1. Reference number	A reference number was assigned to ensure participants' anonymity.	Medical Research Council (2000)
2. Participant Characteristics	Specific participant information was used to highlight any unique characteristics evident in the population of infants and children with FSD.	
2.1. Biographical Information	The description of biographical and case history information provided the researcher with relevant background information and supported other information collected.	
Birth Weight	Children with a significantly lower birth weight for gestational age are at risk for developing FSD.	Rommel et al. (2003)
Gestational Age	Gestational age (GA) was used to identify premature participants.	Delaney & Arvedson (2008); Hall (2001)
Prematurity	Prematurity has been linked to FSD.	Arvedson & Brodsky (2002); Field et al. (2003);Hall (2001); Rommel et al. (2003); Winstock (2006)
Date of birth	The participants' dates of birth were documented in order to record their age.	-

Age at presentation	Literature has indicated that children below 2 years of age are at a higher risk for feeding disorders. Documenting the age at which FSD first present could inform early intervention programmes that target FSD.	Rommel et al. (2003)
Sex	Literature has documented sex-related developmental differences in the maturation of the neuromuscular systems required for successful swallowing.	Delaney & Arvedson (2008)
Growth faltering	Documented reports of malnutrition are relevant to this study as feeding disorders could contribute to participants' compromised nutritional status. Dieticians' reports of chronic malnutrition, growth faltering and/or failure to thrive were captured.	Arvedson (2008); Grimberg et al. (2009); Kirby & Noel (2007)
Tracheostomy	Infants and children with tracheostomies are known to be at risk for FSD.	Norman et al., (2007)
2.2. Residential Area	The documentation of participants' place of residence may assist in identifying the needs of infants and children with feeding disorders with regards to service delivery and could identify sub-districts who could potentially benefit from service delivery at primary or secondary level.	Groenewald et al.(2003)
2.3. Medical Information	The description of medical conditions provided information about the underlying etiologies associated with FSD.	
2.3.1. Lower respiratory tract infections (LRTI)/ pneumonias	Recurrent LRTI's may be associated with FSD as persistent aspiration has been linked with recurrent pneumonia.	Arvedson & Brodsky (2002); Sheikh et al. (2001)
Hospitalizations for LRTI/ Pneumonia	The number of hospitalizations associated with LRTI and pneumonia was documented for comparison with feeding and/or swallowing-related services.	Lefton-Greif et al. (2006); Sullivan et al., (2006)
2.3.2. Medical Categories	Medical conditions documented in the sample were collapsed into composite medical categories to facilitate statistical manipulation. The categories allocated were guided by the main system affected by the recorded pathology. For example, cerebral palsy was categorized under *neurologic* to reflect the main site of pathology. HIV/AIDS and TB are known to have a high prevalence in South Africa and these conditions were documented separately.	Arvedson & Brodsky (2002); Hall (2001); Groenewald et al.(2003); WHO (2010a), WHO (2010b)
Neurologic	Children with neurologic impairments (central and/or peripheral nervous system) are at increased risk for FSD. For example, cerebral palsy and meningitis.	Arvedson (2008); Arvedson & Brodsky (2002); Arvedson, Rogers, Buck, Smart, & Msall (1994); Field et al. (2003); Hall (2001); Rommel et al. (2003); Winstock (2006)

	Genetic	A number of syndromes and genetic conditions are associated with dysphagia. For example, Down Syndrome (T21).	Arvedson (2008); Arvedson & Brodsky (2002); Cooper-Brown et al. (2008); Hall (2001); Rommel et al. (2003); Winstock (2006)
	Gastro-Intestinal Tract (GIT)	Multiple studies have identified associations between GI disorders and paediatric FSD, For example, Gastro-oesophageal Reflux/Disease (a sign of a GIT condition).	Arvedson (2008); Arvedson & Brodsky (2002); Field et al. (2003); Hall (2001); Rommel et al. (2003); Winstock (2006)
	HIV/AIDS	HIV/AIDS has been associated with FSD and has a high prevalence in South Africa. Participants' HIV status will be documented if it is available in the medical records.	Cooke et al. (2009); Groenewald et al. (2003); Hall (2001); Pressman (1992); Winstock (2006); Wright & Goddard (1997)
	Tuberculosis	The documentation of TB in the sample population is relevant as South Africa has the third largest incidence of TB globally.	WHO (2010b)
	Craniofacial/ Structural	Craniofacial and structural abnormalities, such as cleft lip and/or palate, are associated with FSD.	Arvedson (2008); Arvedson & Brodsky (2002); Baudon et al. (2009); Field et al. (2003); Hall (2001); Rommel et al. (2003); Winstock (2006)
	Respiratory and ENT	Infants with respiratory difficulties have a high frequency of dysphagia or aspiration. For example, Bronchopulmonary dysplasia or chronic lung disease. Ear-nose-and throat (ENT) related abnormalities that interfere with respiration were grouped with respiratory conditions. For example, Chronic upper airway obstruction may negatively influence feeding.	Arvedson (2008); Field et al. (2003); Hall (2001); Rommel et al. (2003); Winstock (2006)
	Cardiovascular	Infants with cardiac abnormalities are known to have reduced endurance during feeding. Cardiac surgery may also increase an infant's risk for vocal fold paresis, placing them at risk for silent aspiration. Congenital cardiac abnormalities such as Atrioventricular Septal Defect will be documented.	Arvedson (2008); Einarson & Arthur (2003); Field et al. (2003); Hall (2001); Rommel et al. (2003); Sachdeva et al. (2007); Truong et al. (2007); Winstock (2006)
	Developmental Delays	Developmental delays may occur without the presence of underlying medical conditions. Children with developmental delays may present with feeding difficulties related to the developmental progression of feeding skills.	Arvedson & Brodsky (2002); Barratt & Ogle (2010); Burklow et al. (1998)
	Other	Any other conditions that are not described by the above categories were documented in the category *other,* for example, metabolic disorders, renal disease, and food allergy.	Arvedson (2008); Field et al. (2003); Winstock (2006)

3. Feeding and Swallowing Assessment Results (clinical and/or instrumental)		The results of the feeding assessment reflected both signs and underlying impairments that are often used by clinicians to describe the nature of FSD. The results of any clinical and/or instrumental feeding and swallowing assessment which fell within the timeframe of the study were documented. Given the retrospective nature of the study, the only aspects of feeding that were documented in medical records were swallowing difficulties and general signs of feeding difficulties.	
3.1. General Signs of Feeding Disorders		The participant's capacity/skill set to feed, emotional and physiologic state, factors within the mealtime environment and interaction with the feeder were documented.	Arvedson & Brodsky, (2002); Rudolph & Thompson, (2002); Winstock, (2006)
3.2. Swallowing Disorders		Any signs of difficulties within the four phases of swallowing (oral preparatory, oral, pharyngeal and oesophageal) were documented in order to fully illustrate the nature of participants' swallowing disorders.	Arvedson & Brodsky, (2002); Groher, (1997); Hall, (2001); Rodgers & Arvedson, (2005); Winstock, (2006).
3.2.1.	Oral Preparatory Phase (bolus formation)	The oral preparatory phase of swallowing requires the voluntary intake of food followed by oral manipulation in order to form a manageable bolus for later posterior propulsion. Bolus formation is routinely assessed clinically.	Arvedson (2007); Arvedson (2008); Arvedson & Brodsky (2002); Hall (2001); Logemann (1998)
	i. Primarily oral sensory difficulties	Oral sensory responses may hinder bolus formation due to difficulties such as aversive reactions to food or utensils, or the presence of a hyperactive gag response.	Arvedson (2008); Arvedson & Brodsky (2002); Hall (2001)
	ii. Primarily oral motor difficulties:	Detailed documentation of oral motor difficulties facilitated the description of the nature of feeding and swallowing difficulties where for example reduced lingual movement restricted bolus formation.	Arvedson (2007); Arvedson (2008); Arvedson & Brodsky (2002); Hall (2001); Logemann (1998)
3.2.2.	Oral Phase (oral transit)	The oral phase of swallowing requires the voluntary propulsion of the bolus into the pharynx through negative pressure in the oral cavity created by the inward movement of the buccal muscles and the posterior movement of the tongue until the pharyngeal swallow is initiated.	Arvedson (2007); Arvedson (2008); Arvedson & Brodsky (2002); Hall (2001); Logemann (1998)
3.2.3.	Pharyngeal Phase	Pharyngeal swallow initiation: the pharyngeal swallow may be initiated as the bolus reaches any of the following points: the anterior tonsillar pillars, base of tongue or valleculae. Pharyngeal Phase: Following the initiation of the swallow, a sequence of actions can be observed: velopharyngeal closure; elevation and anterior movement of the hyoid and larynx; laryngeal closure and protection of the airway; opening of the upper oesophageal sphincter; and propulsion of the bolus into the oesophagus through base of tongue retraction and pharyngeal wall contraction. **The pharyngeal phase can only be assessed instrumentally, whereas clinical signs may assist the clinician to make inferences about the presence of pharyngeal difficulties**.	Arvedson (2007); Arvedson (2008); Arvedson & Brodsky (2002); Groher (1997); Logemann (1998)
3.2.4.	Oesophageal Phase	Oesophageal phase difficulties and/or abnormalities may result in FSD.	Arvedson (2007); Arvedson (2008); Arvedson & Brodsky (2002); Hall (2001)

4. Services utilized for FSD	Profiling the services that infants and children with FSD received may assist in identifying this population's service needs and may be utilized for the management of these difficulties and prevention or promotion strategies.	
4.1. Referral Sources	Identifying the referral sources of an established feeding and swallowing service may assist start-up services by identifying education and training needs. Already established services may also utilize this information to further optimize referral structures.	-
4.2. Professionals consulted regarding feeding and swallowing difficulties	Infants and children with FSD may require the services of multiple professionals. The professionals consulted by the participants were documented to describe the range of professionals.	Arvedson & Brodsky (2002); Hall (2001)
4.3. Management recommendations made by speech-language therapists	The service needs of the study population may be identified by recommendations made by the speech-language therapist following the feeding assessment, for example, the need for further instrumental assessment.	-
5. Interventions pertaining to FSD	Participants' need for various interventions relating to FSD was documented to profile service delivery needs. Infants and children with FSD and additional health issues may need surgical intervention, alternative feeding methods or adaptations of meals to ensure that their health and nutritional status are not compromised.	
5.1. Clinical and Instrumental Feeding and Swallowing Assessments	Clinical and instrumental investigations provide information to diagnose and guide the management of infants and children with FSD. The number and type of assessments participants received aimed at diagnosing FSD were documented in order to identify the service delivery needs of this population. Specific instrumental assessments that were included: • *Barium swallow study/Oesophagram:* used to define the anatomy and function of the upper through lower GI-tract. • *Videofluoroscopic Swallow Study (VFSS)/Modified Barium Study (MBS):* considered the "gold standard" for the assessment of swallowing. It is a radiographic study that provides a dynamic view of all phases of the swallow process.	Arvedson & Brodsky (2002); Hall (2001)

5.2. Surgical interventions related to feeding and/or swallowing	The surgical interventions related to FSD that were documented: • *Nissen Fundoplication:* This anti-reflux procedure involves the wrapping of the stomach fundus around the gastro-oesophageal junction resulting in a narrowing of the lower oesophageal sphincter. The goal of this procedure is often to alieviate severe or chronic GOR. • Percutaneous Endoscopic Gastrostomy (PEG)-placement/gastrostomy: A surgical procedure where an artificial opening is made into the stomach for food to bypass the swallowing mechanism. A description of surgical interventions received by the population of infants and children with FSD will form part of the desciption of the management of FSD in this population.	Arvedson (2008); Arvedson & Brodsky (2002); Hall (2001)
5.3. Feeding methods utilized during intervention for FSD	Infants and children with feeding disorders often require alternative feeding methods to ensure safe feeding and optimal nutrition. The variety of feeding methods were documented to identify the different methods used in infants and children with FSD.	Arvedson & Brodsky (2002); Hall (2001)
5.4. Speech-Language Therapy (SLT)-related interventions provided for FSD	Infants and children with FSD may receive a variety of SLT interventions that promote adequate nutrition and developmentally appropriate feeding skills. The SLT interventions that participants received were documented in order to profile current South African SLT-practices pertaining to FSD.	Arvedson & Brodsky (2002); Hall (2001)
Compensatory Strategies	Compensatory intervention strategies aim to adapt the feeding environment in order to assist the infant or child to feed succesfully. These strategies include: • *Position and posture management:* the alteration of the child's stance/seating to enhance stability whilst feeding. • *Modified consistency:* the alteration of the viscosity of food to compensate for swallowing disorders to try to decrease the risk of aspiration. • *Modified temperature, volume, taste:* specific food presentations that may increase sensory awareness of the bolus orally and may aid successful feeding and swallowing. • *Adaptations made to utensils:* may be used to compensate for oral motor disorders and can help establish adequate nutritional intake as well as promote self or assisted feeding.	Arvedson & Brodsky (2002); Hall (2001)
Facilitative Strategies	Treatment strategies that assist infants and children to acquire developmentally appropriate feeding skills are called facilitative strategies. These strategies include, but are not limited to: • *Oral sensorimotor therapy:* is a multimodal approach to FSD that facilitates oral feeding. This section included all aspects of direct intervention, for example establishing non-nutritive sucking or stimulation of anatomic structures for function. • *Behavioral interventions:* specific approaches such as behavioral modification aimed at facilitating developmentally appropriate feeding skills.	Arvedson & Brodsky (2002); Hall (2001)

Parent training	Therapy techniques are transferred to parents or caregivers to ensure generalisation of skills targeted during intervention to the infant/child's home environment.	-
Support services Other	The families of infants and children with FSD may experience increased stress and may benefit from support services. The support services that participants received were documented to illustrate the range of services available at a tertiary hospital in the Cape Metropole. For example, Parent/caregiver counseling or the provision of resources (such as utensils).	Stoner et al. (2006)

6. Feeding and swallowing intervention outcomes (as recorded at last consultation)	Participant outcomes provided information regarding the development, duration and resolution of FSD. This information may assist healthcare professionals in planning services as the duration of services and interventions required will be documented.	
6.1. Patient and Attendance Outcomes	The documentation of participants' attendance trends and outcomes may assist healthcare professionals by providing information about caseload management, for example, how many participants were discharged. This will provide an indication of how many participants completed intervention.	Rommel et al. (2003)
6.2. Feeding method outcome	The last entered feeding mode in participants' medical records was documented to determine the feeding outcomes after intervention.	Arvedson (2008); Arvedson & Brodsky (2002); Hall (2001)
6.3. Duration of SLT-services required for FSD and number of SLT-contacts	The duration for which services were rendered for feeding disorders as well as the frequency of SLT contacts will identify service needs and could be utilized to motivate for SLT posts at hospitals and clinics.	-

2.4.3. Reliability

Reliability refers to the replication potential and consistency of the checklist used in data collection (Bowling, 1997; Gomm, 2008; Irwin et al. 2008). Reliability was addressed through intra- and inter-rater reliability measures (Creswell, 2008; Gomm, 2008).

Intra-rater reliability measures compare a single researcher's consistency in the use of the checklist over the course of time (Gomm, 2008). The researcher randomly selected approximately 5% of the study sample that she had reviewed previously and completed the checklist for a second time, but on a separate sheet. To ensure that the researcher was blinded to the previous results, the re-administration of the checklist took place at least 1 week to 1 month after the initial review. The two data sets were then compared and the researcher's consistency rating was 97.6%, which met the predetermined 95% criterion level that had been set prior to the review (Gomm, 2008; Jackson, 2009).

Inter-rater reliability provides information on the consistency of the checklist when used by multiple researchers to document the same phenomenon (Gomm, 2008; Litwin, 1995). A second researcher (a qualified speech-language therapist with experience in paediatric dysphagia) administered the checklist on approximately 10% of the sample, blind to the initial results obtained. The medical records included in the inter-rater reliability measures were randomly selected from the list of records already reviewed. The data sets

recorded by the two independent researchers were then compared and met the predetermined criterion of 95% (Gomm, 2008; Jackson, 2009). A 95.9% level of agreement was established.

2.5. Ethical Considerations

Responsible conduct and integrity should be a priority for all researchers (Medical Research Council (MRC), South Africa, 2000). The World Medical Association (WMA) Declaration of Helsinki (Seoul version, 2008), a statement of ethical principles, has been integrated with the principles of biomedical ethics to ensure that appropriate safeguards are in place to protect the rights of all participants (Irwin et al., 2008; MRC, 2000; WMA Declaration of Helsinki, 2008). The WMA Declaration of Helsinki (2008) specifically promotes autonomy, beneficence, non-maleficence and justice – principles that are considered throughout the design of this study. The researcher obtained ethics approval from the UCT Faculty of Health Sciences Human Research Ethics Committee (FHS HREC) to ensure that the study was ethically sound (Appendix B).

Autonomy relates to human dignity and stresses the importance of respect for the person (MRC, 2000). This principle requires that participants, or their legal proxy, control or consent to what happens to them (MRC, 2000). According to the MRC (2000) a retrospective study involving medical record review does not need individual participant consent when anonymity and confidentiality are ensured, as is the case in this research project. Although there was no direct human participation in this study, the researcher ensured the anonymity and confidentiality of the participants' information by making use of reference numbers to safeguard their rights (MRC, 2000; WMA Declaration of Helsinki, 2008).

Participants' identities were kept confidential, except to the main researcher and second researcher assisting with the inter-rater reliability measures. Multiple precautions were set in place to safeguard participants' privacy. Medical records were assigned reference numbers which replaced any identifiable information on data sheets (MRC, 2000). The key for these reference numbers was maintained by the researcher in the event of the need to re-access individual records, but was stored securely and separate from the checklist information. Upon completion of the research, anything that could identify a participant to the researcher will be destroyed and only the reference codes will remain to distinguish among data.

Beneficence is the second principle that was addressed and it required the researcher to assess any benefits the research brings to participants (MRC, 2000, WMA Declaration of Helsinki, 2008). Although there were no direct advantages for participants, data from this study may benefit future individuals by facilitating early identification of infants and children with FSD. It could also be beneficial to professionals working in the field of paediatric FSD, as it may provide insights into the nature and frequency of FSD and may potentially improve the services needed by this population.

The third principle, non-maleficence, required the researcher to ensure that the participants were not harmed (MRC, 200; WMA Declaration of Helsinki, 2008). The study was non-invasive due to its retrospective nature and held no risk to participants. There was no foreseeable physical, legal, social, or economic harm to participants in this sample.

Lastly, justice was also taken into account when the sample population of the study was selected. Justice entails the equal distribution of risks and benefits between communities and protects specific populations from being exploited (MRC, 2000). The proposed area of enquiry cannot be administered in an adult population as there are differences between FSD in adults and children (Groher, 1997). It should also be noted that the medical records of all patients meeting pre-established criteria at the research site were reviewed. The study sample also included individuals from a range of communities and cultures that share the same phenomenon: FSD. The sample was spread over a wide geographical area even though only one tertiary hospital in the Cape Metropole was included in this research project. No one community was singled out to bear any possible risks. The benefits of the study could apply to any infant or child with FSD in any community within the Cape Metropole and may extend beyond the present research site.

All of the above principles have been upheld by the researcher. The researcher is a qualified speech-language therapist registered with the Health Professions Council of South Africa. The results of the study will be made available to the research site's Medical Superintendent and the Speech-Language Therapy Department. The proposed research is a requirement for a Masters Degree qualification. A journal article may be published.

2.6. Procedure

2.6.1. Data Collection

Ethics approval for the research project was obtained from the UCT Faculty of Health Sciences Human Research Ethics Committee (FHS HREC; reference: 342/2009) (Appendix B). Following ethics approval, permission was obtained from the Medical Superintendent at the research site (a paediatric tertiary hospital in the Western Cape) in order to conduct the study at the institution (see Appendix A).

The Speech-Language Therapy Department's statistical records were then requested and 1128 potential participants were identified. Upon completion of the pilot study (Section 2.6.2.), the medical records were requested from the hospital Records Department and reviewed at the research site. Of the 1128 potential participants, 446 medical records met the study inclusion criteria and were allocated a reference number (MRC, 2000). The checklist was then used to capture all relevant data from medical records and contained no identifiable participant information, only the participant reference number.

2.6.2. Checklist Pilot

A pilot study involves a small-scale trial where data are collected from a partial section of the sample, to ensure the validity and reliability of the instrument intended for measuring a phenomenon (Du Plooy, 2009). The pilot was conducted before the actual study commenced and the use of the checklist for data collection was assessed to ensure that it functioned as a valid and reliable tool for gathering information. The sample for the pilot study was randomly drawn from the list of potential participants. Approximately thirty medical records were chosen for piloting the checklist during the planning phase of the research project as the initial sample size was expected to range between 250-300 participants. These records were reviewed and 13 records met the study's inclusion criteria. The checklist was then administered for the 13 records and its usefulness assessed.

The use of the checklist was deemed effective for data collection and refined after the pilot study before the study began. The only change to the content of the checklist included the addition of fill-in spaces named *other* which allowed the researcher to capture unforeseen data. Following the pilot study, the researcher decided to record data directly onto an electronic checklist and the format of the checklist was changed to enable optimal and efficient use on a laptop computer. Medical records used for the pilot study were not included in the main study.

2.6.3. Data Analysis

Descriptive and inferential statistical methods were used to quantify and analyze data, in order to provide a comprehensive description of the phenomena being explored (Fink, 1995; Irwin et al., 2008; Leedy & Ormrod, 2004). Ms Anneli Hardy, a statistician from the UCT Statistical Consultation Services, was consulted regarding appropriate methods of analysis for the study and assisted with all inferential statistical analyses and descriptions of frequency distributions. Data analysis was conducted with the use of PASW (SPSS) Statistics Version 18 and 19 and Microsoft Excel spreadsheets.

Descriptive statistics were used to organize the nominal and binary data extracted from the checklist. Frequency counts and distributions patterns (measures of central tendency, variance and range) were used to describe the nature and frequency of FSD, the age at which participants first sought services for FSD, and the nature of service delivery. Cross-tabulations were used to determine the frequency of swallowing difficulties within the varied medical conditions and to explore possible associations among these variables.

Before the medical information could be analysed, medical conditions had to be collapsed into composite medical categories to facilitate statistical manipulation. Appendix D reflects the medical conditions within the composite medical categories: Neurologic, Gastro-intestinal, Cardiopulmonary, Respiratory/ENT, Genetic/Syndromic, Developmental delay, HIV/AIDS, TB, and Other. A list of mutually exclusive medical conditions and combinations were then identified (see Appendix E) which were used for further statistical analyses.

Inferential statistics were employed to determine the significance and nature of possible associations among variables (Creswell, 2008; Leedy & Ormrod, 2004). An alpha level of .05 was used for all statistical analyses. Chi-square tests were used to analyze categorical data and significance was reported.

The association between aspiration and lower respiratory tract infections or gastro-oesophageal reflux was explored with the use of a Pearson's Chi-Square Test. This analysis was also appropriate to explore the following relationships: swallowing difficulties in participants with a history of premature or term birth, FSD and aspiration in different medical conditions, the association between surgical interventions, and SLT management recommendations.

The researcher also explored comparisons between groups by making use of *t*-tests and nonparametric tests where appropriate. The ages at which treatment was first sought

were compared for participants with a history of premature and term birth by first establishing whether the distribution of age followed normal distribution patterns by conducting tests of normality (Kolmogorov-Smirnov, Shapiro-Wilk). The assumption of normality was violated and therefore a Mann-Whitney U test was used to explore the distribution of age between participants with a history of premature and term birth.

The ages at which treatment was first sought was also explored for different medical conditions. Tests of homogeneity of variances (Levene Statistic), the Brown-Forsythe Robust Test of Equality and Kruskal-Wallis indicated that the distribution of age was not the same across medical conditions. Multiple comparisons using a Dunnett T3 test were made. A t-test was then performed to explore the differences in the ages across medical conditions.

Where undocumented or missing data points from participants' medical records were encountered, the researcher used the data points that were available and adjusted the N for the analysis of that specific variable. The researcher therefore omitted the specific participant's medical record from the analysis of the specific missing variable and included data from it in the analysis of the other variables (Bowling, 1997; Cole, 2007; Nolan & Heinzen, 2008).

3. Results

The results are presented in accordance with the aims and objectives of the study.

3.1. The nature and frequency of feeding and swallowing difficulties

3.1.1. The general signs of feeding difficulties

General signs of feeding difficulties were reported in 112 participants. Of the participants who presented with general signs associated with feeding difficulties, 49.1% (55/112) had prolonged feeding times of more than 30 minutes. Other general signs of feeding difficulties that were documented included decreased endurance (37.5%, 42/112), crying with feeding (9.8%, 11/112), arching during/after feeding (9.8%, 11/112), and increased respiratory rates during feeding (8.0%, 9/112).

3.1.2. The signs and disorders in the different phases of swallowing

Ninety-five percent (424/446) of participants were reported to have swallowing difficulties. Participants presented with difficulties in all phases of swallowing, with oral preparatory phase difficulties occurring most frequently. Figure 3 shows the frequency of the swallowing difficulties (also dysphagia) in the different phases.

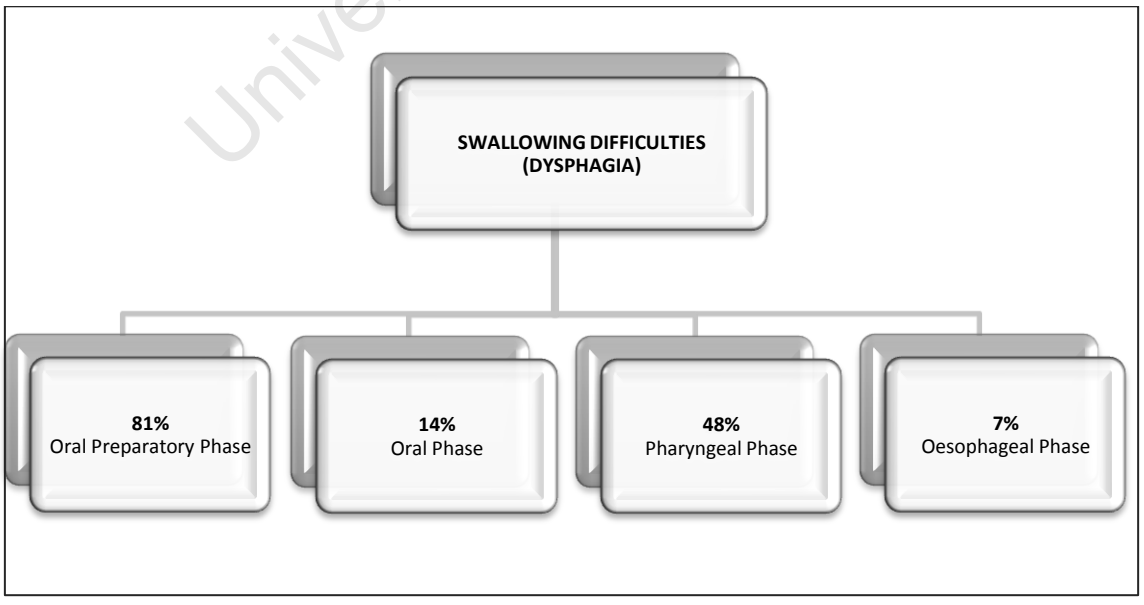

Figure 3. The Nature and Frequency of Swallowing Difficulties (*N* = 446)

Oral Preparatory Phase

Oral preparatory phase difficulties were most frequently reported (81.2%, 362/446) among participants. Signs and disorders of the oral preparatory phase are often divided into oral motor and oral sensory difficulties. This distinction is however not always possible as many participants could present with both types. The frequency of the signs and difficulties in the oral preparatory phase of swallowing are presented in Table 4.

Table 4
Signs and Difficulties in the Oral Preparatory Phase of Swallowing (n = 362)

SIGNS AND DIFFICULTIES OF ORAL PREPARATORY PHASE (OPP) OF SWALLOWING	*n*	% within OPP (*n* = 362)	% of sample (*N* = 446)
Poor lip closure/anterior spillage	174	48.1	39.0
Poor oral skills (general descriptor of phase)	148	40.9	33.2
Weak, uncoordinated or absent suck	136	37.6	30.5
Uncoordinated or reduced lingual control/ poor bolus formation	123	34.0	27.6
Aversion or refusal of feeds	86	23.8	19.3
Tongue thrust/ immature posterior-anterior movement	62	17.1	13.9
Pooling of secretions or bolus	60	16.6	13.5
Drooling/poor saliva control	55	15.2	12.3
Hyperactive gag response	50	13.8	11.2
Tonic bite	30	8.3	6.7
Aversion or resistance to non-food (oral stimulation or utensils)	27	7.5	6.1
Reduced mandibular movement/ ineffective chewing	18	5.0	4.0
Reduced buccal tone/ residue or pooling in lateral sulcus	12	3.3	2.7
Inadequate latching	11	3.0	2.5
Jaw clenching	7	1.9	1.6
Increased oral sensitivity	6	1.7	1.3
Teeth grinding	3	0.8	0.7
Decreased oral sensation	2	0.6	0.4

Note. The values reflected in this table are not mutually exclusive. Therefore signs will not add up to 100% as these difficulties occurred simultaneously in some participants.

Difficulties reported most frequently for participants appeared to be primarily oral motor difficulties such as poor lip closure and lingual coordination. These difficulties may have resulted in inadequate bolus transfer/manipulation or anterior loss of the bolus. Sucking difficulties were also frequently reported. Food aversion or refusal, which may be a result of underlying sensory and/or motor difficulties, was also documented.

Oral Phase

Only 63 of 446 (14%) participants were reported to have oral phase difficulties. Premature spillage of the bolus into the pharynx prior to the initiation of the pharyngeal swallow was among the reported signs and may compromise the safety of swallowing. The frequency of the signs and disorders in oral phase of swallowing are presented in Table 5.

Table 5
Signs and Disorders in the Oral Phase of Swallowing (n = 63)

SIGNS AND DISORDERS OF THE ORAL PHASE (OP) OF SWALLOWING	*n*	% within OP (*n* = 63)	% of sample (*N* = 446)
Increased Oral Transit Time	47	74.6	10.5
Reduced linguavelar seal/ premature spillage of bolus into pharynx	17	27.0	3.8
Reduced anterior-posterior lingual movement/poor bolus propulsion	13	20.6	2.9
Reduced tongue elevation/ residue on hard palate	2	3.2	0.4

Pharyngeal Phase

Pharyngeal phase difficulties were defined via instrumental assessment and occurred in 48.2% (215/446) of the sample. Signs that may compromise the safety of swallowing were frequently reported. In participants with pharyngeal phase difficulties, confirmed aspiration (via instrumental assessment) was documented in 69.8% (150/215). A further 79.5% (171/215) demonstrated laryngeal penetration and 66.1% (142/215) had delayed initiation of the pharyngeal swallow. In 9.8% (21/215) of participants the pharyngeal swallow initiation was absent. The frequency of the signs and disorders in the pharyngeal phase of swallowing are presented in Table 6.

Table 6
Signs and Disorders in the Pharyngeal Phase of Swallowing (n = 215)

SIGNS AND DISORDERS OF THE PHARYNGEAL PHASE (PP) OF SWALLOWING	*n*	% within PP (*n* = 215)	% of sample (*N* = 446)
Laryngeal penetration	171	79.5	38.3
Confirmed aspiration (via instrumental assessment)	150	69.8	33.6
Delayed swallow initiation/ bolus in pyriform sinuses or valleculae	142	66.1	31.8
Reduced velopharyngeal closure/ nasopharyngeal backflow	37	17.2	8.3
Residue (location unspecified)	27	12.6	6.1
Absent swallow initiation	21	9.8	4.7
Reduced anterior laryngeal movement/ residue in pyriform sinuses	20	9.3	4.5
Reduced tongue base retraction/ residue in valleculae	16	7.4	3.6
UOS dysfunction/ reduced pharyngeal pressure/ slow movement of bolus through UOS	15	7.0	3.4
Multiple swallows per bolus	11	5.1	2.5
Increased pharyngeal transit time >1½s	6	2.8	1.3

Oesophageal Phase

Oesophageal phase difficulties were documented in only 6.5% (29/446) of the participants. Both oesophageal dysmotility (69.0%, 20/29) and structural abnormalities (51.7%, 15/29) were frequently reported for this phase.

3.1.3. The medical conditions prevalent in participants with FSD

Participants presented with complex medical histories. Almost two thirds of participants (65.3%, 291/446) presented with multiple co-existing conditions from various medical categories while only 30.7% (137/446) had a single documented condition. Four percent (18/446) of participants did not have any medical condition documented.

The medical categories with the most frequently occurring medical conditions are presented in Table 7. The complete list of medical conditions included in the different medical categories is in Appendix D. The medical categories shown in Table 7 are not mutually exclusive as many participants presented with conditions from more than one category.

Table 7
Medical Conditions Organized According to Medical Categories (N = 446)

Medical Category	Most Frequently Occurring Medical Condition [a]	*n*	% of category	% of sample (*N*=446)
Neurologic (Neuro)		248		55.6
	Cerebral Palsy	141	56.6	31.6
Gastro-Intestinal Tract (GIT)		238		53.4
	Gastro-oesophageal Reflux	224	93.3	50.2
Respiratory and ENT (Resp/ENT)		85		19.1
	Upper Airway Obstruction	38	44.7	8.5
Cardiovascular (Cardio)		65		14.6
	Congenital Malformations of the Cardiac Septa [b]	43	66.2	9.6
HIV/AIDS (HIV)		55	-	12.3
Tuberculosis (TB)		53	-	11.9
	Pulmonary TB	40	75.5	9.0
Genetic/Syndromic (Gen)		45		10.1
	Down Syndrome (Trisomy 21)	15	33.3	3.4
Cranio-Facial Abnormalities (Cranio)		32		7.2
	Cleft lip and/or Palate	16	48.5	3.6
Other		24		5.4
	Congenital CMV/Rubella	4	16.7	0.9
Developmental delays (Dev)		13		2.9
	Global Developmental Delays	9	69.2	2.0

Note. [a] *Details of all the medical conditions included under each medical category are available in Appendix D.*
[b] *Congenital Malformations of the Cardiac Septa include: Ventricular Septal Defect (VSD), Atrial Septal Defect (ASD), Atrioventricular Septal Defect (AVSD), and Tetralogy of Fallot (ToF).*

The medical categories with co-existing medical conditions are presented in Table 8. The medical categories and combinations in Table 8 are mutually exclusive, i.e. the grouped combinations of medical conditions cannot occur simultaneously in one participant. There were 79 different combinations of medical co-morbidities (refer to Appendix E), however only those combinations with $n \geq 10$ are included in Table 8.

Table 8
Participants presenting with Co-existing Medical Categories (N = 446)

Mutually Exclusive Medical Categories	*n*	% (*N* = 446)
Neuro	75	16.8
Neuro+GIT	69	15.5
GIT	24	5.4
Neuro+TB	18	4.0
No Medical Condition	18	4.0
Neuro+GIT+Resp/ENT	13	2.9
Neuro+Resp/ENT	12	2.7
HIV/AIDS	10	2.2
GIT+HIV/AIDS	10	2.2
Neuro+GIT+TB	10	2.2
Other medical categories and combinations (<10 participants/group) [a]	187	41.9
Total	446	100.0

Note. [a] *Details of the other medical categories and combinations are available in Appendix E.*

Neurologic conditions were reported most frequently in participants (55.6%, 248/446). Most of the participants within the neurologic category (69.8%, 173/248) had co-existing medical conditions which demonstrate the complex medical histories of infants and children with FSD. Only 29.1% (75/248) had an isolated neurologic condition (Table 8).

Gastro-intestinal tract (GIT) conditions were the second largest group of medical categories (53.4%, 238/446), and comprised mostly of gastro-oesophageal reflux (Table 7). Ninety percent (214/238) of GIT conditions were documented in combination with other medical conditions, whilst isolated GIT conditions were present in only 10.1% (24/238) of the sample (Table 8). Individually and in combination, the neurologic and gastro-intestinal tract conditions were most prevalent in the sample.

3.1.4. The nature and frequency of FSD in the different medical conditions

The frequency of difficulties in the phases of swallowing in different medical conditions

The nature of swallowing difficulties in the present study was described in the mutually exclusive medical categories in order to consider the influence of co-morbidities. The swallowing difficulties reported in participants with different medical conditions are presented in Table 9. Only medical co-morbidities with $n \geq 10$ are included in Table 9. Participants presented with difficulties in multiple phases of swallowing regardless of the presence of isolated conditions or co-morbidities.

Table 9

Swallowing Difficulties Prevalent in the Different Medical Conditions (*n* = 380)

Phase of Swallowing Difficulties	Medical Conditions	Neuro (*n* = 75)	GIT (*n*=24)	HIV (*n*=10)	Neuro +GIT (*n* =69)	Neuro +TB (*n* =18)	Neuro +Resp/ ENT (*n*=12)	GIT +HIV (*n*=10)	Neuro +GIT +Resp/ ENT (*n*=13)	Neuro +GIT +TB (*n*=10)	Neuro +GIT +all (*n*=24)	Neuro +all excl. GIT (*n*=27)	GIT +all excl. Neuro (*n*=88)
% Oral Preparatory (*n*)		**93.3** (70)	**75.0** (18)	**90.0** (9)	81.2 (56)	**88.9** (16)	**83.3** (10)	40.0 (4)	**84.6** (11)	70.0 (7)	87.5 (21)	**81.5** (22)	**71.6** (63)
% Oral (*n*)		9.3 (7)	0.0(0)	0.0(0)	26.1 (18)	38.9 (7)	33.3 (4)	20.0 (2)	46.2 (6)	0.0(0)	33.3 (8)	11.1 (3)	8.0 (7)
% Pharyngeal (*n*)		33.3 (25)	54.2 (13)	30.0 (3)	**85.5** (59)	27.7 (5)	16.7 (2)	**80.0** (8)	69.2 (9)	**90.0** (9)	**91.7** (22)	11.1 (3)	60.2 (53)
% Oesophageal (*n*)		2.7 (2)	16.7 (4)	0.0 (0)	5.8 (4)	0.0 (0)	0.0 (0)	0.0 (0)	7.7 (1)	10.0 (1)	12.5(3)	3.7 (1)	14.8 (13)

Note. The values reflected in this table are not mutually exclusive. Therefore difficulties in the phases of swallowing will not add up to 100% as these difficulties occurred simultaneously in some participants.

**The boldface values reflect the phase which presented with the most difficulties in each medical condition.*

Oral preparatory phase difficulties were reported most frequently in participants with isolated neurologic conditions (93.3%, 70/75) and HIV/AIDS (90.0%, 9/10). While participants with isolated GIT conditions also presented with a high frequency of oral preparatory phase difficulties (75.0%, 18/24), more than half (13/24) also had pharyngeal phase difficulties. Oral phase difficulties were most frequently (46.2%, 6/13) reported in participants with neurologic, GIT and respiratory co-morbidities.

The frequency of participants who had reported pharyngeal phase difficulties was 33.3% (25/75) in isolated neurologic and 54.2% (13/24) in isolated GIT conditions, but increased to 85.5% (59/69) in the combined neurologic and GIT participants (Table 9). The highest frequency (91.7%, 22/24) of participants with pharyngeal phase difficulties was reported in participants with a combination of 3 or more co-morbidities (which included both neurologic and GIT conditions). However, more participants with co-morbidities including GIT were reported to have pharyngeal phase difficulties (60.2%, 53/88) when compared to co-morbidities including neurologic conditions in absence of GIT conditions (11.1%, 3/27).

Oesophageal phase difficulties were reported more frequently when participants had a GIT condition or co-morbidity (14.8%, 13/88) when compared to neurologic categories (3.7%, 1/27).

The age at initial feeding and swallowing assessment in the different medical conditions

The mean ages at which treatment was first sought by participants with different medical categories for FSD are displayed in Figure 4.

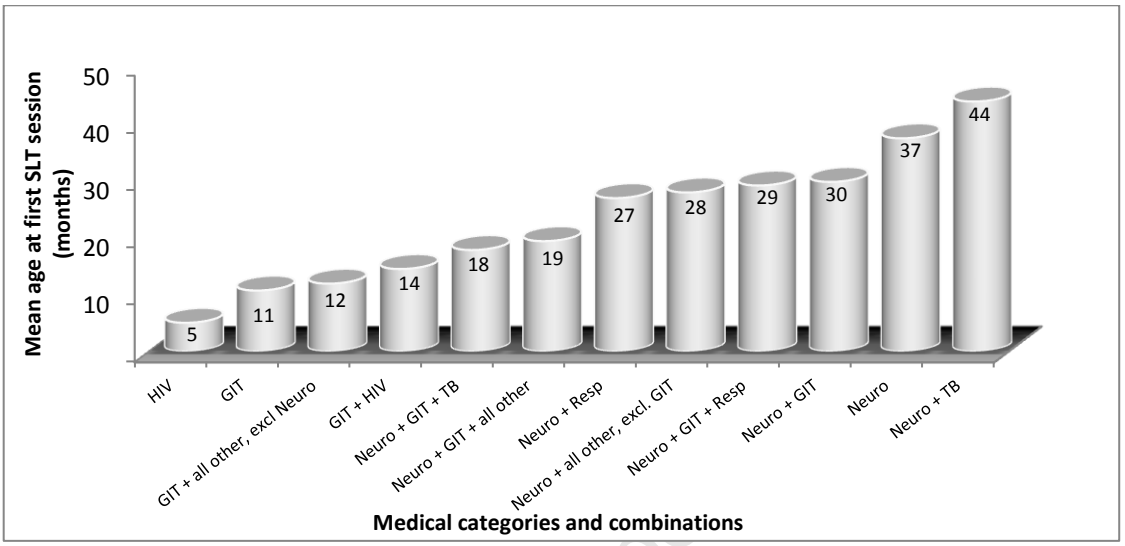

Figure 4. Age at which Participants with Different Medical Conditions Presented with FSD (*N* = 379)

Participants with HIV/AIDS or GIT conditions received treatment for FSD significantly earlier than participants who had neurologic conditions (in isolation or combination with GIT or TB). Participants with HIV/AIDS sought treatment for FSD the earliest at a mean age of 5 months.

The ages at which treatment was first sought for FSD between participants with single versus multiple co-existing medical conditions were also explored. Participants with multiple medical conditions sought treatment at a mean age of 22 months compared to 25 months for those with single medical conditions. The difference between the mean ages at which participants with single versus multiple medical conditions sought treatment for FSD was not statistically significant (t (225.91) = 1.02, p = .310).

3.1.5. A comparison of FSD in participants with a history of term versus premature birth

The age at initial feeding and swallowing assessment in participants with a history of term versus premature birth

The mean age at which services were first sought for FSD for participants born at term was 22 months (*SD* = 27, range = 0.2 - 148.2) and for those with a history of prematurity, 17 months (*SD* = 21, range = 0.4 - 112.3). There is no statistically significant difference (p = .206) in the distribution of the ages at which services were first sought for FSD between participants born at term and those with a history of prematurity.

A comparison of swallowing difficulties in participants with a history of term versus premature birth

Statistically significantly more participants with a history of a term birth presented with oral phase difficulties than those with a history of prematurity (x^2 = 4.926, p < .05). There were no other statistically significant differences (p > .05) in the nature of swallowing difficulties between the two groups.

3.1.6. Aspiration in infants and children with FSD

The frequency of aspiration

Clinical signs of possible aspiration (e.g. coughing or changes in voice quality during feeding) were reported for 48.7% (217/446) of the participants. Aspiration of food or fluids was confirmed (via instrumental assessment) in over a third (33.6%, 150/446) of the participants. Of the confirmed cases of aspiration, 19.3% (29/150) aspirated silently and 7.3% (11/150) also aspirated from gastro-oesophageal reflux.

The frequency of aspiration in the different medical conditions

Table 10 shows the percentage of confirmed aspiration (via instrumental assessment) that was reported in participants with different medical conditions. Aspiration was reported in all of the medical conditions with frequency ranging from 3.7% to 80.0% depending on the different medical conditions or combinations. The medical condition with the highest proportion (80.0%, 8/10) of participants who aspirated was the

combination of GIT conditions with HIV, followed by the combination of neurologic and GIT conditions (63.8%, 44/69).

Table 10
Presence of Confirmed Aspiration in Different Medical Conditions (n = 148)

Confirmed Aspiration	Medical conditions	Neuro (*n* = 75)	GIT (*n*=24)	HIV (*n*=10)	Neuro +GIT (*n* =69)	Neuro +TB (*n* =18)	Neuro +Resp/ ENT (*n*=12)	GIT +HIV (*n*=10)	Neuro +GIT +Resp/ ENT (*n*=13)	Neuro +GIT +TB (*n*=10)	Neuro +GIT +all (*n*=24)	Neuro +all excl. GIT (*n*=27)	GIT +all excl. Neuro (*n*=88)
% Aspiration present (*n*)		21.4 (16)	41.6 (10)	20.0 (2)	**63.8** (44)	16.6 (3)	8.3 (1)	**80.0** (8)	46.1 (6)	**60.0** (6)	**62.5** (15)	3.7 (1)	40.9 (36)
% Aspiration absent (*n*)		**78.6** (59)	**58.3** (14)	**80.0** (8)	36.2 (25)	**83.4** (15)	**91.7** (11)	20.0 (2)	**53.9** (7)	40.0 (4)	37.5 (9)	**96.3** (26)	**59.1** (52)

Note. The largest percentage within each medical condition is in boldface.

The association between aspiration and lower respiratory tract infections

Sixty-two percent of participants had one or more lower respiratory tract infection (LRTI) during the study period with varying etiologies. Figure 5 illustrates the different etiologies reported for the lower respiratory tract infections.

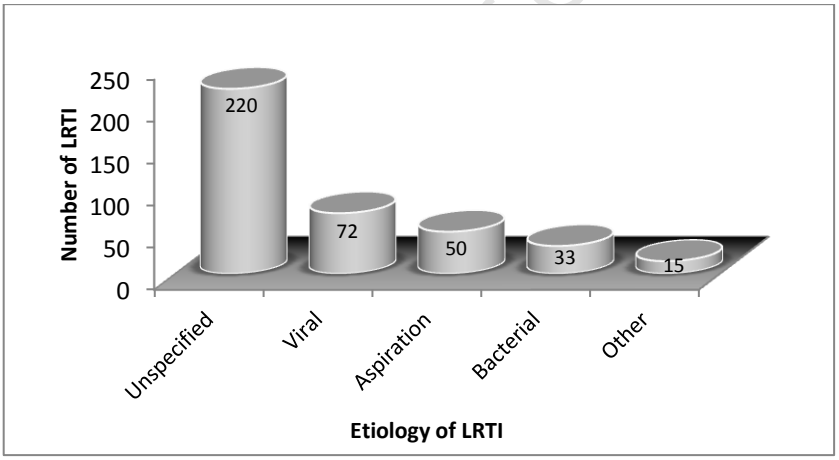

Figure 5. Different Lower Respiratory Tract Infections (n = 278)

Aspiration pneumonia was documented in 18% (50/278) of the participants with LRTI. The majority (79.1%, 220/278) of lower respiratory tract infections had an unspecified etiology. Confirmed aspiration (via instrumental assessment) was statistically significantly associated with aspiration pneumonia (x^2 = 26.4314, p < .001) and unspecified LRTI (x^2 = 21.2757, p < .001). Ninety-four percent (260/278) of participants with LRTIs were hospitalized for respiratory compromise with 53.9% (140/260) of these

being hospitalized once and the remaining 46.2% (120/260) with multiple admissions (range = 2 to 12 admissions).

The association between aspiration and gastro-oesophageal reflux

The majority (82%, 123/150) of participants with confirmed aspiration (via instrumental assessment) also presented with gastro-oesophageal reflux (GOR). Statistically significantly more participants with GOR aspirated (x^2 = 91.2842, p < .001) than those participants without GOR.

The presence of aspiration in participants with isolated versus multiple medical conditions

Confirmed aspiration (via instrumental assessment) was recorded more frequently among participants with multiple medical conditions (80.0%, 120/150) when compared to those with isolated medical conditions (20.0%, 30/150). Statistically significantly more participants with multiple medical conditions aspirated (x^2 = 21.6951, p < .001) when compared to those participants with a single medical condition.

3.2. The nature of service delivery for FSD

3.2.1. The referral sources for feeding and swallowing assessments

Twenty-four percent (106/446) of participants' referral sources were undocumented. The majority (73.8%, 251/340) of participants were referred for a feeding and swallowing assessment by Medical Specialists whilst 14.1% (48/340) of participants were referred by Dieticians. Other Healthcare Professionals (such as Physiotherapists, Occupational Therapists, Speech-Language Therapists, Nursing Sisters with specialized stoma training, and Audiologists) referred 10.3% (35/340) of the participants. The caregivers of 1.8% (6/340) of participants sought help directly from a speech-language therapist for FSD.

3.2.2. T he management of FSD

3.2.2.1. The professionals consulted in the management of FSD

Table 11 shows the number of participants who received services from different professionals within the inter-/multi-disciplinary team in the management of FSD. The professions most frequently consulted in the management of FSD at the research site were: Speech-Language Therapy, Paediatrics, Dietetics, Radiology, Gastroenterology, Paediatric Surgery, and Nursing (specifically a Stoma Specialist).

Table 11
Professionals Consulted in the Management of FSD

Professionals	*n*	% consulted (*N*=446)	% referred by SLT
Speech-Language Therapist (SLT)	446	100.0	-
Dietician	351	78.7	22.5
Paediatrician/Doctor	330	74.0	-
Radiologist	252	56.5	80.2
Gastroenterologist	129	28.9	36.4
Surgeon	109	24.4	-
Nursing sister (Stoma Specialist)	102	22.9	-
ENT	76	17.0	28.9
Neurologist/Developmental Neurologist	56	12.6	-
Pulmonologist	53	11.9	9.4
Cardiologist	38	8.5	-
Physiotherapist	26	5.8	-
Other* (<10 participants/group)	14	3.1	-

*Note.**Other health care services included: Allergy Clinic, Dentist, Cleft Clinic/Plastic Surgery, Social Worker, Genetics, Paediatric Psychology, and Occupational Therapy

3.2.2.2. The frequency of clinical and instrumental assessments for FSD

The majority (77.6%, 346/446) of participants were assessed clinically. Fifty-nine percent (263/446) of the sample were assessed instrumentally, of which 35.2% (157/446) were assessed with Modified Barium Swallow (MBS) / Videofluoroscopic Swallow Studies (VFSS) (Figure 6). Thirty-seven percent (166/446) of participants were assessed with Barium Swallow Studies/Oesophagrams that documented oropharyngeal dysphagia.

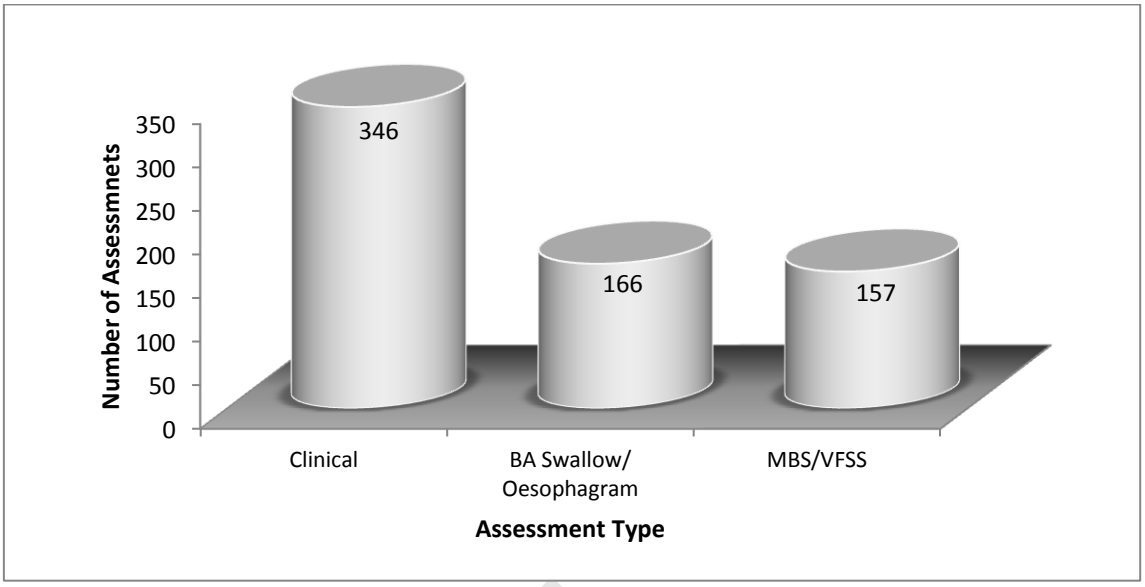

Figure 6. Feeding and/or Swallowing-Related Assessments (*N* = 446)

Note. The assessment types in the figure are non-mutually exclusive as some participants may have been assessed multi-modally.

3.2.2.3. The surgical interventions related to FSD

A quarter (25.3%, 113/446) of the sample received surgical intervention to manage difficulties related to feeding and/or swallowing, of which the combination of a Nissen Fundoplication with a Percutaneous Endoscopic Gastrostomy (PEG)/gastrostomy was the most common (63.7%, 72/113). Almost a quarter (23.5%, 105/446) of the sample received a PEG/gastrostomy tube for long term enteral feeding. Figure 7 illustrates the surgical interventions carried out for the management of FSD.

Of the participants that received a PEG/gastrostomy tube for the management of FSD, 74% had a history of growth faltering. Statistically significantly more participants with PEG/gastrostomy tube placements had a history of growth faltering (x^2 = 12.951, p < .001) than those without a PEG/gastrostomy tube.

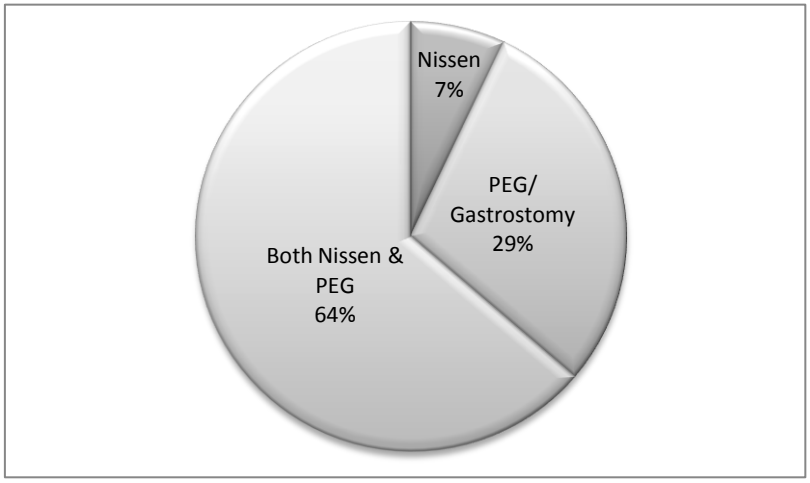

Figure 7. Surgical Interventions Related to FSD (*n* = 113)

3.2.2.4. Speech-Language Therapy services

Management recommendations during the intervention period for FSD

The recommendations made by SLT as part of the management of FSD are presented in Table 12. Of the participants who were assessed clinically, 58.4% (202/346) were referred for further instrumental assessment. SLTs referred almost a quarter of the sample for the assessment and management of gastro-oesophageal reflux (GOR). A statistically significant association was found between a referral from a SLT for GOR management and confirmed GOR (x^2 = 122.669, p < .001).

Table 12
Recommendations by Speech-Language Therapist for the Management of FSD

Recommendations made by SLT	*n*	% (*N* = 446)
Instrumental Assessments	202	45.3
Nil per Oral until further assessment or management	121	27.1
Referral for GOR assessment/management	100	22.4
Long term (non-oral) management for feeding	71	15.9
Admit/remain in hospital	9	2.0
PEG removal	3	0.7

The SLT recommendation for the long term management of FSD (often surgical) was statistically significantly associated with the presence of a history of growth faltering (x^2 = 11.672, $p \leq .001$), aspiration (x^2 = 33.913, p < .001), as well as the presence of multiple medical conditions (x^2 = 10.669, $p \leq .001$).

Intervention Strategies

Strategies speech-language therapists employed in the management of FSD are shown in Table 13 (*n* = 407). Facilitative strategies were used most frequently. Oral sensorimotor intervention and parent training were the main facilitative strategies SLTs used. The use of behavioural management for FSD was reported in only 5.9% (24/407) of participants.

Management involving compensatory strategies was provided to 74.7% (322/407) of participants and modifications to the consistency of feeds were made in 45% (183/407). Sixty percent (245/407) of participants were documented to have received support services, such as additional counseling of caregivers by SLTs for FSD. Referrals were also made to other professionals such as social workers or nursing sisters (stoma specialist) for the counseling of caregivers (see section 3.2.2.1. *The professionals consulted in the management of FSD*).

Table 13
Intervention Strategies Employed in the Management of FSD (n = 407)

Feeding and Swallowing Intervention Strategies	*n*	%
Facilitative Strategies	**322**	**79.1**
Oral Sensorimotor Therapy	300	73.7
Parent Training	247	60.7
Interventions for Behavioural Feeding Difficulties	24	5.9
Compensatory Strategies	**304**	**74.7**
Modified Consistency	183	45.0
Adapted Utensils/Teats	155	38.1
Position and Posture Changes	141	34.6
Modified Temperature, Volume, Taste, and Rate of presentation	63	15.5
Support Services	**245**	**60.2**
Counseling	207	50.9
Provided Resources	74	18.2
Literature/Pamphlets Provided	11	2.7

Seventy-six percent (310/407) of the sample were provided a combination of these intervention strategies. Management in 42.9% (175/407) of participants involved the combination of compensatory, facilitative, and support strategies.

Duration and frequency of services

The majority of participants (91.3%, 407/446) received management for FSD from a speech-language therapist. Figure 8 shows the duration of the SLT intervention period for FSD. The average duration of SLT intervention for FSD was 6.2 months (*SD* = 8.45,

range = 1 day - 35.6 months, *N* = 446). More than half of the participants (56.7%, 253/446) received intervention for a duration of 1-3 months from the time of the first feeding and swallowing assessment. Forty-one percent of participants had intervention sessions for only one month.

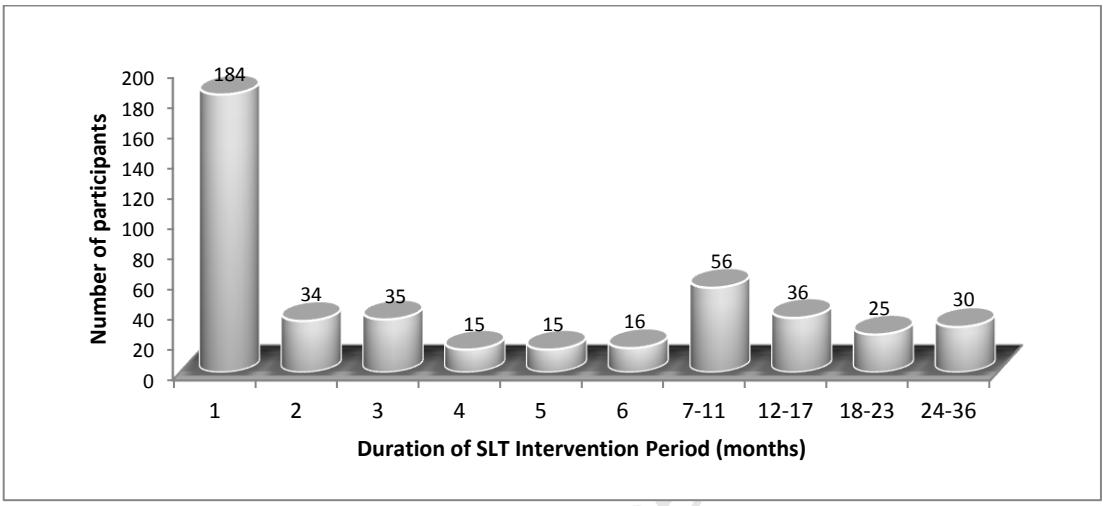

Figure 8. The Duration of the SLT Intervention Period (*N* = 446)

Participants attended an average of 6 SLT treatment sessions for FSD (*SD* = 4.80, range = 1-24). Figure 9 illustrates the mean number of SLT sessions received per period of intervention for FSD. Participants who received short intervention periods (1 - 4 months) had more regular SLT sessions. As the length of time attending SLT increased, the frequency of sessions participants attended decreased. Participants who received intervention for a period between 12 to 36 months attended a mean of 1 SLT treatment session every 2 months.

Of the 8.7% (39/446) of participants who did not receive treatment, 41% (16/39) defaulted their scheduled outpatient therapy sessions. Intervention was completed in 43.0% (175/407) of the sample. Thirty-seven percent (150/407) had defaulted on their scheduled follow-up appointments and 20.1% (82/407) were still receiving ongoing intervention at the end of the data collection period.

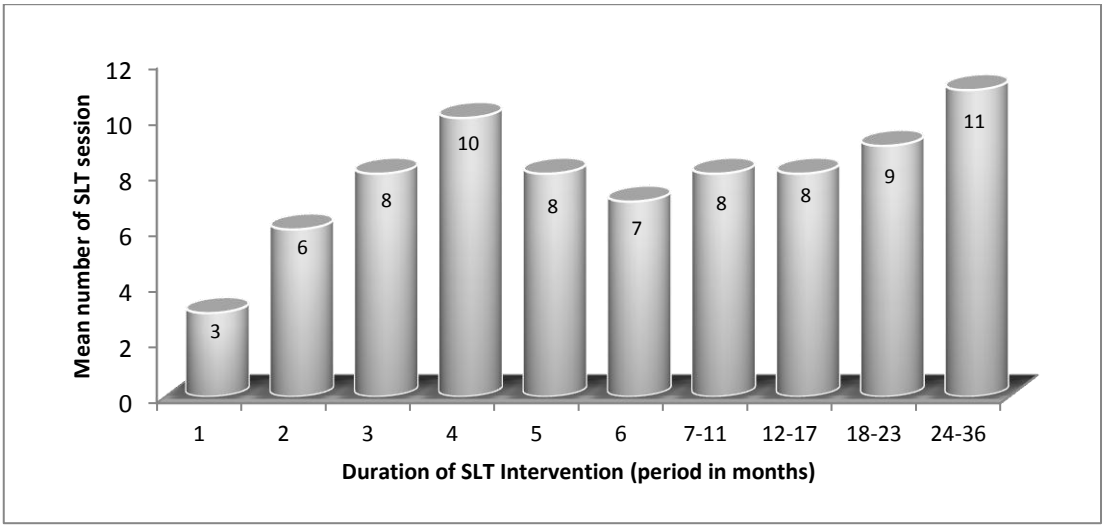

Figure 9. The Average Number of SLT Sessions Attended during Intervention (*N* = 446)

Duration of services in participants with different medical conditions

The frequency of participants with different medical conditions who received an intervention period of less than 1-month or longer can be seen in Table 14. Statistically significantly more participants with multiple medical conditions received intervention for a period of more than one month when compared to participants with an isolated medical condition (x^2 = 5.031, p < .05). Participants who presented with a combination of neurologic and GIT conditions together with a third co-morbidity (such as either respiratory/ENT conditions or TB) often received intervention for a period of longer than one month. Seventy percent of participants with isolated HIV/AIDS were seen for a 1-month intervention period or less.

Table 14
Medical Conditions Associated with a less than 1-Month or Longer SLT Intervention Period

Medical Conditions	% with ≤1-month SLT intervention period	% with >1-month SLT intervention period
Neuro + GIT + Resp/ENT	23	**77**
Neuro + GIT	25	**75**
Neuro + GIT + all	29	**71**
Neuro + GIT + TB	30	**70**
GIT + no Neuro + all	31	**69**
GIT	37	**63**
Neuro	43	**57**
Neuro + no GIT + all	48	**52**
HIV	**70**	30
GIT + HIV	**60**	40
Neuro + Resp/ENT	**58**	42
Neuro + TB	**56**	44

3.2.2.5. Mode of intake

During the SLT intervention period

Seventy-three percent (325/446) of participants with FSD received enteral feeding at some point during the SLT intervention period. The most frequently used enteral feeding methods in the study population were naso-gastric (NG) tube feeding followed by the combination of NG tube and oral feeds. Table 15 shows participants' mode of intake during the SLT intervention period.

Table 15
Mode of Intake Utilized by Participants with FSD during the SLT Intervention Period (N = 446)

Type of Feeding Method	***n*** during management	**%** during management
Oral	332	74
NG tube	285	64
Oral and NG	133	30
NJ tube	101	23
PEG/ gastrostomy	91	20
Oral and PEG	43	10
Oral and NJ	9	2

Note. The values reflected in this table are not mutually exclusive as the mode of intake may have changed during the intervention period.

Upon completion of SLT treatment

The mode of intake during management and at the last SLT session for participants who completed intervention for FSD is presented in Table 16.

Table 16
Mode of Intake recorded during Intervention and at the last SLT Session for Discharged Participants (n = 175)

Type of Feeding Method	***n*** during management	**%** during management	***n*** at the last session	**%** at the last session	**%** difference*	
Oral	125	71	131	75	5	↑
NG tube	108	62	12	7	89	↓
Oral and NG	62	35	17	10	73	↓
NJ tube	33	19	1	1	97	↓
PEG/ gastrostomy	22	13	11	6	50	↓
Oral and PEG	14	8	5	3	64	↓
Oral and NJ	6	3	0	0	100	↓

*Note.**Percentage difference were obtained by subtracting the smallest *N* from largest *N*, divided by largest *N*

The mode of intake for participants who completed SLT intervention/treatment for FSD (*n* = 175) was documented during the intervention period and at the last SLT treatment session. Following the completion of intervention, the use of all types of enteral nutrition (NG, NJ and PEG/gastrostomy tubes) was reduced (Table 16).

4. Discussion

The discussion is organized according to the aims and objectives of the present study. The major findings of the project will be presented and considered in light of current and relevant literature. The clinical and research implications of the results as well as the limitations of the study will also be discussed.

The nature and frequency of feeding and swallowing difficulties (FSD)

Findings from the present study suggest that infants and children with a variety of medical diagnoses presenting to a tertiary hospital may have difficulties affecting all of the phases of swallowing. These findings signal that the clinician working in the field of paediatric dysphagia cannot focus on only one phase during assessment as swallowing may be compromised in multiple phases. Infants and children with feeding and/or swallowing difficulties (FSD) may therefore require both clinical and instrumental assessments in order to accurately identify and effectively address the swallowing difficulty.

The presence of difficulties in multiple phases of swallowing in infants and children (with numerous medical co-morbidities) is supported by limited literature (Field et al., 2003; Rommel et al., 2003). However, differences in the definitions and methodologies used by these studies do not facilitate comparison with the present findings. For instance, the broad use of the term *dysphagia* in the study by Field et al. (2003) makes it difficult to determine the nature of the difficulties in the different phases present among their participants. Nevertheless, it was clear that participants in both the studies by Field et al. (2003) and Rommel et al. (2003) presented with either oral preparatory, pharyngeal or oesophageal phase difficulties.

Although difficulties in all of the phases of swallowing were documented in the current study, oral preparatory phase difficulties occurred most frequently. In contrast, fewer than expected participants had documented oral phase difficulties. A possible reason for the large number of documented oral preparatory phase difficulties may relate to the age distribution of the sample. Over half (53%) of the participants were under the age of 1 year and during this period the majority of the infants would be suckling/sucking. The oral

preparatory phase during suckling/sucking mainly relates to latching and milk transfer from a bottle/breast (Arvedson & Brodsky, 2002) whereas the oral phase includes the posterior propulsion of the bolus which is essentially already initiated by the sucking act during milk transfer (Arvedson & Brodsky, 2002). Due to this rapid transition from oral preparatory to the oral phase of swallowing, the separation of these phases in young infants may be difficult to distinguish, possibly resulting in the combined reporting of these two phases which may account for the high frequency of oral preparatory phase difficulties reported for this study's participants. Similarly, half of participants in the study by Rommel et al. (2003) were also aged less than 1 year, and no mention is made of oral phase difficulties specifically. It is unclear whether oral phase difficulties were not reported separately from oral preparatory phase difficulties or were absent in their participants (Rommel et al., 2003). In addition, not all of the participants in the present study were assessed instrumentally, which may have resulted in clinicians reporting on bolus formation and oral transit together.

The high number of oral preparatory phase difficulties reported in participants may also be related to the number of neurologic conditions (56%) underlying FSD in this population. Multiple studies have frequently reported oral preparatory phase difficulties in infants and children with neurologic difficulties – especially among children with cerebral palsy (CP) (Barkat-Masih et al., 2010; Field et al., 2003; Ng, et al., 2004; Reilly et al., 1996; Rommel et al., 2003). Therefore, present results support reports in literature. However, limited information about the nature of FSD reported in these studies hamper comparisons. Some studies described the oral skills of their participants, but omitted descriptions of difficulties in other phases of swallowing (Barkat-Masih et al., 2010; Reilly et al., 1996). Calis et al. (2008) on the other hand documented signs of difficulties in all of the phases of swallowing in children with severe CP but did not report on the frequency of these difficulties. While difficulties in other phases of swallowing may also be prevalent in infants and children with neurologic difficulties, poor oral skills remain the most frequently reported feeding difficulty associated with neurologic conditions.

The present findings suggest that infants and children with FSD frequently present with poor oral skills (Field et al., 2003; Rommel et al., 2003), implying that the majority of this population may be inefficient at managing a bolus. An uncontrolled bolus associated with poor oral skills may result in increased risk of premature spillage and aspiration. The inadequate management of a bolus may therefore have direct implications with regard to the safety of the swallow in terms of airway protection. Poor oral skills may not only

compromise the safety of swallowing, but may also impede an infant or child's ability to receive adequate nutrition and hydration. For example, the continued loss of the bolus anteriorly may result in decreased intake which may be insufficient to maintain growth. While growth faltering may be related to the presence of an underlying medical condition (Rossi et al., 2002), 59% of participants with FSD presented with growth faltering during the review period. Undernutrition before the age of 24-months places an infant at risk for long lasting growth, cognitive, social, emotional, and communication deficits (Arvedson & Brodsky, 2002). Present findings indicate that the nutritional status of infants and children with FSD may be compromised to such an extent that growth faltering may occur and emphasizes the need for the early identification of FSD in order to prevent the cycle of under nutrition and associated morbidity (Arvedson & Brodsky, 2002). Furthermore, these findings reinforce the need for the collaboration of health care professionals in an interdisciplinary team approach and particularly the inclusion of dieticians in the management of FSD.

The presence of poor oral skills may also require an increased amount of time for an infant or child to consume adequate calories. Twenty-five percent of participants in the current study presented with general signs of FSD of which increased feeding times were reported most frequently. While a possible reason for the extended feeding times required by participants may relate to the high number of participants with poor oral skills reported, difficulties in other phases of swallowing may also contribute to the increased time an infant or child needs to complete a meal. Longer feeding times in infants and children may serve as an important indicator of the presence of FSD that could alert clinicians to the need for further investigation.

Although the majority of infants and children presented with poor oral skills, pharyngeal phase difficulties (as documented instrumentally) were recorded in 48% of the participants. The mechanisms involved in airway protection during swallowing may therefore be compromised in many infants and children with FSD (Arvedson, Brodsky, & Christensen, 2002). Almost a third of participants in the present study had a delayed pharyngeal swallow initiation which increases the risk of aspiration as the bolus may pool in the valleculae and/or pyriform sinuses *prior* to the closure of the airway (Arvedson, Brodsky, & Christensen, 2002). Thirty-eight percent of participants presented with laryngeal penetration, and while normally developing infants or children may clear the laryngeal vestibule without difficulty, this may not be possible in a neurologically compromised infant or child and aspiration may follow (Arvedson & Brodsky, 2002). While not all children with laryngeal penetration and/or delayed

pharyngeal swallow initiation aspirate, they remain at high risk for aspiration (Weir et al., 2007) and should be carefully monitored by caregivers and clinicians for signs and symptoms of aspiration. Therefore the clinician managing an infant or child with laryngeal penetration and/or delayed pharyngeal swallow initiation should equip the primary caregiver with the knowledge required to monitor their infant or child for possible signs and symptoms of aspiration. The clinicians should also ensure regular follow up with health care professionals to monitor these at risk infants and children.

Oesophageal phase difficulties were seldom reported (7%). While the frequency of oesophageal phase difficulties was low, the clinical impact of these difficulties on feeding could be of concern. Problems in the oesophageal phase such as structural anomalies and oesophageal dysmotility may result in retrograde movement of the bolus from the oesophagus into the pharynx. This retrograde movement may place an infant or child at risk for aspiration (Arvedson, 2008) and can disrupt successful feeding (Arvedson & Brodsky, 2002).

In addition to difficulties affecting the different phases of swallowing, nearly all of the participants in the current study presented with at least one medical condition underlying their FSD. The majority of participants presented with multiple medical conditions (65%) underlying their FSD. It had been anticipated that the participants would present with a wide variety of medical conditions as documented in literature (Arvedson, 2008; Arvedson & Brodsky, 2002; Cooke et al., 2009; Cooper-Brown et al., 2008; Einarson & Arthur, 2003; Field et al., 2003; Groenewald et al., 2003; Hall, 2001; Kirby & Noel, 2007; Lefton-Greif et al., 2006; Lefton-Greif & Arvedson, 2007; Logemann, 1998; Norman et al., 2007; Pressman, 1992; Rodgers & Arvedson, 2005; Rommel et al., 2003; Sachdeva et al., 2007; Sheikh et al., 2001; Stoner et al., 2006; Sullivan et al. 2006; Truong et al., 2007; Winstock, 2006; Wright & Goddard, 1997). However, the high frequency of co-morbidities with which participants presented is in contrast to reports by Rommel et al. (2003). Almost two thirds of participants presented with more than one medical condition whereas Rommel et al. reported that only a third of their participants presented with multiple co-morbidities.

The increased frequency of co-morbidities in infants and children with FSD in the current study may relate to the different *burden of disease profile* present in South Africa (WHO, 2010a). For instance, the prevalence of prematurity in South Africa is among the highest reported globally (Beck et al., 2010). Preterm birth places an infant at increased risk for medical conditions affecting multiple organ systems and specifically neurologic conditions

(Hawdon et al., 2000; Schädler et al., 2007). In addition, South Africa is faced with poor access to antenatal care and specialized professionals during delivery (South Africa & UNDP, 2010; UN, 2010) which may result in increased birth related complications and morbidity, particularly neurologic sequelae. The high number of participants in the present study with neurologic conditions and medical co-morbidities may therefore relate to the high prevalence of prematurity and lack of services in South Africa. Present findings therefore signal that clinicians based at tertiary health care institutions in South Africa should be aware of the likelihood that two out of three infants and children with FSD will probably have multiple medical conditions. Clinicians should therefore maintain an acute clinical awareness when managing infants and children with multiple medical conditions as they may present with a higher risk for FSD.

Premature infants are a known high risk group for FSD (Arvedson & Brodsky, 2002; Burklow et al., 1998; Giambra & Meinzen-Derr, 2010; Hall, 2001; Lefton-Greif & Arvedson, 2007; Rommel et al., 2003; Sheikh et al., 2001). Similar to reports in literature, almost a third of participants with FSD in the current study had a history of prematurity (Burklow et al., 1997; Rommel et al., 2003; Schädler et al., 2006). However, when participants with a history of prematurity were compared to term participants, they did not present differently with regard to difficulties in the oral preparatory, pharyngeal or oesophageal phases of swallowing. A possible reason for finding no differences in these factors between the two participant groups (those with a history of prematurity and those born at term) may relate to the fact that all of the infants and children in the current study presented with FSD and various underlying medical conditions.

However, current findings signal that in a sample of infants and children with FSD, significantly more participants with a history of prematurity had oral phase difficulties when compared to term participants; this would imply that poor sucking/suckling in the premature infant may relate to poor bolus propulsion. Premature infants (with a gestational age of <34 weeks) often present with disorganized suck/swallow/breathe patterns or immature suckling (Arvedson & Brodsky, 2002; Hall, 2001) as the respiratory and central nervous systems are still developing (Arvedson & Brodsky, 2002; Delaney & Arvedson, 2008) and continue to mature from 34 to 42 weeks gestation (Da Costa, Van den Engel-Hoek & Bos, 2008). However, present findings are limited as swallowing difficulties were documented retrospectively and do not necessarily reflect difficulties experienced by premature infants during the neonatal stage. The presence of oral difficulties associated with a history of

prematurity is however supported by the results of Hawdon et al. (2000). The caregivers of infants with oral motor difficulties in their study continued to report difficulty with feeding at 6 and 12 month follow ups (Hawdon et al., 2000). Oral difficulties may therefore persist in infants with a history of prematurity which may indicate a need for ongoing monitoring and management for FSD in preterm infants. Future prospective studies are needed to compare the prevalence of FSD in premature infants versus those born at term, to determine the nature of difficulties experienced by these groups during infancy, and compare outcomes at later stages in these participants' feeding development.

Participants in the current study presented with a wide range of medical conditions affecting different organ systems. The most frequently reported medical conditions from this record review were neurologic, followed by GIT, and respiratory. The functioning of each of these systems (the neuromuscular and aerodigestive) is required for effective oral feeding (Arvedson & Brodsky, 2002; Hall, 2001) and it is therefore not unexpected that they were most frequently affected in the study participants. Although research identifying medical conditions underlying paediatric FSD has many methodological differences complicating comparisons, the two most frequently reported conditions reported in literature are those affecting neurologic and GIT function (Field et al., 2003; Rommel et al., 2003). The frequency of respiratory conditions however was not reported and future studies may provide a basis for comparison with the present findings.

Neurologic conditions were most frequently reported in present participants and are often mentioned in the literature as a contributing factor to FSD (Arvedson & Brodsky, 2002; Hall, 2001; Rommel et al., 2003; Sheikh et al., 2001; Winstock, 2006). Of the neurologic conditions, CP was most frequently reported. The number of neurologic conditions and CP in the present study appears to be higher than that reported by other studies (Field et al., 2003; Rommel et al., 2003). Field et al. (2003) reported neurologic conditions in 30% of their participants of which 42% had CP. The high number of neurologic conditions in the present study may again relate to the different burden of disease profile of South Africa (WHO, 2010a). Various factors including the high prevalence rate of prematurity (Beck et al., 2010) and poor access to services required to reduce birth complications (South Africa & UNDP, 2010; UN, 2010) may result in increased neurologic morbidity in South Africa. Furthermore, 41 - 60% of premature infants with FSD also have neurologic conditions, of which cerebral palsy (CP) is the most common (Hawdon et al., 2000; Schädler et al., 2007).

Neurologic conditions in present participants were often reported with associated co-morbidities of which GIT conditions were most frequently documented. These results are supported by Rommel et al. (2003) who also found neurologic and GIT conditions frequently co-existed in their participants. Of the GIT conditions, GOR (a sign of a GIT condition) was reported most frequently in study participants, which is similar to the findings reported by Field et al. (2003) and Rommel et al. (2003). Some studies have found that infants with GOR present with more FSD, particularly food refusal (Duca et al., 2008; Field et al., 2003; Mathisen et al., 1999) than those without GOR. Even though a large number of infants and children with FSD may present with GOR/D (Field et al., 2003; Rommel et al., 2003), the impact of GOR/D on feeding and the swallowing mechanism is not yet well defined and no causal relationship has been established (Vandenplas et al., 2009). Studies are needed to establish whether the successful medical and/or surgical treatment of GOR/D resolves FSD in infants and children.

The frequency of HIV/AIDS reported in study participants was lower (12%) than had been anticipated for the study sample, in light of the high prevalence of HIV/AIDS in South Africa (UNAIDS, 2010a, 2010b). However, when compared to the prevalence rate of the Western Cape (15.7%) rather than South Africa as a whole (31%) (South African Department of Health, 2007), the frequency of HIV/AIDS reported in the current study is more consistent with the prevalence rates reported for the province. The present study population with HIV would have received anti-retroviral (ARV) treatment if indicated, which may account for a lower frequency of infants and children with HIV in this population with FSD. However there is no literature available describing the impact of ARV treatment on FSD in infants and children with HIV. Even though infants and children with HIV/AIDS are a known risk group for FSD, only dated international prevalence reports for FSD in this population are available and range from 21% (Pressman, 1992) to 50% (Melvin et al., 1997). These prevalence rates may however no longer reflect current frequencies as the studies were conducted before ARV treatment programmes were established. Future studies may wish to ascertain the incidence and prevalence rates of FSD in infants and children with HIV/AIDS in South Africa.

Infants and children with HIV/AIDS in the present study may have been identified and managed earlier than other participants (at the mean age of 5 months) as they are especially vulnerable to respiratory infections (Graham, 2003; Zar, 2004). Pneumonia is reported as the most frequent reason for hospitalization or mortality before the age of 6 months in infants with HIV/AIDS (Finlayson & Eley, 2007; Weakley et al. 2009). While there

are no data available linking FSD in infants with HIV/AIDS to the high prevalence of pneumonia specifically, the earlier hospitalization of this population may be the reason for the earlier detection of FSD. Future studies may determine whether the presence of FSD is associated with an increased frequency of pneumonia in infants with HIV/AIDS.

While the present study set out to identify and describe difficulties in specific phases of swallowing in different medical conditions, the high frequency of co-morbidities made it difficult to link the presenting swallowing problem to a particular medical condition. Furthermore, participants presented with difficulties in multiple phases of swallowing regardless of the presence of isolated medical conditions or co-morbidities. The present findings therefore provide insight into the clinical picture of paediatric dysphagia by illustrating the multiplicity of difficulties, as most participants had more than one phase affected as well as multiple underlying co-morbidities. Although literature documenting the nature of FSD in different medical conditions is limited, the presence of difficulties in multiple phases of swallowing has been reported (Baudon et al., 2009; Calis et al., 2008; Duca et al., 2008; Eischer et al., 2000; Hopkin et al., 2000; Lefton-Greif et al., 2006; Mathisen et al., 1999; Ng et al., 2004; Norman et al., 2007; Pressman, 1992; Rommel et al., 2003). Clinicians cannot assume that an infant or child with a specific medical condition will present with only one type of FSD or difficulty in any one particular phase of swallowing. Feeding and swallowing therefore need to be comprehensively assessed.

More than half (57%, 150/263) of the participants in the present study, who were assessed instrumentally, aspirated on food or fluids during feeding. This suggests that the mechanism protecting the airway was often compromised in the study participants, leaving them vulnerable to potential respiratory sequelae or life threatening episodes (Arvedson & Brodsky, 2002; Kirsch & Sanders, 1988; Lodha et al., 2002; Loughlin, 1989; Owayed et al., 2000; Weir et al., 2007). Clinical signs of possible aspiration were reported in 49% of participants whilst 34% of all participants were confirmed to aspirate via instrumental assessment. Two reasons may be offered for the 15% discrepancy between the reported clinical signs of possible aspiration and the presence of confirmed aspiration. The management of FSD for some participants was still ongoing at the end of the data collection period, and these participants may have been waiting to be assessed instrumentally. The cases of confirmed aspiration may therefore have increased if the instrumental assessment results for all of these participants were available at the time of data collection.

Another reason may be offered for the discrepancy between the frequency of clinical signs of possible aspiration and confirmed aspiration in the present study. Clinical signs of possible aspiration cannot be used to confirm the presence of aspiration as it may also relate to underlying medical conditions. These signs are less specific than instrumental findings, but does allow the clinician to comment about the inferred risk of/or possible presence of aspiration. The nature of clinical signs may therefore result in an over-referral for instrumental assessments (DeMatteo et al., 2005). The discrepancy between clinical signs of possible aspiration and confirmed aspiration may be clarified by the findings of DeMatteo et al. (2005). They demonstrated that the clinical feeding and swallowing assessment administered by experienced clinicians have 92% sensitivity for detecting fluid aspiration, but only 33% for the aspiration of solids. While clinicians were more confident and able to positively infer the presence of fluid aspiration, 46% of their referrals to VFSS were false-positives where participants with clinical signs of fluid aspiration did not aspirate on VFSS (DeMatteo et al., 2005). In addition, the absence of clinical signs during silent aspiration may make the clinical inference regarding the presence of possible aspiration impossible. Literature shows a high frequency of silent aspiration in infants and children with FSD (Mathisen et al. 1999; Sheikh et al., 2001), particularly in children with neurologic difficulties (Arvedson et al., 1994; Giambra & Meinzen-Derr, 2010). The instrumental assessment of swallowing is therefore crucial for the accurate diagnosis of aspiration and appropriate management.

The present findings also signal that aspiration is significantly associated with the presence of GOR/D in participants and supports reports in literature (Duca et al., 2008; Giambra & Meinzen-Derr, 2010). The presence of GOR/D may lead to the inflammation of the mucosa of the upper aerodigestive tract which may impede the normal initiation of swallowing and mechanisms of airway protection, placing infants and children with GOR/D at a higher risk for aspiration (Arvedson & Brodsky, 2002; Rossi et al., 2002). Field et al. (2003) proposed that the early management of GOR/D in infants and children may prevent the development of FSD. Future research is needed to establish whether the management of GOR/D may reduce the presence of aspiration and related respiratory sequelae in the paediatric population.

The frequency of aspiration in the current study varied among different medical conditions and increased in the presence of co-morbidities. Significantly more participants with multiple medical conditions underlying FSD aspirated when compared to those with

isolated conditions. Infants and children with multiple medical conditions underlying FSD present with a higher risk for aspiration and associated respiratory disease (Weir et al., 2007) than those with isolated medical conditions. This finding has direct clinical implications as it signals that clinicians should maintain an acute clinical awareness when managing infants and children with multiple medical conditions as they may present with a greater risk for aspiration. Clinicians working with medically complex patients with FSD should therefore be skilled in identifying the clinical signs of possible aspiration and interpreting the results of instrumental assessments (American Speech-Language-Hearing Association, 2001) to ensure that aspiration is detected and managed promptly and effectively to attempt to reduce preventable respiratory sequelae.

Lower respiratory tract infections (LRTI) were often reported (62%) among participants of which the cause was mostly unspecified in medical records. While a causal relationship between aspiration and LRTI has not been established in the literature, an association between the two has been described (Kirsch & Sanders, 1988; Lodha et al., 2002; Loughlin, 1989; Owayed et al., 2000; Weir et al., 2007). The findings in the current study support this association and suggest that when the etiology of LRTI was unspecified, participants were likely to have a history of aspiration. Literature also supports the possible link between LRTI with an unidentified etiology in infants and children with FSD and aspiration (Bossley et al., 2010; Lefton-Greif et al., 2006). Therefore, in infants and children with FSD, clinicians should consider the presence of aspiration in the differential diagnosis of LRTI with an unknown cause. The respiratory consequences of aspiration have been reported by various authors (Kirsch & Sanders, 1988; Lodha et al., 2002; Loughlin, 1989; Owayed et al., 2000; Weir et al., 2007). Therefore, when left untreated, aspiration and associated respiratory sequelae may place a high burden on the health care system of a developing country. Ninety-four percent of participants with LRTI in the present study were hospitalized for respiratory compromise and some required up to 12 admissions. These findings have several implications for the possible prevention and treatment of LRTI/pneumonia, one of the leading causes of infant mortality in the Western Cape and globally (Groenewald et al., 2003; UN, 2010; WHO, 2010a). The early identification and management of aspiration associated with FSD in infants and children may resolve respiratory symptoms (Sheikh et al., 2001), prevent further pulmonary morbidities (Khooshoo et al., 2001) and reduce associated hospitalizations (MacIntyre et al., 2003).

The nature of service delivery for feeding and swallowing difficulties (FSD)

The main referral sources for dysphagia services for the assessment of feeding and swallowing in the present study were medical practitioners/specialists. This finding may relate to the research setting for this study; a dysphagia service based at a tertiary hospital. Given the complex medical histories with which participants presented, it was to be expected that medical practitioners would play an important role in identifying possible signs of FSD. The frequency of referrals by participants' caregivers (2%) however was lower than had been anticipated. A few suggestions may be offered for the low frequency of self-referrals to the tertiary dysphagia service: parents may seek help at community clinics which are more easily accessed, where community health workers or medical personnel would make the necessary referrals to tertiary services (South African Department of Health, 2009). FSD may be underestimated by parents (Calis et al., 2008), where they may not see the need to seek help to manage difficulties. Parents may also be unaware of the services available to them for the management of FSD, or referrals may be the result of respiratory illness or other health-related factors rather than identified FSD, implying late identification and later in-hospital referrals for feeding and swallowing assessments.

Tertiary level care in South Africa should be typically preceded by management at primary/district level services (Mojaki et al., 2011). However, as there are currently no SLT posts or dysphagia clinics available at primary levels of care in the Western Cape (National Speech Therapy/Audiology Forum, 2007; South African Department of Health & Provincial Government of the Western Cape, 2007), infants and children with FSD should have direct access to services at whatever level it is available. Present findings however indicate that very few participant caregivers made self-referrals which suggest that infants and children with FSD are reliant on health care professionals for referrals. Furthermore, the provision of dysphagia services only within a tertiary level does not situate well within current South African health policies as it does not fit into the proposed shift from curative to preventative health care (South African Department of Health, 1997, 2011).

Paediatric dysphagia services should be available at primary and secondary levels of health care as the provision of these services solely at a tertiary level may create problems of accessibility. Within the developing context of South Africa with limited resources, not all caregivers of infants or children with FSD would have the means to commute long distances to access dysphagia services at a tertiary hospital. The provision of dysphagia services only at

a tertiary level may increase already inflated SLT caseloads (National Speech Therapy/Audiology Forum, 2007) and create long waiting periods, thereby reducing access even further. The provision of dysphagia services at primary/community levels would therefore relieve tertiary caseload burdens and improve accessibility for patients. Community-based dysphagia services may have similar successful outcomes to that of nutritional intervention provided at primary levels of health care in Bangladesh (Hossain, Nahar, Hamadani, Ahmed, & Brown, 2011). The provision of community-based services for nutritional intervention has proved successful in increasing the attendance to nutritional services, reducing costs and improving growth outcomes (Hossain, et al., 2011; WHO, World Food Programme, UN System Standing Committee on Nutrition & UN Children's Fund, 2007). Similar community-based dysphagia services in South Africa could increase access to services, provide intervention for FSD early, and focus on the prevention of FSD-related respiratory sequelae and growth faltering.

Participants in the present study received services from a wide variety of health care professionals related to the FSD and multiple medical conditions with which they presented. The management of paediatric FSD typically is better through the collaboration of multiple health professionals which suggests that interdisciplinary teamwork, as advocated by some authors, would optimize outcomes (Arvedson & Brodsky, 2002; Ayoob & Barresi, 2007; Barratt & Ogle, 2010; Field, et al., 2003; Hall, 2001; Rommel et al., 2003; Silverman, 2011). Professionals consulted by over half of the participants included: SLT, dietician, paediatrician, and a radiologist. The identification of this core team of professionals consulted for FSD at a tertiary level provides insights into the requirements of future community-based dysphagia services in the context of a developing country with limited resources.

The South African Department of Health (2011) has recently proposed the use of district-based clinical specialist support teams together with a plan for re-engineering the provision of primary health care (PHC) services. These district-based specialist teams will include: an obstetrician, gynaecologist, paediatrician, family physician, anaesthetist, midwife, and a nurse with the specific aim at reducing maternal and infant mortality rates in South Africa (South African Department of Health, 2011). However, there is no mention in the proposal of the inclusion of rehabilitation health care professionals, and thus the management of infants and children with FSD may not be adequately addressed at the primary level of care. Present findings support the inclusion of dieticians and SLTs in the core

specialized team based at the district level in order to facilitate the promotion, prevention, early identification, and management of FSD at primary levels of health care.

Considering the complex nature of FSD with which infants and children present, the comprehensive assessment of these difficulties may be two-tiered and may include both a clinical and instrumental swallow assessment (Arvedson & Brodsky, 2002; DeMatteo et al., 2005; Hall, 2001). The majority (77%) of participants in the present study were assessed clinically which allowed SLTs to determine the functioning of the oral preparatory and oral phases as well as a child's relative risk for aspiration through the observation of clinical signs (Arvedson & Brodsky, 2002; DeMatteo et al., 2005). The presence of aspiration can only be confirmed via instrumental assessment. Clinicians would therefore require access to VFSS/MBS radiographic facilities in order to establish not only the presence of aspiration but the reason for aspiration, and to make specific statements about other difficulties in the pharyngeal and oesophageal phases of swallowing. Due to the nature of the research site, a tertiary paediatric hospital, some participants were likely referred from another site specifically for an instrumental swallowing assessment and therefore not all study participants were assessed clinically. Poor access to this type of specialized equipment (VFSS/MBS) along with limited SLT posts in the South African public health sector, is concerning, as individuals may not be assessed comprehensively, which will negatively impact the effectiveness of the subsequent management of FSD.

Following the assessment of feeding and swallowing, almost a quarter of study participants were referred by SLTs for the evaluation and management of GOR/D. Furthermore, a statistically significant association was found between a referral from Speech Therapy for the management of GOR/D and the actual presence of GOR/D. While it is not within the scope of practice of SLTs to diagnose or manage GOR/D, the present findings suggest that SLTs may act as important referring agents for the identification and management of GOR/D in infants and children with FSD. SLTs need to collaborate closely with other medical practitioners when treating FSD to ensure that underlying GOR is promptly and effectively managed to minimize its' potentially negative impact on feeding and swallowing.

In light of the complex medical histories underlying FSD with which participants presented, the collaboration of a range of health care professionals using an interdisciplinary team approach is best suited in the management of FSD (Arvedson, 2008; Arvedson & Brodsky, 2002; Ayoob & Barresi, 2007; Barratt & Ogle, 2010; Craig et al., 2003; Field, et al.,

2003; Hall, 2001; Lefton-Greiff & Arvedson, 2008; Rommel et al., 2003; Silverman, 2011). As part of the team, the SLT in South Africa is responsible for the assessment of feeding and swallowing difficulties as well as the implementation of oral sensorimotor intervention programmes where appropriate (HPCSA, 2008; SASLHA Ethics and Standards Committee, 2011). The SLT management strategies most frequently reported in participants included the combination of facilitative, compensatory and support strategies. This combination of strategies may be best suited to develop appropriate feeding skills, target mealtime participation and interaction whilst achieving adequate nutrition and hydration through the promotion of safe swallowing. Literature supports the use of combined strategies to maximize treatment outcomes (Arvedson, Brodsky, & Reigstad, 2002; Gisel, 2008; Hall, 2001). The management of paediatric FSD is most effective when the infant or child is considered holistically (Arvedson, 2008; Arvedson, Brodsky, & Reigstad, 2002). The SLT management strategies should therefore not be rigid, but rather mirror the complexity of the FSD with which the infant or child may present, together with a consideration for the home environment.

SLTs also aimed to carryover the techniques for the management of FSD to participant caregivers through *parent/caregiver training*. The caregivers of infants and children with FSD also often received support in the form of counselling related to FSD as well as management options as provided by the SLT. Further counselling may also be provided by other health care professionals such as social workers, psychologists and nursing sisters (with specialised stoma training). Literature highlights the need for parent support as caregivers often report feeling neglected in terms of the management of their child's FSD at home as well as the provision of adequate information (Hewetson & Singh, 2009; Stoner et al., 2006). Caregivers should be included in the management of their infant or child's FSD and should always form part of the decision-making process (Craig et al., 2003; Petersen et al., 2006). The management of paediatric FSD should therefore be family-centred where the provision of *parent training*/counselling forms an integral part of management strategies. Continued support may be provided to the families of infants and children with FSD by establishing caregiver support groups which may be used as a platform for providing information specifically targeting the evolving needs of caregivers.

The management of paediatric FSD may also require periods of non-oral feeding when nutritional intake orally is inadequate or the safety of the swallow has been compromised (Arvedson, Brodsky, & Reigstad, 2002). Enteral feeding was required in the

majority (73%) of participants in the present study at some point during their management, in contrast to only a quarter of participants in the study by Rommel et al. (2003). Participants in the current study presented with more multiple medical conditions (65%) than reported in the study by Rommel et al. (33%) which may indicate greater medical complexity requiring more enteral feeding in present participants. Furthermore, while over a third of participants in the present study aspirated, the frequency of aspiration was not documented in the study by Rommel et al.; therefore the majority of infants and children with FSD in the present study may have been deemed to have an *unsafe* swallow for which alternative feeding methods may have been considered. Clinicians would need to consider the medical conditions underlying FSD and collaborate with other health care professionals regarding the need for short- versus long-term enteral feeding.

Twenty-five percent of participants in the present study required long-term enteral feeding, implying that a quarter could not adequately or safely meet nutritional needs through oral feeding. The surgical intervention received most often was a combination of a Percutaneous Endoscopic Gastrostomy (PEG)/gastrostomy tube and Nissen Fundoplication which is expected in light of the high frequency of participants who presented with GOR/D. The recommendation for long-term enteral management of FSD was associated with a history of growth faltering, aspiration, and the presence of multiple co-morbidities. These findings are supported by multiple studies (Fortunato, et al., 2010; Norman et al., 2011; Novotny et al., 2009; Van der Merwe et al., 2003) documenting dysphagia, aspiration, and growth faltering as the most common indications for long-term enteral feeding. Norman et al. (2011) also suggest that the majority of PEG/gastrostomy tube candidates had multiple medical co-morbidities. The decision regarding a child's need for a PEG/gastrostomy tube may therefore be influenced by multiple factors where specific consideration must be given to factors such as the presence of co-morbidities, aspiration, and growth faltering.

Following the completion of intervention for FSD, the use of all enteral modes of feeding was markedly reduced with the majority of participants no longer requiring enteral feeding. Even the use of long-term enteral feeding was reportedly reduced by more than half in participants who were discharged from SLT services. These findings are in contrast to Van der Merwe et al. (2003) who reported PEG/gastrostomy tube removal in only a limited number (10%) of their participants, most of whom had cerebral palsy (CP). A possible reason for the contrasting results may relate to the high number of children with CP in Van der Merwe's study. While FSD in children with a chronic condition such as severe CP could be

addressed with compensatory techniques (e.g. positioning and posture changes), the underlying neurologic cause of the FSD cannot be resolved. It is therefore likely that long-term enteral feeding in children with CP may be used as a more permanent solution to FSD where the use of compensatory techniques might not be sufficient. Long-term enteral feeding among children with CP or severe neurologic conditions have been linked to positive health and growth outcomes (Craig et al., 2006; Sullivan et al., 2005; Sullivan et al., 2006).

Another reason for the difference in frequency of PEG/gastrostomy tube removal reported in the present study when compared to the findings by Van der Merwe et al. (2003) may be offered. Current findings only reflect the outcomes of those participants who were discharged from SLT services, implying that a higher number of PEG/gastrostomy tube may have been removed as FSD in these participants were resolved. Present findings are however limited as the medical conditions of the discharged participants were not described. The use of short/long term enteral feeding may be utilized as a effective support strategy in the presence of paediatric FSD by providing adequate nutritional support and potentially preventing aspiration-related respiratory morbidity (Arvedson, Brodsky, & Reigstad, 2002; National Alliance for Infusion Therapy & ASPEN Public Policy Committee and Board of Directors, 2010; Townsend et al., 2008).

The number of participants who completed intervention and were discharged from SLT services (43%) may be an under-representation of the true number of participants whose FSD resolved because 37% defaulted on scheduled follow-up appointments. Although the reasons for missed follow-up appointments are unknown, a number of suggestions may be offered: Participants' FSD may have been resolved and caregivers saw no need to keep scheduled appointments. Furthermore, follow-up appointments may have been scheduled as out-patient services which required commuting long distances for some participants as almost two thirds of participants resided outside of the hospital's catchment area with a few even from neighbouring African countries. The attendance at SLT services may therefore have been influenced by the accessibility of these services.

Other reasons for poor attendance to out-patient SLT services in general are offered by Overett & Kathard (2006). They describe that participants may not want therapy when it is offered, and may no longer see the need for intervention. They also suggested that a lack of understanding the nature of diagnoses and need for its' management may influence attendance, which emphasises the importance of providing caregivers of infants and children with FSD with information, education, and counselling. Overett & Kathard suggest that

attendance to services may be improved by explaining the nature of the diagnosis, and discussing the roles/responsibilities of the caregiver and SLT in the management of difficulties. By ensuring that the suggestions by Overett & Kathard are included in caregiver training sessions, attendance to dysphagia services specifically may be increased. A strategy offered by international literature to increase the attendance at services is the use of phone calls/reminders prior to appointments (McPhail et al., 2010); however in the context of a developing country with limited resources and large proportions of economically disadvantaged people, this may not be a viable strategy.

The duration of SLT intervention varied according to the medical conditions and/or co-morbidities with which participants presented. While the majority of participants received SLT intervention for 1-month or less, the average intervention period was 6-months. A reason for the high number of participants who had a shorter intervention period may relate to services received on an in-patient basis or defaulting of follow-up appointments. Present findings suggest that infants and children with multiple medical conditions underlying their FSD received intervention over a longer period than participants with an isolated medical condition. As demonstrated earlier in this discussion, participants presenting with multiple co-morbidities have a higher risk of aspiration and are more likely to receive long-term enteral feeding; all of which may require a longer period of management. Therefore, by focusing early intervention programmes on high risk infants with FSD and multiple medical conditions, clinicians may identify FSD and aspiration earlier and essentially shorten the duration of intervention required for FSD.

The present profile provided an overview of the characteristics of infants and children with FSD in a South African context as well as the services received by this population. While the limitations of the study mostly relate to restrictions of the retrospective design, this design was the best suited to achieve the aims of the study. Another limitation of the study may relate to the mode of assessment as not all participants were assessed both clinically and instrumentally. The lower frequencies reported for pharyngeal and oesophageal phase difficulties could therefore relate to the lower number of instrumental assessments. It is however clinical practice to only refer infants and children with FSD for an instrumental assessment when there is concern regarding the safety of the swallow or a need to define the physiology or anatomy of the upper gastro-intestinal tract (Arvedson & Brodsky, 2002). Therefore, it could be argued that not all participants needed an instrumental assessment as clinicians did not infer the presence of any pharyngeal or

oesophageal phase difficulties clinically and that the results of the present study reflect clinical practice.

Throughout this discussion, various areas for future research have been identified. However, in order to manage the challenges posed by the complex nature of FSD, future studies may optimize outcomes by utilizing multi-centre methods through collaboration with multiple researchers. Prospective multi-centre studies may reduce the limitations that arose from the retrospective nature of the present study. Multi-centre studies may also provide larger study samples allowing for increased group sizes of medical conditions whereby the nature of FSD in more mutually exclusive co-morbidities may be reported. Future multi-centre studies may wish to establish the incidence and prevalence of paediatric FSD in South Africa as there are currently no such data available to inform health care policies.

5. Conclusion

The present study has provided a description of the nature of FSD within a paediatric population attending a tertiary dysphagia clinic in the Western Cape, South Africa. The nature of paediatric FSD and the associated medical histories with which these infants and children may present is complex. All of the phases of swallowing were affected and multiple medical conditions were reported in the participants. Furthermore, multiple phases of swallowing were affected regardless of the medical conditions or combinations underlying FSD. Present findings have therefore provided insight into the clinical picture of paediatric dysphagia in South Africa which may prepare clinicians for the multiplicity of FSD, the need for comprehensive feeding and swallowing assessment and interdisciplinary collaboration to manage both FSD and associated co-morbidities.

The present study also established that over a third of infants and children with FSD aspirated and that the presence of multiple medical conditions may increase the risk for aspiration. The respiratory consequences of aspiration are well documented in the literature (Arvedson & Brodsky, 2002; Baudon et al., 2009; Kirsch & Sanders, 1988; Lodha et al., 2002; Loughlin, 1989; Mizuno & Ueda, 2005; Owayed et al., 2000; Weir et al., 2007). The majority of the participants in the present study had a history of lower respiratory tract infections (LRTI) of which the cause was mostly unspecified. Present findings suggested that when the cause of the LRTI was unspecified, participants were likely to have a history of aspiration. This significant association between aspiration and LRTI with unspecified cause stresses the need for the early identification and management of FSD in order to prevent respiratory sequelae additional to already complex medical histories. Health care professionals may therefore utilize this information by including aspiration into the differential diagnosis of LRTI with unspecified cause in infants and children with FSD.

The majority of infants and children with FSD presented with LRTI and growth faltering in addition to multiple medical conditions. This population of infants and children are therefore at a higher risk for acquiring preventable morbidities associated with FSD. With under-nutrition and LRTI as the leading causes of infant and child mortality in South Africa (Groenewald et al., 2003; UN, 2010; WHO, 2010a), present findings have demonstrated the need for the early identification of FSD in infants and children. The provision of nutritional intervention at a primary level of health care has achieved success in Bangladesh as

increased access to services improved attendance and optimized growth outcomes (Hossain, et al., 2011). The management of FSD at primary levels of care in South Africa may prove just as successful, where the early identification and management of FSD may subsequently prevent aspiration-related respiratory morbidities, under-nutrition related to poor oral skills and unnecessary hospitalizations.

The present study has provided a description of the services received by infants and children with FSD at a tertiary level of care. This information may be utilized to inform national policies (South African Department of Health, 2011) of the need for dysphagia services at all levels within the South African health care system with particular emphasis on primary health care services. The proposed re-engineering of the primary health care system in South Africa, in particular the district-based specialized teams (South African Department of Health, 2011) may provide the ideal avenue through which the prevention, promotion, and early identification of FSD may be achieved at a primary level of care. Present findings therefore advocate for the inclusion of SLTs and dieticians into the community-based specialized teams.

Unrecognised FSD can severely compromise a child's health with direct cost implications due to increased hospital admissions. In light of only 4 years remaining for South Africa to attain the UN Millennium Developmental Goals (UN, 2010), the findings of the present study has promoted the role of the SLT in the early identification and management of infants and children with FSD at primary levels of care which may reduce preventable morbidities such as under-nutrition or aspiration-related respiratory conditions.

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7. Appendices

Appendix A: Permission Letter to Medical Superintendent

School of Health and Rehabilitation Sciences
Faculty of Health Sciences

Divisions of Communications Sciences and Disorders, Nursing and Midwifery, Occupational Therapy, Physiotherapy

F45 OldMainBuilding, GrooteSchuurHospital,
Observatory 7925
Tel: +27 (0) 21 406 6401 Fax: +27 (0) 21 406 6323

Attention:
Senior Medical Superintendent
Research Site: Paediatric Tertiary Hospital, Western Cape

Re. Permission to access medical records for the use of research

I am a Masters (MSc. Speech-Language Pathology) student at the University of Cape Town intending to conduct research within the field of paediatric feeding and swallowing difficulties. The title of my research project is: The profile of the paediatric population with feeding and swallowing difficulties at a tertiary hospital in the Western Cape.

Approval from the UCT Faculty of Health Sciences', Human Research Ethics Committee has been obtained (REC reference number: 342/2009) to conduct the proposed study. I hereby request permission to review the medical records of participants at your institution on hospital grounds from October 2009 to February 2010.

The study is a descriptive, retrospective review of medical records, which will describe the nature of paediatric feeding and swallowing difficulties as there is very limited South African based research in this field. This research will yield information aimed at describing:

- The nature of feeding and/or swallowing difficulties,
- Underlying or other medical conditions,
- Any relationships between underlying or other medical conditions and the nature of feeding and/or swallowing difficulties,
- The range of interventions and services pertaining to feeding and/or swallowing difficulties received at tertiary hospitals,
- The outcomes of interventions and services pertaining to feeding and/or swallowing difficulties

This information may equip speech-language therapists and health care practitioners working in the field of paediatric dysphagia with information describing the risk populations presenting with feeding and/or

swallowing difficulties as well as the nature of these difficulties in the South African context. This information may be applied by professionals to guide early intervention programmes aimed at the promotion and prevention of paediatric feeding and/or swallowing difficulties.

This study holds no risks to participants, due to its' retrospective nature and there will be no costs involved for the hospital. The researcher will ensure that patient anonymity and confidentiality will be maintained and the hospital's identity will be kept confidential. The researcher will additionally request permission from the Speech-Language Therapy Departments before the study commences.

Please do not hesitate to contact me if any additional information is required.

Thank you for your consideration.

Kind regards,

Ms Nici Oosthuizen
Speech-Language Therapist
Ph: 072 179 1141
nici.oosthuizen@gmail.com

Prof Marc Blockman
Chairperson of the Research Ethics Committee
Contact Details: 021 406 6492

Mrs Vivienne Norman
Research Supervisor
Division of Communication Sciences and Disorders
School of Health and Rehabilitation Sciences
University of Cape Town
Ph: +2721-4066317
Fax: +2721- 4066323
vivienne.norman@uct.ac.za

Please sign below if permission is granted:

I, [redacted], Medical Superintendent of [redacted], hereby grant permission for the study (A Profile of the paediatric population with feeding and/or swallowing difficulties at tertiary hospitals in the Western Cape) to be conducted at this research site. The nature and purpose of the study has been explained to me and I have been given the opportunity to ask questions and gain further information.

Signature: ..... Date: 27/10/09

Appendix B: Ethics Approval Letter

UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • **Facsimile** [021] 406 6411
e-mail: nosi.tywabi@uct.ac.za

09 October 2009

REC REF: 342/2009

Ms N Oosthuizen
Communication Sciences & Disorders
Health & Rehabilitation

Dear Ms Oosthuizen

PROTOCOL TITLE: A PROFILE OF THE PAEDIATRIC POPULATION WITH FEEDING & SWALLOWING DIFFICULTIES AT TERTIARY HOSPITALS IN THE WESTERN CAPE

Thank you for submitting your study to the Research Ethics Committee for review.

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

Approval is granted for one year until 16 October 2010.

Please submit an annual progress report if the study extends beyond the approval period. Alternatively, please submit a brief summary of your findings so that we can close our records.

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

Yours sincerely

Wesley Henley

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS
This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

lemjedi

Appendix C: Data Collection Checklist

Reference Number:			001	002	003	004
Research Site:						
A. Participant Characteristics	1. Geographic Information	Place of residence				
		Sub-District				
		Drainage (Southern or Klipfontein)				
	2.Biographical Information	Birth weight (g)				
		Gestational Age (weeks)				
		Prematurity (y/n)				
		Date of birth: Year				
		Date of birth: Month				
		Date of birth: Day				
		Sex (m/f)				
		Growth faltering (yes/no)				
		Tracheostomy				
	3. Medical Information	NEURO				
		GIT				
		RESP				
		CARDIAC				
		CRANIO				
		GEN				
		DEV				
		HIV				
		TB				
		OTHER				
		Number of bacterial LRTI				
		Number of viral LRTI				
		Number of aspiration related LRTI				
		Number of unspecified LRTI				
		Number of LRTI with other causes				
		Number of hospitalizations for LRTI				
		Gastro-oesophageal Reflux (GOR) confirmed via instrumental assessment				

B. Feeding and Swallowing Assessment Results (Clinical and/or Instrumental)	General Signs of Feeding Disorders	Increased resp. rate, decreased SATS				
		Tires, fatigues, decreased endurance				
		Crying, becomes distressed				
		Cough (not related to aspiration)				
		Pushes into extension, arching				
		Longer mealtimes >30min, slow feeds, not completing feeds				
		Other				
	Signs and disorders recorded in the phases of swallowing: 1.a. Oral preparatory – primarily sensory difficulties	Aversion/resistance to non-food (oral stimulation or utensils)				
		Aversion or refusal of feeds				
		Tonic bite/bites down on finger				
		Hyperactive gag response				
		Increased oral sensitivity				
		Decreased oral sensation				
		Jaw clenching				
		Teeth grinding				
		Other				
	1.b. Oral preparatory – primarily motor difficulties	Poor oral phase (General summary)				
		Drooling, poor saliva control				
		Weak/uncoordinated/absent suck				
		Poor lip closure/ant. spillage				
		Pooling of secretions/bolus				
		Uncoordinated or reduced lingual control/ poor bolus formation				
		Tongue thrust, immature A-P movement				
		Inadequate latching				
		Reduced buccal tone/ residue or pooling in lat. sulcus				
		Reduced mandibular movement/ Ineffective chewing				
		Other				
	2. Oral Phase	Reduced ant.-post. lingual movement/ poor bolus propulsion posteriorly				
		Reduced tongue elevation/ residue on hard palate				
		Increased oral transit time > 1½s				
		Reduced linguavelar seal/ premature spillage of bolus into pharynx				
		Other				
	3. Pharyngeal Phase (via instrumental assessment)	Delayed initiation of swallow/ bolus in pyriform sinuses or valleculae				
		Absent swallow initiation				
		Reduced velopharyngeal closure/ nasopharyngeal backflow				
		Laryngeal penetration				
		Aspiration (before the swallow)				
		Aspiration (during the swallow)				

		Aspiration (after the swallow)				
		Residue unspecified				
		Reduced ant. laryngeal movement/ residue in pyriform sinuses				
		Multiple swallows per bolus				
		Reduced tongue base retraction/ residue in valleculae				
		UES dysfunction/ reduced pharyngeal pressure/slow movement of bolus through UES				
		Increased pharyngeal transit time >1½s				
		Other				
	4. Oesophageal Phase (via instrumental assessment)	Oesophageal dysmotility/ retrograde bolus movement into pharynx or within oesophagus				
		Structural abnormalities				
		Other				
	Other assessment findings	Clinical signs of possible aspiration				
		Aspiration from GOR (via instrumental assessment)				

C. Services for feeding and/or swallowing disorders	1. Reason for Referral	No reason specified				
		GOR related				
		Feeding and swallowing related				
	2. Referral Date	Referral: year				
		Referral: month				
		Referral: day				
	3. Referring Agent	Medical professional (MD's)				
		Dietitian				
		Physiotherapist, OT, SLT, stoma sister, audiologist				
		Self referral, care center				
		Other				
	4. Professionals contributing to the management of feeding disorders	Speech-language therapist				
		Dietician				
		Radiologist/ Radiographer				
		Gastroenterologist				
		Stoma therapist				
		Surgeon				
		Pulmonologist				
		ENT				
		Paediatrician/doctors				
		Physiotherapist				
		Neurologist, neuromuscular, neurodevelopmental				
		Cardiologist				
		Geneticist				
		Psychologist				
		Paediatric plastic surgery				
		Occupational therapist				
		Dentist				
		Social worker				
		Other				
	5. Referrals made by SLT	Occupational therapist (sensory)/Physiotherapist				
		SLT language/audio				
		Interpreter/ counseling				
		ENT				
		GIT referral + consult				
		Dietitian				
		Respiratory clinic				
		MDRC/Toy Library				
		Other: allergy clinic, stoma, CP clinic, NDC, dentist, cleft clinic/plastics, SW, surgical Mx, school, genetics				
		Other				

	6. Management recommendations made by SLT	Recommendations made re GOR Mx, referrals made for GOR Mx				
		Referral for instrumental assessment				
		Recommend NPO				
		Long term management of FSD, surgical referral for PEG/Gastrostomy and/or Nissen Fundoplication				
		PEG removal				
		Admit/ remain hospitalized				
		Other				

D. Interventions for feeding and/or swallowing disorders	1. Feeding-related assessments	Number of clinical assessments					
		Number of instrumental assessments	Scintigraphy (Milk scan)				
			Barium swallow				
			VFSS/Modified Barium Swallow				
	2. Feeding-related surgical interventions		Nissen Fundoplication/ Anti-reflux procedure				
			Percutaneous Endoscopic Gastrostomy (PEG)-placement/ Gastrostomy				
	3. Feeding Methods		Oral				
			Naso-Gastric (NG) tube				
			Naso-Jejunal (NJ) tube				
			PEG/ Gastrostomy				
			Oral and NG				
			Oral and NJ				
			Oral and PEG				
			Total Enteral				
	4. Compensatory Strategies		Position and posture management				
			Modified temperature, volume, taste, rate				
			Modified consistency				
			Adapted utensils/teat				
	5. Facilitative Strategies		Oral sensorimotor therapy				
			Interventions for behavioural feeding difficulties				
			Parent training				
	6. Support services		Parent/caregiver counseling				
			Literature/pamphlets provided				
			Provided resources, for example, utensils				

E. Outcomes (as recorded at last SLT consultation)	1. Patient Outcomes		Discharged				
			Defaulted				
			Ongoing intervention				
			Mortality: year				
			Mortality: month				
			Mortality: day				
	2. Outcomes of SLT-related interventions pertaining to FSD	Feeding outcome	Oral				
			Naso-Gastric (NG) tube				
			Naso-Jejunal (NJ) tube				
			PEG/ Gastrostomy				
		Intervention outcomes: Compensatory Strategies	Position and posture management				
			Modified temperature, volume, taste, rate				
			Modified consistency				
			Adapted utensils				
		Intervention Outcomes: Facilitative Strategies	Oral sensorimotor therapy				
			Interventions for behavioural feeding difficulties				
			Parent training				
		Duration of SLT-services required for FSD:					
		Number of SLT-contact/services received 2007-2009					

Appendix D: Medical Conditions within Composite Medical Categories

Medical Categories	Medical Conditions	N	% (N=446)
Neurologic		**248**	**55.6**
	Cerebral Palsy	141	31.6
	Seizures/Epilepsy	18	4.0
	Hypoxic Brain Damage	17	3.8
	Encephalitis/Encephalopathy	11	2.5
	Hydrocephalus	11	2.5
	Neuromuscular Disorders	10	2.2
	Meningitis	8	1.8
	Congenital Brain Abnormalities	8	1.8
	Brain Infarction	8	1.8
	Cerebral Atrophy	6	1.3
	Head Injuries	5	1.1
	Brain Tumors	5	1.1
	Guillain-Barre Syndrome	5	1.1
	Cerebrovascular Accident	2	0.4
	Intraventricular Haemorrhage	1	0.2
	Frontal Empyema	1	0.2
	Spinal Bifida/Dysraphism	1	0.2
	Reye's Syndrome	1	0.2
	Infantile Parkinsonism	1	0.2
Gastro-Intestinal		**238**	**53.4**
	Gastro-oesophageal Reflux	224	50.2
	Oesophageal Structural Abnormalities	11	2.5
	Oesophagitis	10	2.2
	Structural Abnormalities of the Bowel	9	2.0
	Gastric Abnormalities	9	2.0
	Chemically Caused Pharyngeal Stricture	2	0.4
	Chronic Atrophic Duodenitis	2	0.4
	Duodenal Ulcer	1	0.2
	Chronic Gastroenteritis	1	0.2
	Omphalocoele	1	0.2
Respiratory		**85**	**19.1**
	Upper Airway Obstruction	38	8.5
	Chronic Lung Disease	29	6.5
	Plural disease	20	4.5
	Compromised Respiratory Function	6	1.3
	Hyaline Membrane Disease	3	0.7
	Tracheoesophageal Fistula	3	0.7
	Asthma	2	0.4
	Lung Bullae	1	0.2
	Pneumo-mediastinum	1	0.2
	Pulmonary Hypoplasia	1	0.2
	Pulmonary Oedema	1	0.2
Cardiovascular		**65**	**14.6**
	Congenital Malformations of the Cardiac Septa	43	9.6
	Congenital Malformations of the Great Arteries	38	8.5
	Pulmonary Hypertention	9	2.0
	Congenital Malformations of the Cardiac Chambers	7	1.6
	Congenital Malformations of the Pulmonary & Tricuspid Valves	3	0.7
	Congenital Malformations of the Great Veins	2	0.4
	Cardiomegaly	2	0.4
	Inflammation	2	0.4
	Patent Foramen Ovale	2	0.4
Genetic/Syndromic		**45**	**10.1**
	Down's Syndrome	15	3.4

	Fetal Alcohol Syndrome	7	1.6
	22Q deletion	4	0.9
	Edward's Syndrome	3	0.7
	Arthrogryposis	2	0.4
	Patau Syndrome	1	0.2
	Walker Warburg Syndrome	1	0.2
	VACTRL association	1	0.2
	Rubenstein Syndrome	1	0.2
	Cornelia De Lange Syndrome	1	0.2
	Tay Sach's Disease	1	0.2
	William's Syndrome	1	0.2
	Prader Willi Syndrome	1	0.2
	Chromosome 3p Deletion	1	0.2
	Incontinentia Pigmenti	1	0.2
	Sick Euthyroid Syndrome	1	0.2
	Cri Du Chat Syndrome	1	0.2
Cranio-Facial Abnormalities		**32**	**7.2**
	Cleft lip and/or Palate	16	3.6
	Micrognathia	11	2.5
	Pierre Robin Sequence	9	2.0
	Mandible Fracture	1	0.2
HIV/AIDS		**55**	**12.3**
Tuberculosis		**53**	**11.9**
	Pulmonary TB	40	9.0
	TB Meningitis	15	3.4
	Milliary/Disseminated TB	6	1.3
	Abdominal TB	1	0.2
	Tuberculoma	1	0.2
	Laryngeal TB	1	0.2
Developmental Delays		**13**	**2.9**
	Global Developmental Delays	9	2.0
	Mild-Moderate/Moderate-Severe Intellectual Disabilities	2	0.4
	Gross motor Delays	1	0.2
Other		**24**	**5.4**
	Congenital CMV/Rubella	4	0.9
	Glutaric Aciduria	2	0.4
	Metabolic Disorders	2	0.4
	Herpes Somatitis/Oral Ulcers	2	0.4
	Tumors	2	0.4
	Submental Abcsess/Thyroglossal Cyst	2	0.4
	Chemical Ingestion	2	0.4
	Thoraco-Omphalopagus Conjoined Twins	2	0.4
	Food Allergies	2	0.4
	Renal Impairment	1	0.2
	Central Diabetes Insipidus	1	0.2
	Common Variable Immunodefisiency	1	0.2
	T-Cell Immunodeficiency	1	0.2
	Acute Myoblastic Leukaemia	1	0.2

Appendix E: Mutually Exclusive Medical Categories and Combinations

MUTUALLY EXCLUSIVE CATEGORIES	N	% (446)
Neuro	75	16.8
Neuro+GIT	69	15.5
GIT	24	5.4
Neuro+TB	18	4.0
No Condition	18	4.0
Neuro+GIT+Resp/ENT	13	2.9
Neuro+Resp/ENT	12	2.7
HIV	10	2.2
GIT+HIV	10	2.2
Neuro+GIT+TB	10	2.2
Caridac+Gen	9	2.0
GIT+Cardiac	9	2.0
Cranio	8	1.8
GIT+Resp/ENT	8	1.8
Neuro+HIV	8	1.8
GIT+Gen	7	1.6
GIT+Cardiac+Resp/ENT	7	1.6
Neuro+GIT+HIV	7	1.6
GIT+Caridac+Gen	7	1.6
Other	5	1.1
GIT+Other	5	1.1
GIT+DEV	5	1.1
GIT+HIV+TB	5	1.1
Gen	4	0.9
Resp/ENT	4	0.9
GIT+TB	4	0.9
GIT+HIV+Resp/ENT	4	0.9
Neuro+Cardiac+Resp/ENT	4	0.9
Neuro+GIT+Cardiac	4	0.9
GIT+Cardiac+Gen+Resp/ENT	4	0.9
Dev	3	0.7
Neuro+Cardiac	3	0.7
Cardiac	2	0.4
TB	2	0.4
HIV+TB	2	0.4
GIT+Cranio	2	0.4
Neuro+Cranio	2	0.4
GIT+Cranio+Resp/ENT	2	0.4
GIT+Gen+Resp/ENT	2	0.4
Neuro+HIV+TB	2	0.4
GIT+Gen+Cranio	2	0.4
GIT+Cardiac+Cranio	2	0.4
Neuro+GIT+Cranio	2	0.4
GIT+Gen+Cranio+Resp/ENT	2	0.4

Neuro+GIT+Cranio+Resp/ENT	2	0.4
Neuro+GIT+Cardiac+Resp/ENT	2	0.4
Neuro+GIT+Cradiac+Resp/ENT +Other	2	0.4
GIT+Cardiac+Gen+TB+Resp/ENT	2	0.4
Resp/ENT +Other	1	0.2
Dev+Other	1	0.2
Cranio+Other	1	0.2
Neuro+Other	1	0.2
TB+Resp/ENT	1	0.2
Cardiac+Resp/ENT	1	0.2
Gen+Cranio	1	0.2
Cardiac+Cranio	1	0.2
TB+Resp/ENT +Other	1	0.2
Neuro+Resp/ENT +Other	1	0.2
GIT+HIV+Other	1	0.2
GIT+Cardiac+Other	1	0.2
Neuro+GIT+Other	1	0.2
GIT+DEV+Resp/ENT	1	0.2
GIT+TB+Resp/ENT	1	0.2
Neuro+TB+Resp/ENT	1	0.2
Neuro+HIV+Resp/ENT	1	0.2
Gen+Cranio+Dev	1	0.2
GIT+Cranio+Dev	1	0.2
GIT+Gen+HIV	1	0.2
Neuro+Cardiac+Cranio	1	0.2
Neuro+Cardiac+Gen	1	0.2
Neuro+Cardiac+Resp/ENT +Other	1	0.2
Neuro+GIT+HIV+Other	1	0.2
GIT+TB+Dev+Resp/ENT	1	0.2
GIT+HIV+TB+Resp/ENT	1	0.2
Neuro+HIV+TB+Resp/ENT	1	0.2
Neuro+GIT+Gen+Resp/ENT	1	0.2
Neuro+GIT+HIV+TB	1	0.2
GIT+Cardiac+Cranio+Resp/ENT +Other	1	0.2
Neuro+GIT+Cardiac+Gen+Cranio	1	0.2
TOTAL	**446**	**100**