

The Nature of Feeding and Swallowing Difficulties in the Paediatric Cerebral Palsy Population who have had Videofluoroscopic Swallow Studies

by

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ABSTRACT

Background: Feeding and/or swallowing difficulties (FSD) are frequently reported in children with cerebral palsy (CP). Although FSD in children with CP have received attention in international literature, research specific to FSD, in children with CP who reside in developing countries, such as South Africa, is limited. FSD may be associated with negative health outcomes such as respiratory problems and poor growth, which may contribute to morbidity and mortality. The successful planning and implementation of FSD services for children with CP, depends on the availability of information relating to the prevalence and nature of FSD in this population, as well as required services.

Research aims: To describe the nature of FSD in the paediatric population with CP who have had videofluoroscopic swallow studies (VFSS) at a tertiary hospital in the Western Cape. Objectives included a description of the (i) indicators for a VFSS, (ii) frequency and nature of FSD, (iii) association, if any, between the classification of CP and nature of FSD, (iv) nature of services provided to participants subsequent to the VFSS and (v) changes in health and feeding outcomes following the VFSS.

Methods: A descriptive, retrospective review of the medical records of 123 children with CP, who had VFSS between January 2007 and December 2009, was conducted. The median age of participants at the time of the first VFSS was 2 years, with a range from 1 month to 12 years 5 months. Male participants accounted for 50.4% of participants, and 49.6% were female. The data were described using frequency trends, and where possible, associations among variables were analysed statistically.

Results: The two main indicators for a VFSS were investigations for aspiration (81%) and gastro-oesophageal reflux (GOR) (58%). The majority of participants (86%) in this study presented with FSD. FSD were observed across all phases of swallowing, with oral preparatory (62%) and pharyngeal phase (88%) difficulties noted most frequently. Participants who presented with CP characterized by more motor and/or limb involvement, such as those with spastic quadriplegia, demonstrated FSD more frequently (87%), than those with spastic hemiplegia (60%). Seventy-seven percent of participants demonstrated aspiration on a VFSS. Aspiration was noted more frequently with liquids (77%) than with semi-solids (35%). A fifth of participants demonstrated silent aspiration on a VFSS. Participants who demonstrated aspiration on a VFSS demonstrated significantly less ($Z=2.068$; $p=.0386$) admissions related to LRTI six months after the first VFSS and subsequent management of FSD, in comparison to six months before the first VFSS without any management of FSD. Participants received services from a team of health care professionals with the speech-language therapist (SLT) (92%) and dietician (86%) consulted most frequently. Recommendations regarding the safest mode of intake (87%) was the main intervention provided by the SLT. Thirty-three percent ($n=35$, $N=105$) of participants required long-term enteral feeding post the VFSS.

Conclusions: Children with CP who presented for VFSS, demonstrated FSD across all phases of swallowing. The presence of pharyngeal phase difficulties highlights the need for an instrumental assessment, such as a VFSS in this population. Children may, irrespective of their classification of CP, demonstrate FSD, suggesting that all children with CP should be screened and monitored for FSD. The need for SLTs to be involved at all levels of health care in the Western Cape and other provinces of South Africa, has been identified, to ensure early identification and management of FSD in children with CP.

Keywords: cerebral palsy (CP), feeding and swallowing, paediatric, speech-language therapy services, videofluoroscopic swallow studies (VFSS)

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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 secretions, food or liquids in the airway below the level of the true vocal cords, which may occur before, during or after swallowing (Arvedson, 2008; Arvedson & Brodsky, 2002; Benfer, Weir, Bell, Ware, Davies & Boyd, 2012a).

Cerebral palsy

A group of non-progressive disorders of the developing brain, which severely affects movement and/or posture. Cerebral palsy (CP) is often accompanied by the presence of a range of other disorders, including cognitive, perceptual and communication difficulties (Araújo, Silva & Mendes, 2012; Arvedson & Brodsky, 2002; Bax, Flodmark & Tydeman, 2007; Draz, Bayoumi & El-Nagger, 2013; Kim, Han, Song, Oh & Chung, 2013; Rosenbaum, Paneth, Leviton, Godstein & Bax, 2007; Schaefer, 2008).

Classification of CP:

No single classification system exists for CP (Rosenbaum & Rosenbloom, 2012). CP may be classified according to the nature of the movement disorder (e.g. spastic, ataxic, dyskinetic) (O’Shea, 2008; Paneth, 2008; Rosenbaum & Rosenbloom, 2012), the topographic distribution of the motor abnormality (e.g. hemiplegia, quadriplegia) (O’Shea, 2008; Paneth, 2008; Rosenbaum & Rosenbloom, 2012) or the degree/severity of the motor impairment (O’Shea, 2008; Rosenbaum & Rosenbloom, 2012). Some classification systems include the Gross Motor Function Classification System (GMFCS) (Morris & Bartlett, 2004; Palisano, Rosenbaum, Bartlett & Livingston, 1997; Rosenbaum & Rosenbloom, 2012), the Manual Ability Classification System for Children with Cerebral Palsy (MACS) (Eliasson et al., 2006), the Communication Function Classification System (CFCS) (Cooley Hidecker et al., 2011) and the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001).

The classification systems that were used in this study included the topography of the condition and the nature of the movement disorder, based on the classification systems adopted by the research site at the time of data collection:

1. *Spastic CP* - a central nervous system injury characterized by increased muscle tone (Paneth, 2008; Rosenbaum & Rosenbloom, 2012). The topography of spastic CP may include:

1.1. Spastic quadriplegia – involvement of four extremities (Nelson, 2008; Rosenbaum & Rosenbloom, 2012).

1.2. Spastic hemiplegia - involvement of one side of the body (Nelson, 2008; O’Shea, 2008; Rosenbaum & Rosenbloom, 2012).

Other distributions may include triplegia (involvement of three extremities), usually very rare (Jan, 2006); diplegia (involvement bilaterally, but lower limbs usually more affected than the upper limbs) (Nelson, 2008; O’Shea, 2008; Rosenbaum & Rosenbloom, 2012) and monoplegia (involvement of one limb only) (Paneth, 2008).

2. *Ataxia* - characterized by intention tremors and impaired coordination of movement (Paneth, 2008; Rosenbaum & Rosenbloom, 2012).

3. *Dyskinesia* – characterized by changes in muscle tone and posture, with a component of involuntary movement (Himmelman, Hagberg, Wiklund, Eek & Uvebrant, 2007; Paneth, 2008; Rosenbaum & Rosenbloom, 2012); the predominant forms being either athetosis or dystonia (O’Shea, 2008; Paneth, 2008; Rosenbaum & Rosenbloom, 2012).

3.1. Athetosis – characterized by involuntary, writhing movements and abnormal postures (Paneth, 2008; Rosenbaum & Rosenbloom, 2012).

3.2. Dystonia – characterized by abnormal posture due to involuntary fluctuations of muscle tone (Bonouvrié et al., 2013; Paneth, 2008; Rosenbaum & Rosenbloom, 2012).

4. *Evolving CP* - in children younger than one year where signs and symptoms of CP are still developing and a formal diagnosis has not yet been made (Dr K. Donald, Head of Neuro-developmental Services, RCWMCH, personal communication,

October 18, 2009); may also include children who initially have generalized low tone, not related to a myopathy or neuromuscular disease (Paneth, 2008), where the clinical presentation of CP may change as the child becomes older (Rosenbaum & Rosenbloom, 2012). The term “evolving CP” was documented in participants’ medical records and was therefore used as a descriptor.

5. *Mixed CP* - mixed diagnosis where children may demonstrate signs simultaneously of spasticity and dyskinesia (Paneth, 2008). This classification was documented in participants’ medical records by paediatricians and was therefore included.

Enteral feeds

Non-oral feeding via tube (Arvedson & Brodsky, 2002; Hall, 2001); may be used for a short-term (nasogastric or nasojejunal tube feeds) or long-term period (gastrostomy/PEG) (Tutor & Gosa, 2012).

Feeding

A reciprocal process involving interaction between parent/ caregiver and child. It involves the acceptance of either liquid or food and the subsequent preparation, propelling and swallowing thereof (Arvedson & Brodsky, 2002; Benfer et al., 2012a).

Gastro-oesophageal reflux (GOR)

Retrograde movement of gastric contents from the stomach into the oesophagus (Arvedson & Brodsky, 2002; Vandenplas et al., 2009).

Gastrostomy

A surgically created opening in the abdominal wall to provide feeds directly to the stomach (Arvedson & Brodsky, 2002; Hall, 2001; Rosenbaum & Rosenbloom, 2012).

Gross Motor Function Classification system (GMFCS)

A standardized classification system of motor function, namely the Gross Motor Function Classification System (GMFCS) (Morris & Bartlett, 2004; Palisano et al., 1997; Rosenbaum & Rosenbloom, 2012), which was created to describe the severity of activity limitation in CP (Morris & Bartlett, 2004; O'Shea, 2008; Paneth, 2008) from 0 to 12 years (Palisano et al., 1997; Rosenbaum & Rosenbloom, 2012). The original version of the GMFCS (Palisano et al., 1997) has been expanded to include ages up to 18 years (Palisano, Rosenbaum, Bartlett & Livingston, 2008).

Percutaneous endoscopic gastrostomy (PEG)

A feeding tube that is placed directly into the stomach from the skin through the guidance of a fiberoptic endoscope (Hall 2001; Sullivan, 2008).

Scintigraphy

A procedure that uses radionuclide scanning to quantify oesophageal and gastric emptying, GOR and aspiration (Lefton-Greif & Loughlin, 1996).

Silent aspiration

The entry of food into the airway without any obvious choking or coughing (Arvedson, 2008).

Swallowing

The preparation and formation of the bolus, with subsequent propulsion through the pharynx into the oesophagus and then into the stomach (Araújo et al., 2012; Wallis & Ryan, 2012). Swallowing consists of four phases, namely oral preparatory, oral, pharyngeal and oesophageal (Arvedson & Brodsky, 2002).

- a. *Oral preparatory phase* - a voluntary phase of swallowing in which food is accepted into the mouth, with the subsequent preparation and forming of a cohesive bolus (Arvedson & Brodsky, 2002; Benfer, Weir & Boyd, 2012b).
- b. *Oral phase*- a voluntary phase of swallowing where the bolus is propelled posteriorly through the oral cavity toward the pharynx whilst the tongue contracts repeatedly (Arvedson & Brodsky, 2002; Benfer et al., 2012b).
- c. (i) *Pharyngeal phase initiation* - the pharyngeal swallow is initiated voluntarily once the bolus reaches either the anterior tonsillar pillars, the base of tongue or the valleculae (Arvedson, 2007; Arvedson, 2008).

(ii) *Pharyngeal phase* - the pharyngeal phase is under involuntary control and is characterized by a series of actions, namely velar-pharyngeal closure, laryngeal closure, opening of the upper oesophageal sphincter (UOS) and subsequent propulsion of the bolus from the pharynx into the oesophagus (Arvedson, 2008; Arvedson & Brodsky, 2002).
- d. *Oesophageal phase* - opening of the UOS with movement of the bolus through the oesophagus into the stomach through a series of peristaltic waves (Arvedson, 2008; Arvedson & Brodsky, 2002).

Videofluoroscopic swallow study (VFSS)

A radiological procedure that examines the dynamic phases of swallowing; its objectives are both diagnostic and therapeutic (Arvedson, 2008; Arvedson & Brodsky, 2002; De Benedictis, Carnielli & De Benedictis, 2009; Romano, Schultz & Tai, 2012).

ABBREVIATIONS

CFCS: Communication Function Classification System

CP: Cerebral palsy

FSD: feeding and/or swallowing difficulties

FTT: failure to thrive

GMFCS: Gross Motor Function Classification System

GOR: gastro-oesophageal reflux

ICF: International Classification of Functioning, Disability and Health

LRTI: lower respiratory tract infection/infections

MACS: Manual Ability Classification System for Children with Cerebral Palsy

NGT: nasogastric tube

NJT: nasojejunal tube

PEG: percutaneous endoscopic gastrostomy

RCWMCH: Red Cross War Memorial Children's Hospital

SLT: Speech-language therapist

UOS: upper oesophageal sphincter

VFSS: videofluoroscopic swallow study/studies

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1. INTRODUCTION

The survival of children with severe neurological disorders, such as those diagnosed with cerebral palsy (CP), has created considerable challenges for the health care system world-wide (Staiano & Martinelli, 2013; Sullivan, 2008). The health care system of each country subsequently has a great responsibility to provide easily accessible, efficient and optimal health care to these children (Srivastava & Stone, 2011).

Limited access to health care may contribute to increased risks associated with developing CP (Hack & Costello, 2008; Nelson, 2008). South Africa, which is considered a developing country (Schönfeldt, Gibson & Vermeulen, 2010), faces various challenges to provide accessible, as well as effective health care services to all its citizens, including children, particularly in the rural areas where distances to the local clinic or hospital are far and transport options limited and costly (South Africa & UNDP, 2013). Couper (2002) documented a high prevalence of CP (10 in 1000) in children under the age of 10 years in a rural area of Kwazulu- Natal, a province of South Africa, suggesting that the prevalence of CP in South Africa, especially in the rural areas of the country, may be higher than the internationally reported prevalence for CP (1 to 2.5 in 1000 births) (Cans, De-La-Cruz & Mermet, 2008; Mongan, Dunne, O'Nuallain & Gaffney, 2006; O'Shea, 2008; Schaefer, 2008).

There has been an increased awareness among researchers and health care professionals that children who have been diagnosed with CP, are at risk of developing feeding and/or swallowing difficulties (FSD) (Benfer et al., 2012a). FSD may negatively affect various aspects of a child's health, including growth and nutrition (Araújo et al., 2012; Benfer et al., 2012a; Sullivan, 2008), respiratory health (Erasmus, Van Hulst, Rotteveel, Willemsen & Jongerius, 2012; Staiano & Martinelli, 2013) and may even result in strained parent-child interaction as feeding is often described as difficult and slow (Hewetson & Singh, 2009; Prasse & Kikano, 2009). Early detection and management of FSD is associated with preventing or minimizing the negative consequences (Prasse & Kikano, 2009).

The prevalence of CP in the paediatric population of South Africa is unknown (N. Maake, Statistics South Africa, Personal Communication, January 29, 2013), much less the FSD that may co-occur. Planning and providing effective health services specific to the needs of this population is therefore difficult.

The study set out to describe the nature of FSD in the paediatric population with CP who have had videofluoroscopic swallow studies (VFSS) at a tertiary hospital in the Western Cape between January 2007 and December 2009. A retrospective record review was selected to describe the characteristics of participants' feeding in terms of the different phases of swallowing as well as the classification of CP. In addition, the nature of services rendered to the participants and changes in health and feeding outcomes following the VFSS, were documented.

Information regarding the frequency and nature of FSD in children with CP will provide a baseline of knowledge of FSD in children with CP who presented to a tertiary hospital in South Africa, as well as the services that were accessed and outcomes following intervention. Health care professionals can use this information as a starting point to identify signs and symptoms of possible FSD, and to plan service delivery to this population.

Findings from this study may further be useful to educate and train health care professionals in the referral to a speech-language therapist (SLT), and the importance of early assessment and intervention of FSD. Guidelines regarding feeding and/or swallowing services that children with CP may require, may also be used to inform relevant and important stakeholders within health care departments in the government sector regarding the need for speech-language therapy services.

2. LITERATURE REVIEW

South Africa, despite a sophisticated infrastructure, a well-developed private sector and a stable macro-economy (South Africa Government online, 2013), is still considered a developing country (Schönfeldt et al., 2010) that is struggling to achieve at least two of its millennium development goals before the year 2015 (South Africa & UNDP, 2013; Western Cape Government, 2013a), namely to reduce child mortality and improve maternal health (South Africa & UNDP, 2013). Poor maternal health in the context of poverty-stricken areas of South Africa (Schönfeldt et al., 2010), with limited access to health care (Clawson, Kuchinsky & Bach, 2007; Nelson, 2008; Schaefer, 2008; Sullivan, 2008) may subsequently place children who are born, at a higher risk for mortality or associated disabilities such as CP (Ceriati et al., 2006; Hack & Costello, 2008).

Children who are diagnosed with CP are known to be subject to higher mortality than the general population (Blair, Watson, Badawi & Stanley, 2001; Strauss, Cable & Shavelle, 1999). Respiratory diseases have been reported to contribute to the high mortality rate in children with CP (Strauss et al., 1999) and therefore deaths associated with the diagnosis of CP may contribute to an increased infant and under 5 year mortality rate (Blair et al., 2001; Bradshaw, Bourne & Nannan, 2003) in South Africa.

Attempts to improve obstetric practices and peri-natal medicine, which include the use of foetal monitoring and caesarean sections (Ceriati et al., 2006), or the evolution of neonatal intensive care units which provide increasingly aggressive care to premature infants (Hack & Costello, 2008; Sullivan, 2008), may result in survivors who may be diagnosed with CP and its associated co-morbidities e.g. difficulties in mobility, feeding and communication (Clawson et al., 2007; Hack & Costello, 2008; Nelson, 2008; Schaefer, 2008; Staiano & Martinelli, 2013; Sullivan, 2008). An international study by Westbom, Bergstrand, Wagner and Nordmark (2011) examined 708 children with CP in two southern counties in the developed country of Sweden over a prolonged period. These authors confirmed a high survival rate for children with CP, in that 96% of children in their study sample, lived

to 19 years of age (Westbom et al., 2011), indicating that the survival of children with CP places a major responsibility on the health care system to provide long-term accessible and effective health care (Srivastava & Stone, 2011).

International reports on the prevalence of CP in developed and developing countries exist (Cans et al., 2008; Mongan et al., 2006; Odding, Roebroek & Stam, 2006; O'Shea, 2008; Schaefer, 2008; Sullivan, 2008; Von der Luft, DeBoer, Harman, Koenig & Nixon-Cave, 2008). Some researchers report a prevalence that ranges from 1 to 2.5 in 1000 births, in both developed and developing countries (Cans et al., 2008; Mongan et al., 2006; Odding et al., 2006; O'Shea, 2008; Schaefer, 2008; Sullivan, 2008; Von der Luft et al., 2008). Other researchers suggest that there is a developed-developing nation divide with a higher prevalence of CP being reported for developing nations such as Turkey where a prevalence of 4.4 per 1000 children aged 2 to 16 has been documented (Serdaroğlu, Cansu, Özkan & Tezcan, 2006). Various researchers agree that the characteristics of developing nations such as poor socio-economic conditions, together with poor access to health, may contribute to increased disease exposure, including birth asphyxia, prematurity and low birth weight, subsequently placing these children at substantial risk for neurological damage resulting in CP (Clawson et al., 2007; Nelson, 2008; Schaefer, 2008; Sullivan, 2008).

There is a lack of current prevalence information of CP in South Africa (N. Maake, Personal Communication, January 29, 2013). One dated study has however reported the prevalence of CP as 10 in 1000 children under the age of 10 years in rural Kwazulu- Natal, a province of South Africa (Couper, 2002). The reported prevalence in that study is higher than the prevalence (1 to 2.5 in 1000 births) reported in international studies (Cans et al., 2008; Mongan et al., 2006; Odding et al., 2006; O'Shea, 2008; Schaefer, 2008; Serdaroğlu et al., 2006; Sullivan, 2008; Von der Luft et al., 2008) for developed and some developing nations. The higher prevalence as reported in the study of Couper (2002) may in part be explained by the fact that the study was conducted in a rural area of South Africa, characterized by poverty and poor socio-economic conditions (Schönfeldt et al., 2010). Prevalence information plays a key role in the development and planning of appropriate service

delivery to populations such as children with CP. As statistics regarding the prevalence of children diagnosed with CP in South Africa are limited, it is difficult to plan effective services for these children.

Moreover, in planning and providing services for children with CP, the nature of CP has to be taken into consideration. CP produces life-long consequences, resulting in one of the leading burdens of disease in terms of life-years and productive years lost (Tan et al., 2005). CP is one of the most common disorders that severely affect sensory-motor function in young children (Erasmus et al., 2012; Gladstone, 2010; Huang, Sugden & Beveridge, 2008; O'Shea, 2008; Rosenbaum, Paneth, Leviton, Godstein & Bax, 2007). Although CP is a static and non-progressive disorder of the developing brain, clinical symptoms and associated disorders may change as the child becomes older, resulting in progressive disability/dysfunction with increased activity limitations and participation restrictions (Bax et al., 2007; Draz et al., 2013; Erasmus et al., 2012; Kim et al., 2013; Liptak, 2008; Rosenbaum et al., 2007; Schaefer, 2008). The health problems and neuro-developmental disorders (Araújo et al., 2012; Cans et al., 2008; Katz, 2009) that can be associated with CP, such as the impairment of cognition, sensation, perception, as well as endocrine, urogenital, communication disorders, epilepsy, respiratory infections and nutritional problems, may exacerbate the disability conferred by the sensory- motor impairment (Araújo et al., 2012; Cans et al., 2008; Katz, 2009; Odding et al., 2006; O'Shea, 2008; Paneth, 2008; Rosenbaum et al., 2007; Salghetti & Martinuzzi, 2012). The services that children with CP require, should therefore address these many different aspects.

Interestingly, FSD experienced by children with CP, are not listed as one of the co-morbidities in the official definition of CP (Rosenbaum et al., 2007). The presence of FSD has however been widely described for the paediatric population with CP in recent international literature (Araújo et al., 2012; Avivi-Arber, Martin, Lee & Sessle, 2011; Kim et al., 2013).

Feeding and swallowing is a complex process involving a predictable sequence, requiring neuromuscular coordination and integration of motor and sensory pathways; which further depends on the successful coordination of

swallowing and breathing (Araújo et al., 2012; De Benedicits et al., 2009; Erasmus et al., 2012; Prasse & Kikano, 2009; Romano et al., 2012; Suskind et al., 2006; Van den Engel-Hoek et al., 2013; Vijayasekaran, Unal, Schraff, Johnson & Rutter, 2007; Wallis & Ryan, 2012). The underlying sensory-motor problems that children with CP experience, therefore contribute to the presentation of FSD in this population (Bader & Niemann, 2010; Erkin, Culha, Ozel & Kirbiyik, 2010; Lefton-Greif & Arvedson, 2008; Matsuo & Palmer, 2008; Sullivan, 2008).

A number of international studies, some of which are dated, have reported the prevalence of FSD in children with CP, with ranges between 13 to 99% (Benfer et al., 2013; Calis et al., 2008; Dahl, Thomessen, Rasmussen & Selberg, 1996; Del Giudice et al., 1999; Erkin et al., 2010; Fung et al., 2002; Parkes, Hill, Platt & Donnelly, 2010; Reilly, Skuse & Poblete, 1996; Veness & Reilly, 2008; Wilson & Hustad, 2009). The wide range of the reported prevalence in the above mentioned studies may be due to (i) the different methods of research employed to determine the prevalence of FSD, such as the use of parental interviews (Calis et al., 2008) or the outcome of VFSS (Del Giudice et al., 1999; Kim et al., 2013). Parents have been shown to underestimate the presence of FSD in their children with CP (Calis et al., 2008) therefore prevalence data based on parent reports may misrepresent the true prevalence of FSD in this population. Other reasons for the wide prevalence range, may include (ii) a lack of agreement in the construct of FSD (Benfer et al., 2012a; Benfer et al., 2013) and/or (iii) limited sampling representativeness by mostly reporting on children with a more severe form of CP (Benfer et al., 2012a; Calis et al., 2008; Del Giudice et al., 1999), instead of quantifying the prevalence of FSD across all ranges of gross motor function (Benfer et al., 2012a). The prevalence of FSD in the general population of children with CP may therefore be overestimated if prevalence data is only based on those children who have moderate to severe CP (Benfer et al., 2012a). Benfer et al. (2013) reported the prevalence of oropharyngeal dysphagia in preschool children with CP to be 85%. Her study design addressed and improved upon many of the above mentioned methodological issues by determining the prevalence of oropharyngeal dysphagia, as well as the different phases of swallowing, through the use of a cross-sectional

population-based prospective study of a large cohort of preschool-aged children with CP across the full range of gross motor function skills (Benfer et al., 2013). Children were assessed clinically by a trained speech-language therapist who used two direct oropharyngeal dysphagia measures and observations of signs which could indicate pharyngeal phase impairment and difficulties with saliva control (Benfer et al., 2013).

The prevalence of difficulties according to the different phases of swallowing has also been reported in literature (Del Giudice et al., 1999; Kim et al., 2013; Van den Engel-hoek et al., 2013), but available research in the paediatric CP field, tends to describe the prevalence of oral preparatory and oral phase difficulties together, with an unclear distinction between the two phases (Del Giudice et al., 1999; Rogers, Arvedson, Buck, Smart & Msall, 1994; Van den Engel-hoek et al., 2013).

Moreover, a disorder characteristic of the pharyngeal phase, namely a delay in the trigger of the pharyngeal swallow, has also been included under the oral phase in one recent study (Kim et al., 2013). Estimates of the prevalence of FSD in the different phases of swallowing reported in the above-mentioned studies (Del Giudice et al., 1999; Kim et al., 2013; Rogers et al., 1994; Van den Engel-hoek et al., 2013), might therefore be slightly over or underestimated. As there seems to be a lack of consensus amongst researchers regarding the difficulties that should be included in the different phases of swallowing (Del Giudice et al., 1999; Kim et al., 2013; Rogers et al., 1994; Van den Engel-hoek et al., 2013), it is difficult to report the exact prevalence of difficulties in these phases. As oral preparatory phase difficulties are generally more visible (Otapowicz et al., 2010), and may become the focus of concern and intervention, the risk of pharyngeal phase difficulties may be missed, unless information regarding the prevalence of difficulties in other phases are available to guide health professionals in assessment and treatment of FSD in this population.

Currently no information regarding the prevalence and nature of FSD, is available for the South African paediatric population with CP, as far as the author is aware (keywords - feeding, swallowing, dysphagia, cerebral palsy, South Africa; databases - University of Cape Town Health Sciences databases, including CINAHL,

Cochrane Library, Medline, Pubmed). Information regarding the prevalence and nature of FSD are important to direct and guide health care professionals involved with assessing and managing FSD, in clinical practice.

Most authors, despite the use of different classification systems, agree that there is a relationship between motor involvement and the severity of FSD; in that children whose classification of CP is characterized by more extensive motor and/or limb involvement (such as dyskinesia or spastic quadriplegia), are more likely to have more pronounced FSD in comparison to those who have less motor involvement, such as unilateral limb involvement (Benfer et al., 2013; Brooks, Day, Shavelle & Strauss, 2011; Calis et al., 2008; Erkin et al., 2010; Kim et al., 2013; Lefton-Greif & Arvedson, 2008; Lustre, Freire & Silvério, 2013; Otapowicz et al., 2010; Salghetti & Martinuzzi, 2012; Santoro et al., 2012; Sullivan, 2008; Sullivan, 2012; Veugelers et al., 2008). FSD have however been described for children across all levels of gross motor function (Benfer et al., 2013; Kim et al., 2013), demonstrating the need for proactive identification, assessment and management of FSD in all children with CP (Benfer et al., 2013).

Depending on the classification of CP, some or all stages of the feeding and swallowing process may be affected (Benfer et al., 2012b; Erasmus et al., 2012; Erkin et al., 2010; Kim et al., 2013). The challenges that children with CP experience with feeding, as described in international literature (Benfer et al., 2012a; Calis et al., 2008; Ceriati et al., 2006; Erkin et al., 2010; Kim et al., 2013; Van den Engel-Hoek et al., 2013), will be described within the phases of swallowing.

Typical characteristics of the oral preparatory phase in children with CP include difficulties with the coordination and fine motor control of the oral structures such as the lips, tongue, cheeks, jaw and velum (Benfer et al., 2012a; Ceriati et al., 2006; Erkin et al., 2010; Kim et al., 2013; Van den Engel-Hoek et al., 2013) and oral sensory dysfunction (Benfer et al., 2012a; Casas, Kenny & McPherson, 1994; Couriel, Bisset, Miller, Thomas & Clarke, 1993). These difficulties occur as a result of the underlying sensory-motor problems that children with CP experience (Bader & Niemann, 2010; Erkin et al., 2010; Lefton-Greif & Arvedson, 2008). Subsequently, children with CP may demonstrate anterior loss of the bolus

(Ceriati et al., 2006; Erkin et al., 2010), drooling (Reid, Mccutcheon, Reddihough & Johnson, 2012; Senner, Logemann, Zecker & Gaebler-Spira, 2004; Tahmassebi & Curzon, 2003), persistence of abnormal reflexes such as a tonic bite reflex (Clancy & Hustad, 2011, Salghetti & Martinuzzi, 2012; Van den Engel-Hoek et al., 2013) and difficulties in forming and manipulating the bolus (Ceriati et al., 2006; Erkin et al., 2010; Kim et al., 2013).

A delay or absent initiation of the oral swallow is often described as characteristic of the oral phase of swallowing in a child with CP, due to the inability to efficiently organise and distally propel a bolus as a result of oral-sensory motor dysfunction or an apraxia of the swallow (Arvedson, 2008; Arvedson & Brodsky, 2002; Kim et al., 2013; Lustre et al., 2013; Van den Engel-hoek et al., 2013). Inefficient clearance of oral residue is another characteristic of the oral phase which may occur as a result of reduced labial and/or buccal tension, as well as reduced lingual control and strength (Arvedson, 2008; Arvedson & Brodsky, 2002; Kim et al., 2013).

Pharyngeal phase difficulties in children with CP, as described in international literature, may also be present as a result of the sensory-motor impairment (Araújo et al., 2012; Calis et al., 2008; McPherson et al., 1992; Otapowicz et al, 2010) and may include a delay in the trigger of the pharyngeal swallow (Van den Engel-hoek et al., 2013), nasal-pharyngeal backflow and/or regurgitation (Erkin et al., 2010; Kim et al., 2013; Van den Engel-hoek et al., 2013), the presence of aspiration (Bader & Niemann, 2010; Ceriati et al., 2006; Clancy & Hustad, 2011; Kim et al., 2013; Van den Engel-Hoek et al., 2013; Weir et al., 2007a; Weir, McMahon, Taylor & Chang, 2011) and pharyngeal residue after swallowing (Kim et al., 2013; Van den Engel-Hoek et al., 2013; Weir et al., 2007b).

Kim et al. (2013) reported aspiration in 25% of their study sample (n=7, N=29) during a VFSS. Older studies utilizing VFSS estimated the prevalence of aspiration in children with CP to be between 38 -77% (Mirrett, Riski, Glascott & Johnson, 1994; Rogers et al., 1994; Wright, Wright & Carson, 1996). A possible reason for the difference in the reported prevalence of aspiration in these studies, may be due to the fact that the dated studies investigated children with a more

severe form of CP (Mirrett et al., 1994; Rogers et al., 1994; Wright et al., 1996) in comparison to Kim et al. (2013), who investigated a range of children with CP who presented with different degrees of motor involvement. Studies that utilize VFSS report that aspiration is more frequently observed with liquids than purees and solids (Rogers et al., 1994; Van den Engel-hoek et al., 2013; Weir et al., 2007a).

Silent aspiration has been strongly associated with neurological impairment (Weir et al., 2011). The prevalence of silent aspiration in children with CP has been estimated between 71% and 97% for participants who demonstrated aspiration on a VFSS (Kim et al., 2013; Mirrett et al., 1994; Rogers et al., 1994). If children choke or cough, when food or liquid enters the airway, they are more likely to attract attention, whereas a child who presents with no overt signs of aspiration such as coughing or choking, may be left unnoticed until weight loss or respiratory difficulties become more apparent (Arvedson, 2008; Colombo & Hallberg, 2012; Mirrett et al., 1994). Children who aspirate silently, may therefore be at greater risk of delayed identification and management and, as such, early screening for FSD, especially the presence of silent aspiration, should be considered essential in children with CP who are at increased risk of silent aspiration (Benfer et al., 2013; Weir et al., 2011).

Although the evaluation of the oesophageal phase of swallowing is not typically the domain of the SLT, these problems may be present in children with CP (Campanozzi et al., 2007; Ceriati et al., 2006). Research has suggested that poor sitting posture caused by abnormal neurological maturation, increased intra-abdominal pressure secondary to scoliosis, spasticity, the alteration of diet consistency and prolongation of gastric emptying, may be factors that lead to difficulties of the gastro-intestinal system, including oesophageal phase problems in children with CP (Andrew, Parr & Sullivan, 2012; Erkin et al., 2010; De Veer, Bos, Niezen-De Boer, Böhmer & Francke, 2008).

Oesophageal phase problems may furthermore be linked to the presence of gastro-oesophageal reflux (GOR), which is considered a common problem in children with CP (Araújo et al., 2012; Ceriati et al., 2006; De Benedicits et al., 2009; Salghetti & Martinuzzi, 2012; Santoro et al., 2012; Sullivan, 2008). The prevalence

of GOR has been estimated to be as high as 91% in children with CP (Campanozzi et al., 2007; Ceriati et al., 2006; Saadah, 2009). The negative consequences and associations of GOR with ill health, have been widely documented in international literature and may include a spectrum of symptoms ranging from mild to severe, such as pain, recurrent chest infections, haematemesis, chronic oesophagitis, feeding difficulties, iron deficiency anaemia, oesophageal stricture formation and growth faltering (Campanozzi et al., 2007; Mathei et al., 2008; Miyazawa et al., 2008; Sullivan, 2008). As oesophageal phase problems, and particularly the presence of GOR, may negatively impact the efficiency of feeding (Campanozzi et al., 2007; Ceriati et al., 2006), the SLT should demonstrate awareness of these possible problems and refer to other health care professionals as deemed appropriate.

As children with CP may demonstrate FSD in some or all phases of swallowing (Benfer et al., 2012a; Erasmus et al., 2012; Erkin et al., 2010; Kim et al., 2013), the impact and consequences of these difficulties should be considered. The challenges in the oral preparatory and oral phases of swallowing, such as poor bolus management (Benfer et al., 2012a; Ceriati et al., 2006; Erkin et al., 2010; Kim et al., 2013) and propulsion (Kim et al., 2013; Lustre et al., 2013; Van den Engel-hoek et al., 2013), may contribute to slow, effortful feeding with prolonged feeding times (Troughton & Hill, 2001; Wilson & Hustad, 2009), resulting in decreased consumption of food (Erkin et al., 2010; Kim et al., 2013; Troughton & Hill, 2001; Van den Engel-hoek et al., 2013; Wilson & Hustad, 2009). As a result, poor nutrition and growth (Adams et al., 2012; Araújo et al., 2012; Avivi-Arber et al., 2011; Benfer et al., 2012; Brooks et al., 2011; Dahlseng et al., 2012; Morrow, Quine, Loughlin & Craig, 2008; Prasse & Kikano, 2009; Salghetti & Martinuzzi, 2012; Santoro et al., 2012; Sullivan, 2008; Veness & Reilly, 2008; Wilson & Hustad, 2009), and the consequences thereof, may be exacerbated, including reduced quality of life (Araújo et al., 2012) for both caregiver and child and could even result in early death if not addressed (Calis et al., 2008; Miller, 2011; Prasse & Kikano, 2009).

In addition, children with CP, who have FSD, are also at risk of developing aspiration pneumonia, from either oral preparatory, oral and/or pharyngeal phase

difficulties (Arvedson, 2008; Chadwick & Joliffe, 2009; Kim et al., 2013; Petersen, Kedia, Davis, Newman & Temple, 2006). The developing lung may be particularly vulnerable to insults from aspiration (Wallis & Ryan, 2012). Although persistent aspiration considerably increases the chance to develop an acute pneumonia, this doesn't predict whether and when recurrent episodes of acute infection of the lower respiratory tract may in fact lead to chronic lung damage, creating a significant cause of morbidity and mortality (Bach & Saporito, 1996; Chaudri, Liu, Hubbard, Jefferson & Kinnear, 2009; De Benedictis et al., 2009; Erasmus et al., 2012; Miller, 2011; Tutor & Gosa, 2012; Wallis & Ryan, 2012).

The negative impact that FSD may have on the general health status of the child with CP, emphasizes the importance of early assessment and appropriate management. Given that a number of children who have CP, are especially prone to silent aspiration (Weir et al., 2011), it is important to diagnose this more effectively. An instrumental assessment, such as a VFSS, is therefore frequently used to complement the clinical swallowing assessment to assess the presence of FSD, especially to evaluate the pharyngeal (and oesophageal) phases of swallowing (Araújo et al., 2012; Arvedson, 2008; Boesch et al., 2006; De Benedictis et al., 2009; Kim et al., 2013; Staiano & Martinelli, 2013) and to detect silent aspiration (Kim et al., 2013). Specific radiographic findings detected on a VFSS may include information regarding (i) bolus formation, (ii) oral transit time, (iii) pharyngeal phase trigger, (iv) pharyngeal phase and (v) upper oesophageal phase dysfunction (Arvedson, 2008).

There have been limited studies utilizing VFSS results to describe FSD specific to the paediatric population with CP (Arvedson, 2008). Moreover, only two recent international studies (Kim et al., 2013; Van den Engel-hoek et al., 2013) utilizing VFSS in the paediatric population with CP exist, with other available studies being almost 20 years old (Del Giudice et al., 1999; Mirrett et al., 1994; Rogers et al., 1994; Wright et al., 1996). Specific radiographic signs that were documented on a VFSS in children with CP included the presence of (i) oral preparatory phase dysfunction such as the loss of food from the mouth (Mirrett et al., 1994; Van den Engel-hoek et al., 2013; Wright et al., 1996) and abnormal tongue movements

(Rogers et al., 1994; Van den Engel-hoek et al., 2013; Wright et al., 1996), (ii) oral phase difficulties such as reduced tongue movements to transport the food posteriorly (Van den Engel-hoek et al., 2013), (iii) pharyngeal phase abnormalities such as a delayed trigger or aspiration (Mirrett et al., 1994; Rogers et al., 1994; Van den Engel-hoek et al., 2013; Wright et al., 1996) and oesophageal phase abnormalities such as post swallow residue at the upper oesophageal sphincter (Van den Engel-hoek et al., 2013).

Previous research has identified various benefits of the VFSS as an instrumental assessment, which include the (i) detection of aspiration (Arvedson, 2008; Ceriati et al., 2006; Colombo & Hallberg, 2012; Craig et al., 2006; Hiorns & Ryan, 2006; Kelly, Drinnan & Leslie, 2007; Lefton-Greif & Arvedson, 2008; Lefton-Greif, Carroll & Loughlin, 2006; Vijayasekaran et al., 2007; Weir et al., 2007b; Weir et al., 2011), (ii) evaluating specific treatment strategies once the nature of FSD are understood (Boesch et al., 2006; Craig et al., 2006; Lefton-Greif & Arvedson, 2008; Martin-Harris et al., 2008; Tutor & Gosa, 2012; Weir et al., 2007a; Weir et al., 2007b) and (iii) the evaluation of the structural anatomy and functional integrity of each phase of swallowing, which may contribute to FSD if undetected (Marrara et al., 2008; Terblanche, 2011; Vandenplas et al., 2009).

Although the VFSS is considered the "gold standard" to assess all the dynamic phases of swallowing (Arvedson, 2008; De Benedictis et al., 2009; Lefton-Greif et al., 2006; Martin-Harris & Jones, 2009; Romano et al., 2012), limitations of the VFSS are reported in literature (Kim et al., 2013; Miller, 2009). The VFSS exposes a child to radiation, provides a snapshot of a child's swallowing ability in an artificial setting (Boesch et al., 2006; Colombo & Hallberg, 2012; Hiorns & Ryan, 2006; Kim et al., 2013; Miller, 2009; Treves et al., 2011; Tutor & Gosa, 2012; Weir et al., 2007b), and is dependent on the child's cooperation for an accurate assessment (Ko et al., 2011). Moreover, the cost of a VFSS is considered expensive and labour-, as well as resource-intensive, especially when children are being examined (Lee et al., 2012); which may restrict the accessibility of the VFSS for some children in South Africa, especially those living in rural areas. As literature suggests that children with CP may have FSD which might not be detected through clinical evaluation alone

(Araújo et al., 2012; Arvedson, 2008; Boesch et al., 2006; De Benedicits et al., 2009; Kim et al., 2013; Staiano & Martinelli, 2013), the present study includes the results of a VFSS to ensure a more accurate report of the prevalence of the pharyngeal phase difficulties (Araújo et al., 2012; Arvedson, 2008; Kim et al., 2013; Staiano & Martinelli, 2013). It should however be noted that individuals who are referred for a VFSS, may already have a suspected problem (Arvedson, 2008; Colombo & Hallberg, 2012; Lefton-Greif & Arvedson, 2008; Weir et al., 2011) and subsequently the results of the present study may not reflect the general population with CP, but may be more representative of those who are referred for a VFSS.

Once FSD have been detected, modifications and treatment interventions are initially introduced and may include, as described in research, a variety of strategies, such as posture and position alterations, taste, temperature or consistency changes to food or liquids, oral-sensory motor therapy, scheduling of feeding times, pacing of feeds and prescription of specific feeding utensils (Araújo et al., 2012; Arvedson, 2008; Boesch et al., 2006; Calis et al., 2008; Clawson et al., 2007; De Benedicits et al., 2009; Gisel, 2008; Gosa, Schooling & Coleman, 2011; Kim et al., 2013; Morrow et al., 2008; Siĝan et al., 2013; Snider, Majner & Darsaklis, 2011; Park, Seo, Ko & Park, 2013; Tutor & Gosa, 2012; Van Roon & Steenbergen, 2006; Weir et al., 2011). These modifications and treatments are introduced to achieve the main goals of intervention for FSD, which include reducing or eliminating aspiration and subsequently increasing the safety and efficiency of feeding (Araújo et al., 2012; Arvedson, 2008; Calis et al., 2008; Salghetti & Martinuzzi, 2012; Snider et al., 2011). There is preliminary evidence regarding the effectiveness of these different conservative measures to improve eating efficiency and reduce aspiration in children with CP (Snider et al., 2011). Oral sensory-motor approaches to improve oral motor skills and to reduce aspiration in children with CP provide conflicting evidence regarding its effectiveness (Clawson et al., 2007; Gisel, 1996; Snider et al., 2011). An example is the work of Gisel (Gisel, 1996) and her colleagues (Gisel, Applegate-Ferrante, Benson & Bosma, 1996), which demonstrated that oral sensory-motor therapy was effective in improving general

oral motor function, but not in promoting weight gain or airway protection during feeds (Gisel, 1996; Gisel, 2008; Gisel et al., 1996). Limited evidence suggests that appropriate positioning during feeds may result in safer and more efficient feeding than no intervention (Morton, Bonas, Fourie & Minford, 1993; Snider et al., 2011; Vekerdy, 2007) and that the thickening of feeds may be helpful in improving feeding performance in terms of safety and efficiency (Snider et al., 2011).

If conservative management fails and challenges of adequate nutrition, hydration or safety remain, more invasive feeding management is usually considered, e.g. recommendations to change the mode of feeding from oral to long term enteral feeding (Arvedson, 2008; Calis et al., 2008; Tutor & Gosa, 2012). Previous research reported that gastrostomy/percutaneous endoscopic gastrostomy (PEG) feeding appears to be more frequently indicated in children who have neurological involvement, such as CP (Arvedson & Brodsky, 2002; Norman et al., 2011; Sullivan, 2008), due to the presence of chronic FSD (Norman et al., 2011). The use of a gastrostomy/PEG or a gastro-jejunostomy has been reported to be indicated (i) in the presence of life-threatening aspiration (Arvedson, 2008; Boesch et al., 2006; Calis et al., 2008; Colombo & Hallberg, 2012; Craig et al., 2006; Morrow et al., 2008; Ramelli, Aloysius, King, Davis & Muntoni, 2007; Sullivan et al., 2006; Tutor & Gosa, 2012), (ii) to ensure adequate nutrition and hydration (Dahlseng et al., 2012; De Benedictis et al., 2009) and subsequently (iii) to ensure weight gain (Dahlseng et al., 2012; Park et al., 2011). Apart from these above mentioned benefits, it has been suggested that gastrostomy/PEG feeding may improve the quality of life of children and their caregivers (Sullivan et al., 2005) due to decreased burden of care and improved physical comfort of the child (Morrow et al., 2008).

A multidisciplinary or interdisciplinary approach to address FSD in the general paediatric as well as CP population has been advocated in literature (Andrew et al., 2012; Araújo et al., 2012; Arvedson, 2008; Barratt & Ogle, 2010; Boesch et al., 2006; De Benedictis et al., 2009; Salghetti & Martinuzzi, 2012). As the child with CP has many different needs, the clinical expertise of various team members allows for holistic focus on the child and parents/caregivers, providing opportunity for coordinated consultations to address the multiple inter-related

health and feeding issues and allowing for a tailored plan of intervention (Andrew et al., 2012; Arvedson, 2008; Barratt & Ogle, 2010; Calis et al., 2008; Erasmus et al., 2012; Morrow, Quine & Craig, 2006). The SLT is proposed to be one of the key role players in assessing and managing FSD and plays a vital part in making recommendations and modifications regarding feeding and planning interventions to ensure safe and optimal feeding, as part of the multidisciplinary or interdisciplinary team (Andrew et al., 2012; Arvedson, 2008; Calis et al., 2008; Tutor & Gosa, 2012).

An ideal team, as proposed in literature, is not currently a reality in the South African health system at all levels of care, due to a lack of posts in the public sector (Doherty, Conco, Couper & Fonn, 2013). SLTs who are employed by the Western Cape Department of Health, are mainly situated at the three tertiary hospitals in the province (Western Cape Government, 2013c; Western Cape Speech Therapy/Audiology Forum, 2013). Even though it is recommended that tertiary services should only be accessed once management at the primary or district level has been completed or exhausted (Mojaki, Basu, Letskokgohka & Govender, 2011), many children in the Western Cape do not have access to SLTs at the primary health care level (Western Cape Speech Therapy/Audiology Forum, 2013). The initial point of entry to access speech-language therapy services, will therefore be at a tertiary hospital, suggesting that children may have delayed access to SLTs as the lack of on-site speech-language therapy services at the primary or district level may most likely slow down the process of early identification and referral. Tertiary based services are however not always accessible to children due to these hospitals' geographic distribution (Western Cape Government, 2013b), as well as the associated transport costs to travel to these hospitals (Western Cape Government, 2013a). Children with CP who have FSD and are unable to access speech-language therapy services at the tertiary level, may be identified very late or may only present to a hospital when FSD have already negatively impacted the child's health (Adams et al., 2012; Kim et al., 2013; Prasse & Kikano, 2009). It is however promising that the Western Cape Department of Health (Western Cape Government, 2013a), in their Healthcare 2030 plan (draft version 2), proposes a re-orientation of the health care system towards

patient-centred care and that the importance of a well-functioning community-based and primary health care system, with efficient patient transport is recognized. The Healthcare 2030 plan (draft version 2) (Western Cape Government, 2013a) further envisages that speech-language therapy services should in future be regarded as primary health care facility based services, which is a positive step towards realizing the goal of patient-centred care. The establishment of SLTs at the primary or district levels of care, may further contribute to reducing the cost burden of FSD on the South African health care system (Western Cape Government, 2013a). It is however concerning that the Healthcare 2030 plan (draft version 2) (Western Cape Government, 2013a) does not include speech-language therapy services as part of the home-based care teams, which may negatively impact families with children who have CP and FSD.

Early identification and management of FSD have been advocated in literature to contribute to the best possible outcome for children with CP and their families (Miller, 2011; Prasse & Kikano, 2011). As the achievement of the Health Care 2030 plan (draft version 2) (Western Cape Government, 2013a) is only envisaged by the year 2030, it is important to know what the current practices with regards to managing FSD in children with CP are so that areas of service delivery development can be identified. Two questions that should therefore be answered, include: (i) what are the combination of services that children with CP, who have FSD, currently receive with regards to feeding and swallowing and (ii) which health professionals are involved in the assessment and management of children with CP who have FSD? Baseline information regarding the services which were accessed by children with CP who have FSD, will be presented so that the recommended services for FSD in the paediatric population with CP can be considered when relevant stakeholders plan budgets and develop service delivery requirements for this population.

The research question that will be addressed in this study is the following: What is the nature of FSD in the paediatric population with CP (0-12 years) who have had VFSS. It is hoped that the information obtained in this study will result in a better understanding of the nature of FSD within the paediatric population with

CP, who reside in the Western Cape, South Africa. Furthermore, it is anticipated that the reader will understand the influence of the classification of CP on FSD reported for this population as well as the occurrence of aspiration and respiratory illness, which will be investigated in this study. This study will provide baseline information regarding the assessment and management of FSD in the paediatric population with CP within the South African context. The information could be used in educating health care professionals to facilitate earlier referral for feeding and swallowing assessments, which will result in early identification and management of FSD within this population. Early intervention of FSD has been associated with improved health outcomes (Miller, 2011; Prasse & Kikano, 2009) and may result in a reduction of costs for the health care system (Western Cape Government, 2013a), thereby optimizing service delivery.

3. METHODOLOGY

3.1. Aims and Objectives

The aim of this study was to describe the nature of FSD in the paediatric population with CP (0 to 12 years 11 months), who have had VFSS at Red Cross War Memorial Children's Hospital (RCWMCH) from January 2007 to December 2009.

The following objectives were formulated to achieve the research aim:

To describe the following in the paediatric population (0 to 12 years 11 months) with CP:

1. The indicators for a VFSS.
2. The frequency and nature of FSD in the paediatric population with CP (0 to 12 years 11 months) who have had a VFSS.
3. The association, if any, between the classification of CP, and the nature of FSD.
4. The nature of services provided to participants subsequent to the VFSS.
5. The changes in health and feeding outcomes following the VFSS.

3.2. Research Design

A descriptive, retrospective survey design (Welman, Kruger & Mitchell, 2005) was used. A descriptive design was selected as it was best suited to address the aim of the study, namely to describe specific characteristics of feeding and swallowing in the paediatric population with CP (Babbie, 1998; Babbie & Mouton, 2001; Bowling, 1997; Howell, 1999; Nardi, 2006). The design allowed the researcher to "profile" the nature of FSD in this specific population (Nardi, 2006) by documenting and categorising similar FSD experienced by participants as recorded in medical records. The descriptive design also enabled the researcher to examine variables (such as the classification of CP and the nature of FSD) and describe possible associations among variables e.g. the nature of FSD associated with a specific classification of CP (Babbie, 1998; Bowling, 1997; Du Plooy, 2009; Welman et al., 2005).

Descriptive research cannot determine causal relationships (Babbie, 1998) and only possible associations can therefore be described. However, this study did not set out to determine causal relationships, but focused on determining if an association exists between the classification of CP and the nature of FSD.

A retrospective survey design was selected as it facilitated review of existing medical records that described the characteristics of the specific population being studied (Babbie & Mouton, 2001; Bowling, 1997; Fink 1995). As a VFSS exposes patients to radiation (Colombo & Hallberg, 2012; Kim et al., 2013), a retrospective design, which utilizes existing results, was advantageous, as it did not require any study participants to be unduly exposed to radiation for the purpose of the study. The retrospective design further allowed participants to have assessment and treatment for a period of up to three years, which would not have been possible otherwise as a limited time frame for data collection was allowed (Bowling, 1997).

A limitation of retrospective designs is that the quality of the data cannot be controlled (Bowling, 1997). Only two of the SLTs (including the researcher) employed at RCWMCH, had been involved with clinical feeding and swallowing assessments and VFSS during the time period for which the data was to be collected. The researcher was trained by the second SLT and both followed a standard protocol in assessing FSD or conducting a VFSS, therefore increasing the likelihood that the data would be recorded in the same manner.

Another limitation of the retrospective design is the possibility of missing data because the information was originally documented for clinical purposes and not research (Cole, 2008; Neuman, 2006). Missing data in a retrospective survey can be a serious concern which can affect the overall validity and reliability of the study as there may be loss of information (Cole, 2008; Neuman, 2006). Altman and Bland (2007) suggested different ways of handling missing data, namely omitting variables which have many missing values, or omitting the records of participants who do not have complete data or estimating what the missing values were. Omitting a participant's record with incomplete data might lead to a large proportion of data being discarded, which may lead to a great loss of statistical power and was therefore not considered (Altman & Bland, 2007). Nardi (2006)

stated that a missing item can be left blank, or given a specific code, as long as it cannot be misinterpreted as a real answer. Missing data were therefore assigned blanks on participants' checklists and then excluded in the analysis of that specific variable, as suggested by Nardi (2006).

The descriptive, retrospective design was selected to achieve the aims of the study, and specifically describe all phases of swallowing utilizing VFSS, but without exposing participants to radiation specifically for the study.

3.3. Population

3.3.1. Inclusion Criteria

In order for a participant's record to be included in the study, the following criteria had to be met:

3.3.1.1. Age at the initial VFSS: Participants must have been between the ages of 0 to 12 years 11 months, as RCWMCH serves children within these age boundaries (Red Cross War Memorial Children's Hospital, 2013).

3.3.1.2. Cerebral Palsy: All participants had to have a diagnosis of CP or be classified as "evolving CP" at the time of the VFSS as the study focused on FSD within the CP population.

3.3.1.3. VFSS at RCWMCH: All participants must have had a VFSS performed at RCWMCH. A VFSS provides comprehensive information on swallowing, particularly the pharyngeal phase of swallowing (e.g. the presence of silent aspiration), which is often impaired in children with CP and cannot be assessed clinically (Calis et al., 2008; Colombo & Hallberg, 2012; Craig et al., 2006). RCWMCH was selected as it had a well-established paediatric VFSS service and therefore records of children with CP who have had a VFSS were readily available. RCWMCH further serves a large proportion of children with CP as it has an established CP out-patient clinic. Paediatric VFSS services had only recently been established at Tygerberg Hospital and therefore this hospital was excluded.

3.3.2. Exclusion Criteria

Any record that documented an oral structural abnormality (e.g. cleft palate) or additional condition (e.g. a syndrome such as Down syndrome) which may be associated with FSD was excluded from the study (Arvedson & Brodsky, 2002).

3.3.3. Recruitment

Ethics approval to conduct the study was obtained from the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee (Rec 282/2009) (Appendix A). Permission to conduct the study at the hospital was obtained from the medical manager (Appendix B) and arrangements were made with the Head of the Radiology Department to access the Radiology Department's clinical statistics for the period from 2007 to 2009. Potential participants were then identified from the RCWMCH's Radiology Department's clinical statistics i.e. all VFSS studies booked within the stipulated time frame between January 2007 and December 2009. Medical records of potential participants were requested from the hospital's Records Department and reviewed to determine whether they met the study's selection criteria.

3.3.4. Sampling

Non-probability purposive sampling (Jackson, 2009; Leedy & Ormrod, 2010) was used to select the participants' records which met the inclusion criteria (Jackson, 2009; Leedy & Ormrod, 2010; Terre Blanche & Durrheim, 1999). The participants were selected from a group of patients who had a VFSS from January 2007 to December 2009. All eligible participants' records were included in the study.

3.3.5. Sample Size

A total of 1236 medical records of children who had a VFSS were reviewed to determine whether they met the inclusion criteria of the study. One-hundred-and-twenty-three participants' records, which met the inclusion criteria, were included. One-thousand-one-hundred-and-thirteen patients' records were excluded as these patients did not meet the inclusion criteria. The records were excluded for the following reasons: Nine-hundred-and-forty-three patients' records were excluded as they did not have a diagnosis of CP, whilst 12 patients' records were missing and

therefore unavailable for perusal. Twenty-four patients had an invalid folder number as documented in the Radiology Department's booking system. Five patients, although diagnosed with CP, were above the age limit, whilst one patient had an additional condition. Five patients diagnosed with CP had an adapted VFSS via a NGT or PEG and so their swallowing was not assessed. One-hundred-and-twenty-three patients did not attend the scheduled VFSS, although an appointment was recorded in the Radiology Department's booking system.

3.3.6. Description of Participants

3.3.6.1. General Description of Participants

There were 50.4% males (n=62, N=123) and 49.6% females (n=61, N=123) in the study. The median age of participants at the time of the first VFSS was 2 years, with a range from 1 month to 12 years 5 months.

3.3.6.2. Residential Information

Ninety-one percent of participants (n=112, N=123) lived in the eight sub-districts in the Cape Town Metropole (Provincial Government of the Western Cape, 2007). Seven percent of participants (n=9, N=123) lived outside of the Cape Town Metropole, whilst 1.6% of participants (n=2, N=123) resided outside the Western Cape province of South Africa.

3.3.6.3. CP Classification System

The participants were described according to the CP classification system that was adopted by the research site (see glossary for detailed description). This included the topography of the condition and the nature of the movement disorder, as described by paediatricians in the medical records. The Gross Motor Function Classification System (GMFCS) levels (Morris & Bartlett, 2004; Palisano et al., 1997) for participants were only reported occasionally in the medical records and were therefore not used to describe participants in the study.

The majority of participants (61%) presented with spastic CP. Participants who were labelled as 'evolving CP' represented 22.8% (n=28, N=123) of the total sample. Figure 1 represents the participants' classification of CP.

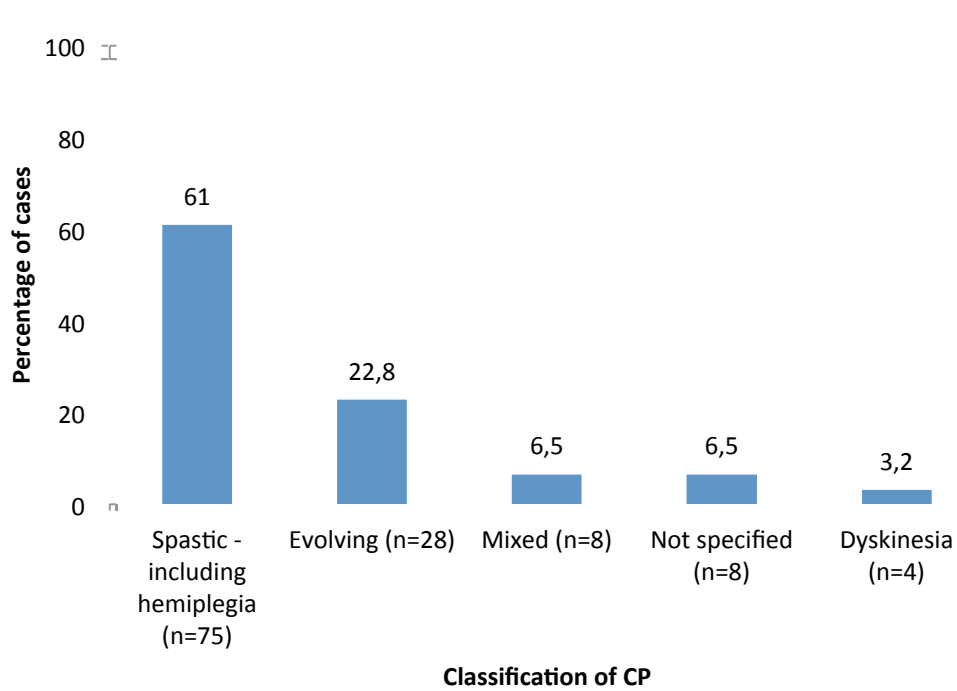


Figure 1. The CP classification of participants (N=123).

The severity of CP for participants in the present study, was assigned and categorised according to the information obtained in the medical records, namely (1) mild, (2) moderate or (3) severe. However, the severity of CP was not documented for 83% (n=102, N=123) of participants and therefore the classification of severity of CP was not used in further analysis in this study. Table 1 presents the severity as recorded for 17% (n=21; N=123) of the participants.

Table 1.

The Severity of Cerebral Palsy Among Participants

| Severity of CP | Number of participants (n=21) | Percentage of cases (N=123) |
|----------------|-------------------------------|-----------------------------|
| Mild | 2 | 2 |
| Moderate | 0 | 0 |
| Severe | 19 | 15 |

3.3.6.4. Other Related Services and Surgery Rendered

Data specific to services post a VFSS were unavailable for one participant (0.8%, N=123), who was not treated at the hospital, but transferred to a secondary level hospital directly after the VFSS. Additional surgery included (1) the insertion of a tracheostomy (2.5%, N=122), (2) tonsillectomy surgery (1.6%, N=122), (3) adenoidectomy surgery (6.6%, N=122) and (4) a Nissen Fundoplication (22.1%, N=122). In addition to the VFSS, 28.7% of participants (n=35, N=122) had Scintigraphy studies and 61.5% of participants (n=70, N=122) received medical treatment (anti-reflux medication) for GOR.

3.4. Measurement Materials

3.4.1. Data Collection Tool

A checklist, namely “*The Checklist for Feeding and Swallowing difficulties in Children (0 to 12 years 11 months) with Cerebral Palsy*” (Appendix C), based on the format by Norman (2006), was developed to act as a “tally sheet” (Jackson, 2009: 83) to capture information regarding the documented FSD of children with CP. The checklist was structured to facilitate data recording:

3.4.1.1. Different items on the data collection tool were selected based on relevant literature on paediatric feeding and swallowing, to enable the researcher to obtain information regarding the FSD of children with CP. The areas of data collection included on the checklist, together with the rationale and references are reflected in Table 2.

3.4.1.2. The data were recorded on the checklist using a tick to indicate absent/present.

3.4.1.3. Provision was made for short answers or descriptors e.g. for the item “indicator for VFSS”, a short phrase was required to state the reason for a VFSS referral.

Table 2.

Areas, Rationale and References for Data Collection Tool

| <i>Data</i> | <i>Rationale</i> | <i>Source</i> |
|--|--|--|
| 1. Reference number | 1. A reference number was assigned to every participant's record to ensure confidentiality and anonymity. | 1. Medical Research Council of South Africa (2000) |
| 2. Demographic data | 2. This information described the demographics of the participants attending RCWMCH. | |
| 2.1. Sex | 2.1. This information was used to provide a description of participants. | 2.1. Hack & Costello, 2008 |
| 2.2. Age at initial VFSS | 2.2. Age at the initial VFSS was an inclusion criteria of the study. | |
| 2.3. Residential area | | |
| 2.4. Sub-districts of Cape Metropole | | |
| 2.5. Areas outside RCWMCH service delivery area | | |
| 2.6. Number of lower respiratory tract infections (LRTI) not leading to hospital admission | 2.6. The number of LRTI which did not lead to hospital admission were recorded over a period of six months before the first VFSS until six months after the final VFSS. FSD may result in LRTI. | 2.6. Erasmus et al., 2012; Rogers, 2004; Seddon & Khan, 2003; Tutor & Gosa, 2012; Wallis & Ryan, 2012; Weir et al., 2011 |
| 2.7. Number of hospital admissions related to LRTIs | 2.7. The number of hospital admissions related to LRTI were recorded over a period of six months before the first VFSS and six months after the final VFSS to determine whether intervention for FSD identified in the VFSS had an effect on the pulmonary status of participants. | 2.7. Tutor & Gosa, 2012; Wallis & Ryan, 2012 |
| 3. Classification of CP | 3. The classification of CP was included in the checklist to determine whether certain classifications of CP resulted in specific FSD. The classification of CP included in the checklist | 3. Arvedson, 2008; Arvedson & Brodsky, 2002; Calis et al., 2008; Erkin et al., 2010; Paneth, 2008; Rogers, 2004; Schaefer, |

was based on the terminology used at the 2008 research site and documented in the medical records: spastic CP, evolving CP, dyskinesia, mixed CP and ataxia.

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| <p>4. Severity of CP</p> | <p>4. FSD in children with CP are related to the severity of the motor impairment. This item was initially included in the checklist to determine if there was an association between the severity of CP and the reported FSD. However, the severity of CP was seldom reported for participants in the study and has therefore been used within the description of participants only.</p> | <p>4. Calis et al., 2008; Paneth, 2008; Rogers 2004; Sullivan, 2008</p> |
| <p>5. Indicators for a VFSS</p> | <p>5. Indicators for a VFSS described health professionals' reasons for requesting a VFSS and provided insight into which indicators health professionals used to query possible FSD. Knowledge of these indicators may help to identify the correct use of a VFSS and may assist in the training of health professionals to appropriately request the VFSS as part of a feeding assessment battery.</p> | <p>5. Arvedson, 2008; Ceriati et al., 2006; Colombo & Hallberg, 2012; Lefton-Greif & Arvedson, 2008; Weir et al., 2011</p> |
| <p>6.Total number of VFSS</p> | <p>6. The total number of VFSS that each participant required during the time frame of 2007 to 2009 was documented to determine how many participants required repeat VFSS for management of FSD.</p> | |
| <p>6. Feeding and Swallowing related signs and disorders</p> <ul style="list-style-type: none"> • <i>Please note: Results of clinical swallowing assessments and VFSS procedures recorded in the medical records were utilized to document the Feeding and Swallowing related signs and disorders. Please see note at the end of Table 2 for a description of the standard clinical swallowing assessment and VFSS procedures conducted at RCWMCH.</i> | | |
| <p>7.1. Oral structure and function</p> | <p>7.1. This item was included as children with CP may have abnormalities of the oral structures such as the tongue and its position and function within the oral cavity. Abnormalities of the oral structures may have an impact on the effectiveness of feeding.</p> | <p>7.1. Arvedson, 2008</p> |

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| 7.1.1. Drooling | 7.1.1. Drooling is a frequent sign of FSD in children with CP. Multiple factors may result in drooling, which may include the (1) inability to swallow effectively as a result of poor lip closure and lingual control, (2) poor dental health, (3) medication, (4) poor postural tone of the head and trunk, (5) upper airway obstruction and (6) sensory difficulties. | 7.1.1. Arvedson & Brodsky, 2002; Ceriati et al., 2006; Erkin et al., 2010; Tahmassebi & Curzon, 2003 |
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| 7.1.2. Presence of abnormal reflexes | 7.1.2. Abnormal reflexes such as a retained rooting reflex occur frequently in children with CP and may influence feeding and swallowing negatively. | 7.1.2. Arvedson, 2008; Benfer et al., 2012a; Salghetti & Martinuzzi, 2012 |
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7.2. Oral preparatory phase:

(Oral preparatory phase difficulties as assessed on clinical assessment up to 6 months prior to the VFSS as well as VFSS results were recorded)

| | | |
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| 7.2.1. Oral sensory motor difficulties, e.g. inability to form a bolus (poor lingual function), anterior food loss (reduced lip closure), oral hyposensitivity, oral hypersensitivity and oral aversion | 7.2.1. Oral sensory motor function is important during the oral preparatory phase of swallowing. Poor oral motor skills have been documented in children with CP and may affect nutrition and hydration. Oral sensory difficulties may result in an inability to accept and tolerate food in the mouth (hypersensitivity) and may ultimately lead to oral aversion. Decreased awareness of the bolus (hyposensitivity) in the oral cavity, may result in anterior spillage with prolonged feeding times. | 7.2.1. Arvedson, 2008; Arvedson & Brodsky, 2002; Benfer et al., 2012a; Ceriati et al., 2006; Erkin et al., 2010; Hall, 2001; Kim et al., 2013; Van den Engel-hoek et al., 2013 |
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7.3. Oral phase:

(Oral phase difficulties as assessed on clinical assessment up to 6 months prior to the VFSS as well as VFSS results were recorded)

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| 7.3.1. Oral residue as a result of (i) reduced labial tension (residue in anterior sulcus), (ii) reduced lingual control and strength (residue on tongue or floor of mouth) and (iii) reduced buccal tone (residue in lateral sulcus) | 7.3.1. Residue from the bolus in the sulci, tongue or floor of mouth indicates the reduced ability to form, hold and propel the bolus to initiate the oral swallow. | 7.3.1. Arvedson, 2008; Arvedson & Brodsky, 2002; Kim et al., 2013 |
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| 7.3.2. Absent or delayed initiation of the oral swallow as a result of (i) apraxia of swallow, (ii) slow lingual initiation to propel bolus posteriorly and (iii) reduced oral sensation | 7.3.2. A delayed initiation or an absent swallow is described as common in children with CP, which may result in inadequate clearing of the oral cavity or place them at risk for aspiration. | 7.3.2. Arvedson, 2008; Arvedson & Brodsky, 2002; Benfer et al., 2012a; Kim et al., 2013; Van den Engel-hoek et al., 2013 |
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7.4. Pharyngeal phase:

(Pharyngeal phase difficulties were only recorded as assessed on a VFSS)

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| 7.4.1. Pooling in the valleculae & pyriform sinuses prior to trigger of swallow (Delayed trigger of the pharyngeal swallow) | 7.4.1. A delayed trigger of the pharyngeal swallow may increase the risk of aspiration as the airway is unprotected. | 7.4.1. Arvedson, 2008; Arvedson & Brodsky, 2002; Mirrett et al., 1994; Van den Engel-hoek et al., 2013; Weir et al., 2007b |
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| 7.4.2. Nasal-pharyngeal backflow (Reduced velar-pharyngeal closure) | 7.4.2. Nasal-pharyngeal backflow indicates poor velum function and a lack of coordination of the oral and pharyngeal phases of swallowing, which may result in poor coordination of breathing and swallowing. | 7.4.2. Arvedson & Brodsky, 2002; Erkin et al., 2010; Kim et al., 2013; Van den Engel-hoek et al., 2013 |
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| 7.4.3. Laryngeal penetration (Reduced laryngeal elevation, reduced closure of laryngeal vestibule) | 7.4.3. Laryngeal penetration may act as a precursor for aspiration which may have a negative effect on the respiratory status of children with CP. | 7.4.3. Arvedson & Brodsky, 2002 |
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| 7.4.3.1. Aspiration (Reduced laryngeal elevation, reduced laryngeal closure, delay in trigger of pharyngeal swallow) | 7.4.3.1. Aspiration in children with CP who have FSD has been estimated as high as 77% and may contribute to the occurrence of recurrent respiratory disease. | 7.4.3.1. Arvedson, 2008; Arvedson & Brodsky, 2002; Del Giudice et al., 1999; Hall, 2001; Mirrett et al., 1994; Rogers et al., 1994; Tutor & Gosa, 2012; Weir et al., 2007a; Weir et al., 2011; Wright et al., 1996 |
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| 7.4.3.2. Silent aspiration (Reduced laryngeal elevation, reduced laryngeal closure, delay in trigger of pharyngeal swallow and/or reduced sensation) | 7.4.3.2. Silent aspiration has been documented in 71-97% of children with CP who demonstrate aspiration. Silent aspiration is less likely to be recognised as there are no explicit external signs to indicate foreign material entering the trachea and may result in respiratory disease. | 7.4.3.2. Arvedson, 2008; Kim et al., 2013; Mirrett et al., 1994; Rogers, 2004; Rogers et al., 1994; Weir et al., 2007a |
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| 7.4.4. Pharyngeal residue in valleculae | 7.4.4. Residue after the swallow may result in | 7.4.4. Kim et al., 2013; Van den |
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| and pyriform sinuses (Reduced tongue base posterior movement and reduced anterior laryngeal movement) | aspiration if not cleared. | Engel-hoek et al., 2013; Weir et al., 2007b |
| 7.5. Oesophageal phase: | | |
| <i>(Oesophageal phase problems were only recorded as assessed on a VFSS)</i> | | |
| 7.5.1. Delayed/insufficient upper oesophageal sphincter opening. | 7.5.1. Upper oesophageal sphincter dysfunction including timing difficulties may be associated with GOR or increased risk of aspiration. The motor dysfunction characteristic of CP may result in delayed/insufficient upper oesophageal sphincter opening. | 7.5.1. Arvedson, 2008; Rosenbaum et al., 2007 |
| 7.5.2. Structural abnormalities | 7.5.2. Structural abnormalities of the oesophagus, such as a trache-oesophageal fistula, may result in FSD. | 7.5.2. Arvedson & Brodsky, 2002; Hall 2001 |
| 7.5.3. Oesophageal motility disorders | 7.5.3. Oesophageal motility disorders are reported for children with CP and may result in swallowing difficulties, pain, aspiration and GOR, all of which may affect feeding efficiency. | 7.5.3. Arvedson & Lefton-Greif, 1998. |
| 8. GOR <i>(GOR was only recorded as assessed on a VFSS, as not all participants had Scintigraphy studies)</i> | 8. GOR occurs when gastric contents move into the oesophagus, and may result in FSD, respiratory problems, oesophagitis and other anatomical abnormalities (e.g. stricture). GOR is a common symptom of children diagnosed with CP and may affect feeding efficiency. | 8. Araújo et al., 2012; Arvedson & Brodsky, 2002; Campanozzi et al., 2007; Hall 2001; Tutor & Gosa, 2012 |
| 9. Nature of services and recommendations provided post VFSS. <i>Feeding intervention:</i> | 9. The types of intervention required for children with CP who presented with FSD was investigated and described within the South African context. Children with CP may need various methods of intervention to ensure safe and optimal feeding and may include alternative modes of feeding to ensure safety, adequate nutrition and hydration. | 9. Andrew et al., 2012; Araújo et al., 2012; Arvedson, 2008; Arvedson & Brodsky, 2002; Calis et al., 2008; Rogers et al., 1994; Snider et al., 2011; Tutor & Gosa, 2012 |
| 9.1. Mode: Oral, Nasogastric tube, Nasojejunal tube, Gastrostomy tube , Combination oral + tube | | |
| 9.2. Consistency: Specify | | |
| 9.3. Utensils: Specify | | |
| 9.4. Oral sensory-motor therapy | | |

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| <p>9.5. Posture and positioning management</p> <p>9.6. Frequency and size of meals</p> <p>9.7. Other: Specify</p> <p>9.8. No intervention</p> | | |
| <p>10. Feeding outcomes</p> <p>10.1. Mode</p> <p>10.2. Consistency: Specify</p> | <p>10. The final feeding outcome of each participant, six months after their final VFSS, was recorded to determine if there was any change from participants' initial to final mode of feeding and what it entailed.</p> | |
| <p>11. Team of health care professionals consulted post VFSS</p> | <p>11. Referrals to other professionals for the management of FSD are essential to provide the best management possible. Although a physiotherapist and an occupational therapist are available as part of a general multi-disciplinary team at the institution, these disciplines were not included as part of the team which were involved in providing direct services to participants with FSD. The physiotherapist and occupational therapist usually focus on general neuro-developmental therapy and only provide indirect intervention related to feeding and swallowing.</p> <p>Interventions by a paediatrician (either as in- or out-patient) were recorded six months post the final VFSS.</p> | <p>11. Andrew et al., 2012; Araújou et al., 2012; Arvedson, 2008; Boesch et al., 2006; Calis et al., 2008; Ceriati et al., 2006; Colombo & Hallberg, 2012; De Benedictis et al., 2009; Lefton-Greif & Arvedson, 2008</p> |

Note. A clinical swallowing assessment was usually conducted for participants who were scheduled to see the SLT prior to the VFSS assessment. The clinical assessment would include an oral structure and function assessment as well as an observation of a mealtime, usually presenting the consistencies and textures that the child typically has at home. These consistencies would include liquids (such as water, milk or juice), a semi-solid consistency (such as cereal or mashed vegetables) and a solid consistency as appropriate.

The type and model of the fluoroscopy equipment used was a *Siemens AX10M Iconos R200* with fixed table height. A standard protocol regarding the VFSS procedure was followed. The frame rate per second was usually set at 7.5 frames per second and 30 frames per second when specifically focusing on the swallow. Water soluble contrast or barium were used to assess the liquid consistency and were presented with a bottle, syringe or cup with a straw (whatever was deemed

appropriate for the participant) by either the nursing sister, the SLT or the caregiver. Liquid barium mixed with cereal to form a semi-solid consistency was prepared by the SLT and presented to the participant using a spoon or a cut-out cup. No participants had solids recorded in their VFSS results which is probably an indication of their ability to manage or tolerate solid consistencies. The VFSS procedure was always recorded, reviewed and analysed by at least two health care professionals (SLT and radiologist) before a report was written.

3.5. Validity

The *“Checklist for Feeding and Swallowing Difficulties in Children (0 to 12 years 11 months) with Cerebral Palsy”* (Appendix C) was developed by the researcher to guide the collection of data from the medical records (Fink, 1995; Jackson, 2009). The validity of an instrument is the extent to which it measures what it is supposed to (Babbie, 1998; Fink, 2008; Jackson, 2009; Leedy & Ormrod, 2010; Litwin, 1995).

The items on the checklist were compiled based on relevant literature on paediatric feeding and swallowing (Araújo et al., 2012; Arvedson, 2008; Arvedson & Brodsky, 2002; Boesch et al., 2006; Ceriati et al., 2006; Erasmus et al., 2012; Kim et al., 2013; Tutor & Gosa, 2012; Van den Engel-hoek et al., 2013; Weir et al., 2007a; Weir et al., 2011) and CP (Andrew et al., 2012; Calis et al., 2008; Campanozzi et al., 2007; Clawson et al., 2007; Del Giudice et al., 1999; Erkin et al., 2010; Hack & Costello, 2008; Mirrett et al., 1994; Morrow et al., 2008; Paneth, 2008; Rogers, 2004; Rosenbaum & Rosenbloom, 2012; Rosenbaum et al., 2007; Seddon & Khan, 2003; Sullivan, 2008; Worley, Stevenson, Rosenbloom & Sullivan, 2007; Wright et al., 1996) and therefore the data collection tool is considered to have face and content validity (Babbie, 1998; Jackson, 2009; Leedy & Ormrod, 2005; Litwin, 1995).

Face validity was further addressed in that the items on the checklist were reviewed by experienced health care professionals in the field of FSD, to ascertain whether it measures, at face value, what is commonly agreed upon as signs of FSD (Babbie, 1998; Jackson, 2009; Leedy & Ormrod, 2010; Litwin, 1995). The checklist was then adapted after these health care professionals provided feedback and re-evaluated, until it was agreed that the data collection tool recorded that for which it was developed, namely FSD data in children with CP.

Content validity was addressed through consulting available literature to ensure that all issues related to feeding and swallowing in the paediatric population with CP were included in the data recording tool (Babbie, 1998; Fink, 2008; Jackson, 2009; Leedy & Ormrod, 2010; Litwin, 1995; Nardi, 2006). Table 2, which provided the rationale and literature to support selection of data collected, represents the content validity of the tool.

3.6. Reliability

Reliability is the consistency with which a data collection tool yields the same result when it is applied repeatedly and the entity being measured has not changed (Babbie, 1998; Fink, 2008; Leedy & Ormrod, 2005; Litwin, 1995). Reliability of the checklist was assessed in two ways during the study, namely intra-rater reliability and inter-rater reliability.

Intra-rater reliability provides a measure of how well the captured data on the checklist can be reproduced when the researcher repeats the process of entering the data obtained from the medical records onto the checklist (Babbie, 1998; Leedy & Ormrod, 2005; Tredoux & Durrheim, 2002). To address intra-rater reliability the researcher reviewed the first participant's medical record and captured data onto the checklist. On a different occasion, after two weeks, without access to the first data-set (hence blind), the researcher repeated the data collection process. The level of agreement between the two data-sets was determined by dividing the number of agreements by the number of possible agreements and establishing the percentage of agreement. A 95% level of agreement was deemed acceptable and was obtained with the exact agreement level being measured at 98.6% (Jackson, 2009).

Inter-rater reliability assesses the agreement of data-sets collected by two or more raters (Fink, 2008; Jackson, 2009; Leedy & Ormrod, 2010; Litwin, 1995). To address inter-rater reliability, another SLT employed at the institution, without access to the first researcher's data sets (hence blind), reviewed 13% of the selected records and captured data onto clean checklists on a different occasion. The level

of agreement between the two data-sets was determined by dividing the number of agreements by the number of possible agreements and establishing the percentage agreement (Jackson, 2009; Stemler & Tsai, 2008). A 95% level of agreement was accepted and obtained, with the exact level of agreement measured at 99.2% (Jackson, 2009).

3.7. Procedure

3.7.1. Data Collection

The following procedures were implemented during the data collection period:

3.7.1.1. Ethics approval for the study was obtained from the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee (Rec Ref 282/2009) (Appendix A). Permission to conduct the research and review medical records was obtained from the medical manager at RCWMCH (Appendix B).

3.7.1.2. Arrangements were made with the Head of the Radiology Department to access information from the department's clinical statistics.

3.7.1.3. Patients who had a VFSS from January 2007 to December 2009, were identified by the researcher from the records of the Radiology Department.

3.7.1.4. Medical records of these patients were requested in order to identify all eligible participants' records that met the selection criteria.

3.7.1.5. Each participant's record was assigned a reference number to ensure anonymity and confidentiality. The list with the assigned reference numbers and participants' names and folder numbers was kept separately and secure to ensure that participants' reference numbers could not be linked to their specific medical records. Post publication of the research, the master list of reference numbers will be destroyed.

3.7.1.6. Information from participants' medical records were extracted and recorded on the checklist.

3.7.1.7. The researcher conducted intra-rater checks at the beginning of the data collection process and a 98.6% level of agreement was measured. Inter-rater reliability assessments were conducted throughout the data collection process on 13% of participants and a 99.2% level of agreement was achieved.

3.7.1.8. All data were coded and entered onto a Microsoft Excel spreadsheet to facilitate the process of data analysis.

3.8. Data Analysis

Data sets as represented by the items on the checklist were categorized according to nominal and ordinal measures (Nardi, 2006). Nominal data are discrete measures to which values are assigned to enable the representation and identification of different categories of entities (Leedy & Ormrod, 2010; Nardi, 2006). Examples of nominal data measurements in this study were the (i) indicators for a VFSS, (ii) nature of FSD as described in the phases of swallowing, (iii) different classifications of CP, (iv) nature of services received, (v) number of LRTI and (vi) number of admissions related to LRTI. The measurements were considered ordinal, when the category values for a variable reflected a certain sequence (Leedy & Ormrod, 2010, Nardi, 2006). An example of an ordinal measurement in this study was the severity of CP.

As Nardi (2006) suggests, univariate analysis (one variable at a time), was done prior to further data analysis. For example, before exploring whether any associations between the classification of CP and FSD could be described, the classification of CP was analysed first.

A statistician was consulted to assist with the process of data analysis. The data was processed using the statistical package STATA (StataCorp, 2009) and analysed using PASW (SPSS) Statistics version 18.0.2 (SPSS Inc, 2010). The alpha level was set at .05. Frequency distributions and cross tabulations, where two variables were looked at simultaneously (i.e. comparing the classification of CP with the presence of FSD), were used to describe, explore and analyse the characteristics of FSD in the sample of participants with CP (Jackson, 2009).

Missing items for participants were assigned blanks and the record, for which a particular item was missing, was excluded in that particular analysis, as suggested by Nardi (2006). When the PASW (SPSS) Statistics version 18.0.2 (SPSS Inc, 2010) computer program was used to analyse data, the program excluded the blank items from the specific analysis and reported it as “missing data” (Nardi, 2006).

Significance analysis was not possible in instances where variables were dependant, which is in keeping with the general assumption that categories should be independent for statistical analysis for most formal tests, such as the Pearson chi-square test (Howell, 2004; Wackerly, Mendenhall & Scheaffer, 2008). The data analysis procedure relating to each objective will be described in the following section:

3.8.1. Indicators for a VFSS

The observed frequencies of indicators were computed across all VFSS. A Pearson Chi-square Test is the ideal statistical procedure to determine whether there is a difference in frequency for the different indicators (Jackson, 2009; Wackerly et al., 2008). The test could however not be performed as participants could have more than one indicator for a VFSS, thereby violating the test’s assumption of independence (Wackerly et al., 2008).

The Pearson Chi-square Test (Jackson, 2009; Leedy & Ormrod, 2010; Wackerly et al., 2008) was however used to determine if there was a significant difference between the numbers of participants who only required one VFSS versus those who required more than one VFSS. For participants who had at least two VFSS, the McNemar Test (Garson, 2008) was used to determine if there was a significant difference for indicators over successive VFSS.

3.8.2. The Frequency and Nature of FSD in the Paediatric Population With CP (0 to 12 years 11 months) who have had a VFSS

The observed frequencies of each sign and disorder for each phase of swallowing were computed across all VFSS. The Pearson Chi-square Test (Jackson, 2009; Wackerly et al., 2008) could not be performed as the assumption that categories

were independent was not met, as participants could have had more than one difficulty within each phase and across the different phases of swallowing. An extended version of the McNemar Test, namely the Cochran Q's Test (Tsoi, 2011) was used to determine if there was a significant difference between the signs and disorders of the pharyngeal phase for the different consistencies of liquids and semi-solids.

3.8.3. The Association Between the Classification of CP and the Nature of FSD

As for objective 2, the observed frequencies of each sign and disorder for the different phases of swallowing for each classification of CP were computed across all VFSS. A formal statistical test for difference in frequencies, such as a Pearson Chi-square Test or Fisher's Exact Test (Wackerly et al., 2008) could not be applied to this data. Participants in the different classifications of CP could have had more than one difficulty within each phase and across the different phases of swallowing, thereby violating the tests' assumption of independence. Moreover, the Pearson Chi-square Test requires an expected count of at least 5 in each category, which was also not satisfied (Garson, 2008; Wackerly et al., 2008).

3.8.4. The Nature of Services Provided to Participants Subsequent to the VFSS

The observed frequencies for services provided to participants were computed across all VFSS. The observed frequencies for specific interventions and recommendations related to speech-language therapy services were also calculated across the VFSS.

3.8.5. Changes in Health and Feeding Outcomes Following the VFSS

To describe changes in health outcomes, a non-parametric inferential test, namely the Wilcoxon Matched-pair Signed-rank Test, was used to determine whether there was a significant change in the recorded number of LRTI not leading to admission, 6 months prior and 6 months after the first VFSS (Jackson, 2009; Leedy & Ormrod, 2005; Leedy & Ormrod, 2010; Pallant, 2005; Tredoux & Durrheim, 2002). Similarly, this test was used to compare whether there was a significant change in the recorded number of hospital admissions related to LRTI, 6 months prior and 6 months after the first VFSS (Jackson, 2009; Leedy & Ormrod, 2010; Pallant, 2005).

The Wilcoxon Test compares two sets of scores derived from the same participant (Jackson, 2009), and therefore this test was best suited to compare the number of LRTI not leading to admission, prior and after the first VFSS, and the number of hospital admissions related to LRTI prior and after the first VFSS.

The Wilcoxon Matched-pair Signed-rank Test was also used to determine whether there was a significant change for participants who demonstrated aspiration on the first VFSS, (i) in the recorded number of LRTI not leading to admission and (ii) admissions related to LRTI, 6 months prior and 6 months after the VFSS.

To describe changes in feeding outcomes, the Pearson Chi-square Test (Jackson, 2009; Leedy & Ormrod, 2010; Wackerly et al., 2008) was used to compare if there was a significant change of participants' documented first mode (mode of feeding directly after the first VFSS) to the final mode (mode of feeding at the final documented VFSS). Furthermore, the observed frequencies for consistency changes made to participants' oral diets were computed across all VFSS.

3.9. Presentation of Data

The researcher has presented information in graphical frequency distributions and tables to assist the reader in processing the data and to make it easy to interpret the distribution of scores (Nardi, 2006; Tredoux & Durrheim, 2002). A frequency distribution showed how often a variable was applicable across participants (Nardi, 2006). The indicators for a VFSS, the nature of FSD, the classification of CP, the different feeding interventions and nature of services post the VFSS were presented through the use of frequency distributions. These graphic representations offer the reader a quick visual description of the different variables (Nardi, 2006; Tredoux & Durrheim, 2002).

3.10. Ethical Considerations

It is important to consider ethical issues when research is conducted (Medical Research Council of South Africa, 2000). This research project was guided by the guidelines of The World Medical Association Declaration of Helsinki (2008) and the four basic ethical principles as set out by Beauchamp and Childress (2009), namely autonomy, beneficence, non-maleficence and justice.

Autonomy refers to the basic right of a person to self-rule. This implies that a person is not influenced by other controlling parties or personal limitations and is therefore free to make meaningful choices (Beauchamp & Childress, 2009; Usher & Holmes, 1997). Pivotal to any research is the issue of informed consent (The World Medical Association Declaration of Helsinki, 2008). As this study is a retrospective review and assigned reference numbers were used to “delink” data, anonymity and confidentiality were maintained and therefore informed consent was not necessary (Medical Research Council of South Africa, 2000). Confidentiality was further maintained by keeping the assigned reference numbers in a secure place for verification purposes. Post publication, the reference numbers will be destroyed so that participants’ reference numbers cannot be linked to their specific medical records.

The Medical Research Council of South Africa (2000) further states that consent should, as far as possible be sought from the health care professional responsible for the care of the patient and therefore the researcher obtained permission from the medical manager at RCWMCH. Careful consideration of the interpretation and representation of data was given to ensure that participants’ identity is not revealed (Jelsma & Clow, 2005). Even though results may be used for publication or during education of students or other health care professionals, anonymity and confidentiality will be maintained at all times.

Beneficence refers to the principle to do good and contribute to a participant’s welfare (Beauchamp & Childress, 2009; Diekema, 2006; Schüklenk, 2000). Although participants in the study will not benefit directly from the results of the research, it is hoped that this study will in future benefit children diagnosed

with CP, by improving service delivery through the promotion of early identification, referral and appropriate management of FSD in this population.

Non-maleficence refers to the obligation not to inflict harm intentionally and to protect participants from possible exploitation (Beauchamp & Childress, 2009; Schüklenk, 2000). There was no risk or harm to participants or their families, as participants were not directly involved in the research (Medical Research Council of South Africa, 2000).

Distributive justice refers to the fair and equal distribution of risks and benefits, especially in the selection of participants (Beauchamp & Childress, 2009; Diekema, 2006; Medical Research Council of South Africa, 2000). This principle requires just procedures and outcomes in the selection of participants (Medical Research Council of South Africa, 2000). The records of all participants had an equal opportunity of being selected once inclusion criteria were met, with an equal distribution of risks and benefits (Medical Research Council of South Africa, 2000).

4. RESULTS

The aim of the study was to describe the nature of FSD in the paediatric population with CP who have had VFSS. The results of the study are presented and discussed in accordance with the aim and objectives of the study, as set out in the methodology.

4.1. Indicators for a VFSS

Participants had one or more indicators for a VFSS. Figure 2 reflects the percentage of cases for each of the indicators for a VFSS.

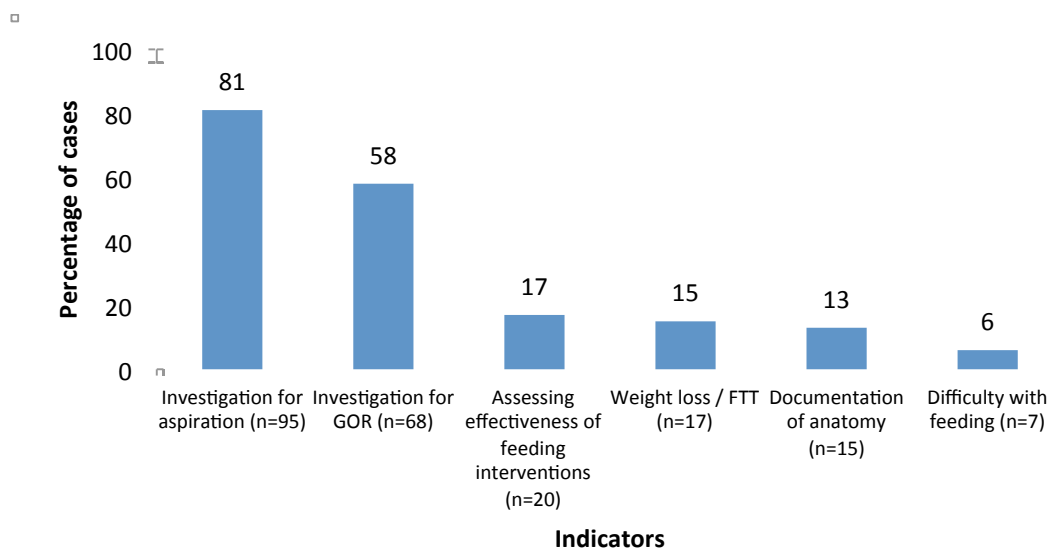


Figure 2. Indicators for a VFSS (n=117).

Note. FTT = failure to thrive

Although all participants had at least one VFSS, indicators for a VFSS were only available for 95.1% of participants (n=117, N=123). The two main indicators for a VFSS were (1) investigations for aspiration and (2) investigations for GOR, which occurred more frequently than the other four indicators, namely (3) assessing effectiveness of feeding interventions, (4) weight loss or failure to thrive (FTT) (5) documentation of anatomy and (6) difficulty with feeding.

There was significantly more participants who required only one VFSS than those who required multiple VFSS ($\chi^2(3) = 190.0732; p < .001$). Twenty-two percent of participants (n=27, N=123) required multiple VFSS, however 78% of participants

(n=96, N=123) only had one VFSS. A description of the different indicators across videofluoroscopic swallow studies, i.e. VFSS 1 to VFSS 4, is reflected in Figure 3.

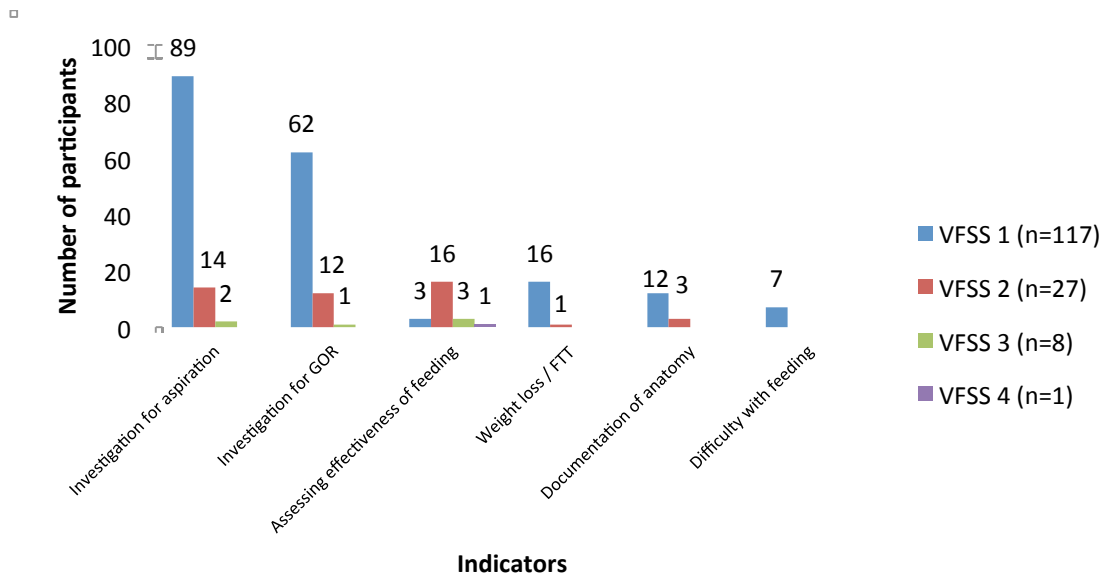


Figure 3. A description of the different indicators for participants across VFSS 1 – 4. In comparing the indicators across VFSS 1 and VFSS 2, there was a significant increase in the number of VFSS requested for the indicator “assessing effectiveness of feeding interventions” from the first to the second VFSS (McNemar’s Test= 14.062 ; $p < .001$).

4.2. The Frequency and Nature of FSD in the Paediatric Population With CP (0 to 12 years 11 months) who have had a VFSS.

Eighty-six percent of participants (n=106, N=123) presented with FSD. All phases of swallowing were affected.

Problems in the oral preparatory and pharyngeal phases were noted more frequently in comparison to difficulties in other phases as illustrated in Figure 4.

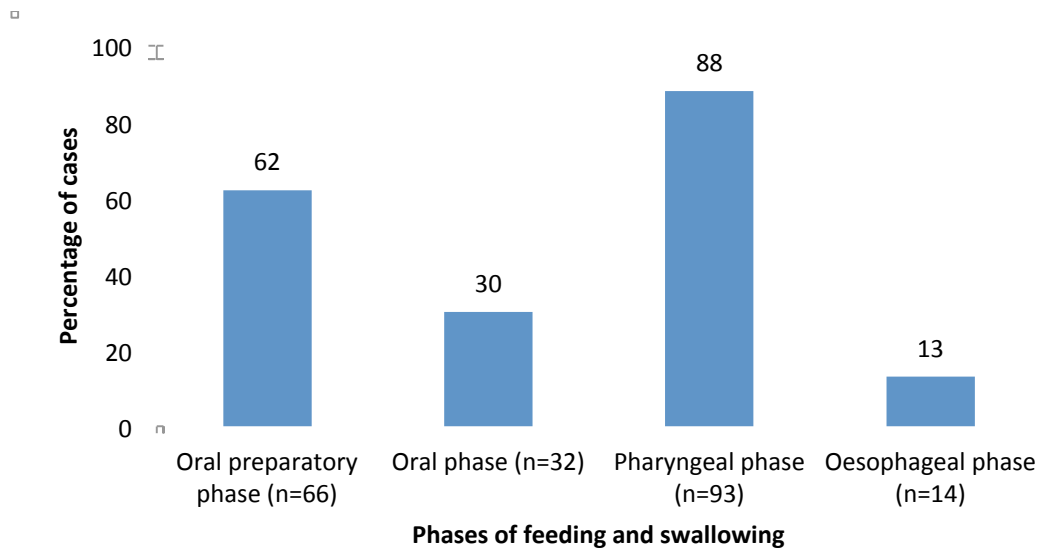


Figure 4. Difficulties in the different phases of swallowing (N=106).

Note. Values reflected in Figure 4 are not mutually exclusive, difficulties in the phases of swallowing will therefore not add up to 100% as phase difficulties may have presented simultaneously in certain participants.

The disorders characteristic of the different phases of swallowing and feeding will be described in the following section.

4.2.1. Oral Structure and Function

During the assessment of oral structure and function, sixteen percent of participants (n=17, N=106) presented with drooling, whilst fifteen percent of participants (n=16, N=106) demonstrated abnormal reflexes, such as the presence of a retained rooting reflex.

4.2.2. Oral Preparatory Phase

Oral preparatory phase difficulties were documented in 62% of participants (n=66, N=106). Anterior food loss (as a result of reduced lip closure) and inadequate bolus formation (as a result of poor lingual function) were noted more frequently than other difficulties in the oral preparatory phase.

Figure 5 provides a summary of the specific oral preparatory phase difficulties.

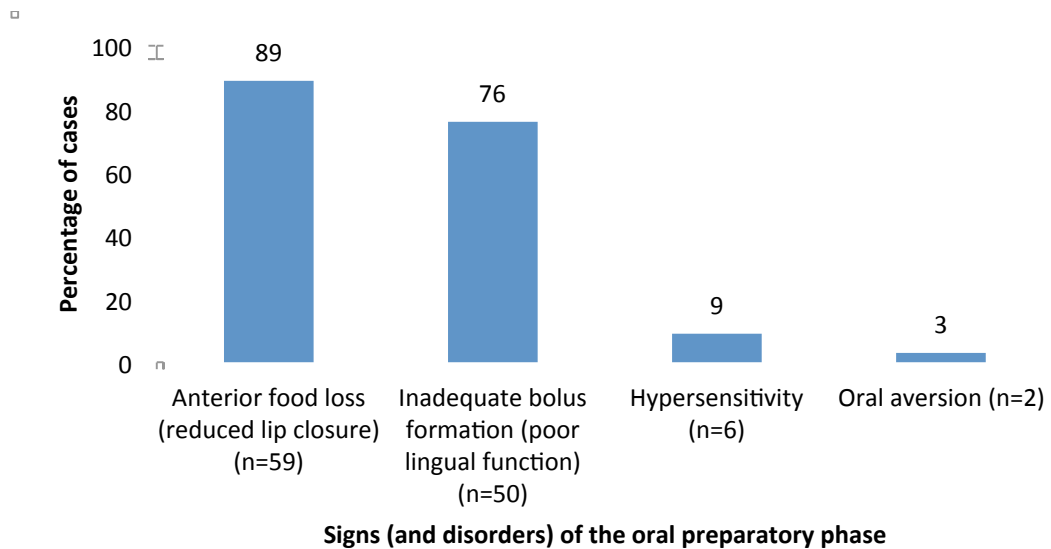


Figure 5. Difficulties in the oral preparatory phase (N=66).

Note. Values reflected in Figure 5 are not mutually exclusive, difficulties in the oral preparatory phase will therefore not add up to 100% as difficulties may have presented simultaneously in certain participants.

4.2.3. Oral Phase

Thirty percent of participants (n=32, N=106) demonstrated oral phase difficulties, which presented either as (1) oral residue as a result of (i) reduced labial tension (residue in anterior sulcus), (ii) reduced lingual control and strength (residue on tongue or floor of mouth) and (iii) reduced buccal tone (residue in lateral sulcus) and an (2) absent or delayed initiation of the oral swallow as a result of (i) apraxia of swallow, (ii) limited lingual movement and (iii) reduced oral sensation.

Ninety-one percent of participants with oral phase difficulties (n=29, N=32) did not initiate the oral swallow, whilst 25% (n=8, N=32) of these participants demonstrated oral residue.

4.2.4. Pharyngeal Phase

Pharyngeal phase difficulties were documented in 88% of participants (n=93, N=106). Figure 6 summarizes the different signs (and disorders) of the pharyngeal phase which were reported for participants. Laryngeal penetration and aspiration were documented more frequently than other difficulties in the pharyngeal phase. Twenty percent of participants (n=19, N=93) demonstrated silent aspiration.

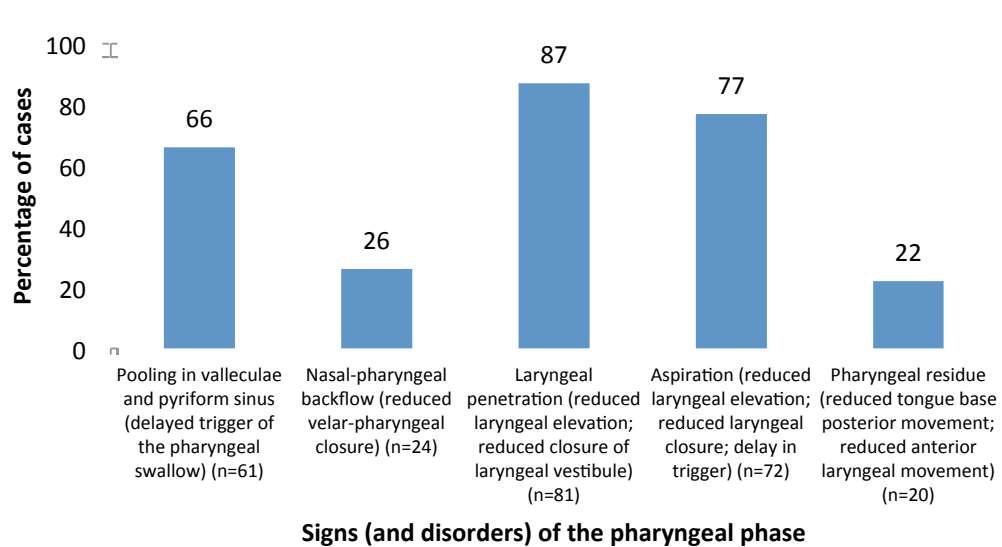


Figure 6. Difficulties in the pharyngeal phase (N= 93).

Note. Values reflected in Figure 6 are not mutually exclusive, difficulties in the pharyngeal phase will not add up to 100% as difficulties may have presented simultaneously in certain participants.

4.2.4.1. The Relative Frequency of Pharyngeal Phase Signs (and Disorders) With Different Consistencies

The relative frequency of pharyngeal phase signs (and disorders) with two different consistencies, namely (1) liquids and (2) semi-solids will be described. Figure 7 summarizes the frequency of pharyngeal phase signs (and disorders) with the two different consistencies.

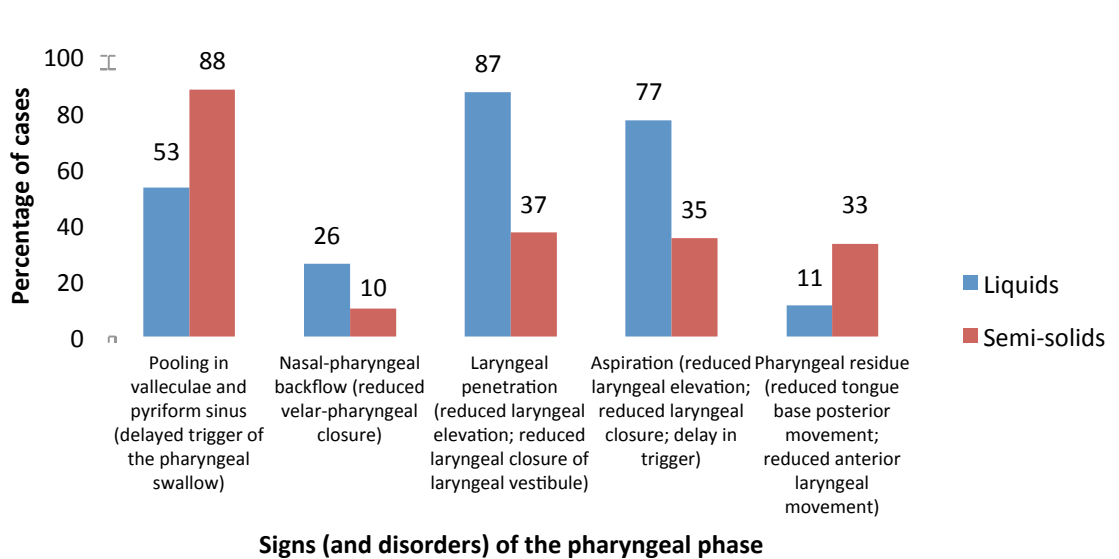


Figure 7. Pharyngeal phase signs (and disorders) for liquids (N=90) and semi-solids (N=49).

Note. Values reflected in Figure 7 are not mutually exclusive, difficulties in the pharyngeal phase for each consistency will not add up to 100% as difficulties may have presented simultaneously in certain participants.

Participants demonstrated more difficulties with liquids than with semi-solids in the pharyngeal phase of the swallow. Seventy-seven percent of participants (n=69, N=90) demonstrated aspiration with liquids, and of these, 18 participants (26%, N=69) aspirated silently. For the 17 participants (35%, N=49) who demonstrated aspiration with semi-solids, 18% of participants (n=3, N=17) did so silently.

In comparing the consistencies of liquids to semi-solids for each pharyngeal sign (and disorder), there were significantly more difficulties with liquids than with semi-solids for all pharyngeal signs (and disorders), except for the presence of pharyngeal residue (reduced tongue base posterior movement; reduced anterior laryngeal movement). Table 3 reflects Cochran Q's Test statistics for the comparison between liquids and semi-solids for each pharyngeal sign (and disorder).

Table 3.

Comparison between Liquids and Semi-solids for Each Pharyngeal Sign (and Disorder).

| Pharyngeal sign | Pharyngeal disorder | N | Test statistic | p-value |
|---|--|----|----------------|---------|
| Pooling in valleculae and pyriform sinus | Delayed trigger of the pharyngeal swallow | 53 | 4.923 | .022 |
| Nasal-pharyngeal backflow | Reduced velar-pharyngeal closure | 52 | 7.111 | .004 |
| Laryngeal penetration | Reduced laryngeal elevation ; reduced closure of laryngeal vestibule | 52 | 32.029 | 0 |
| Aspiration | Reduced laryngeal elevation; reduced laryngeal closure; delay in | 52 | 31.03 | 0 |

trigger of pharyngeal swallow

| | | | | |
|---------------------------|---|----|-------|------|
| Pharyngeal residue | Reduced tongue base posterior movement; reduced anterior laryngeal movement | 52 | 2.083 | .146 |
|---------------------------|---|----|-------|------|

Liquid-consistencies were therefore more difficult to manage than semi-solids in the pharyngeal phase, except for the presence of pharyngeal residue, which were reported more frequently on the thicker consistency. Even though pharyngeal residue was noted more frequently for semi-solids than liquids, a significant difference between the two consistencies was not reported.

4.2.5. Oesophageal Phase

Oesophageal phase problems were noted for 13% of participants (n=14, N=106). Half of the participants with oesophageal phase problems (n=7, N=14) presented with motility disorders and/or structural abnormalities, which included a posterior impression on the oesophagus and an anterior oesophageal web. Figure 8 provides a summary of the specific oesophageal phase problems reported for participants.

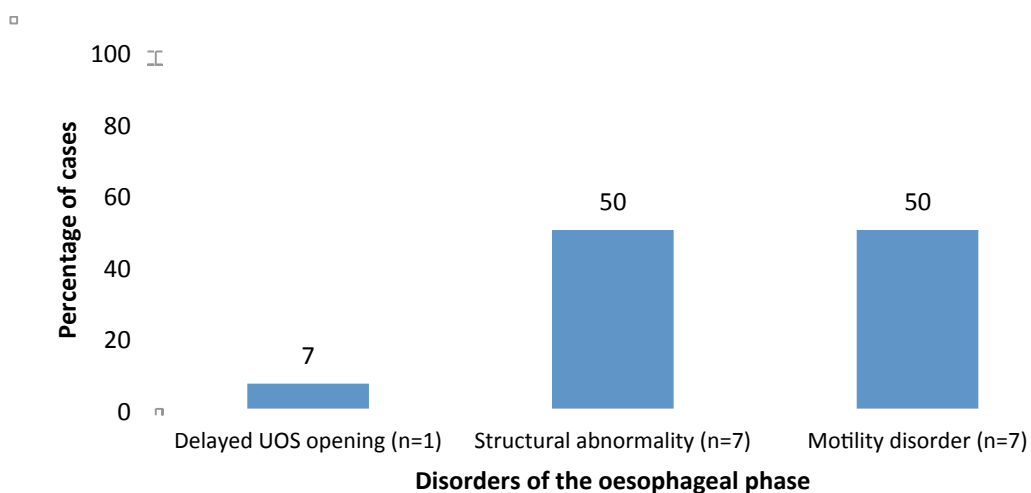


Figure 8. Disorders of the oesophageal phase as reported on a VFSS (N=14).

Note. Values reflected in Figure 8 are not mutually exclusive, problems in the oesophageal phase will not add up to 100% as problems may have presented simultaneously in certain participants.

4.3. The Association Between the Classification of CP and the Nature of FSD.

The following section will describe the association between the different classifications of CP and the nature of FSD. For details of specific disorders of feeding and swallowing within each phase and classification of CP, the reader is referred to Appendix D.

4.3.1. FSD in Participants Classified as Spastic CP

Seventy-five participants (61%, N=123) were diagnosed with spastic CP, either spastic quadriplegia (n=70, N=75) or spastic hemiplegia (n=5, N=75). Sixty-four (85%, N=75) participants with spastic CP demonstrated FSD.

Sixty-one participants (87%, N=70) with spastic quadriplegia demonstrated FSD. These participants demonstrated difficulties in all phases of swallowing, with oral preparatory and pharyngeal phase problems noted more frequently than in other phases of swallowing.

Three participants (60%, N=5) with spastic hemiplegia demonstrated FSD. These participants demonstrated difficulties in the oral preparatory, oral and pharyngeal phases of swallowing, with pharyngeal phase difficulties being observed for all three patients.

Figure 9 reflects the difficulties in the different phases of swallowing for participants with spastic CP.

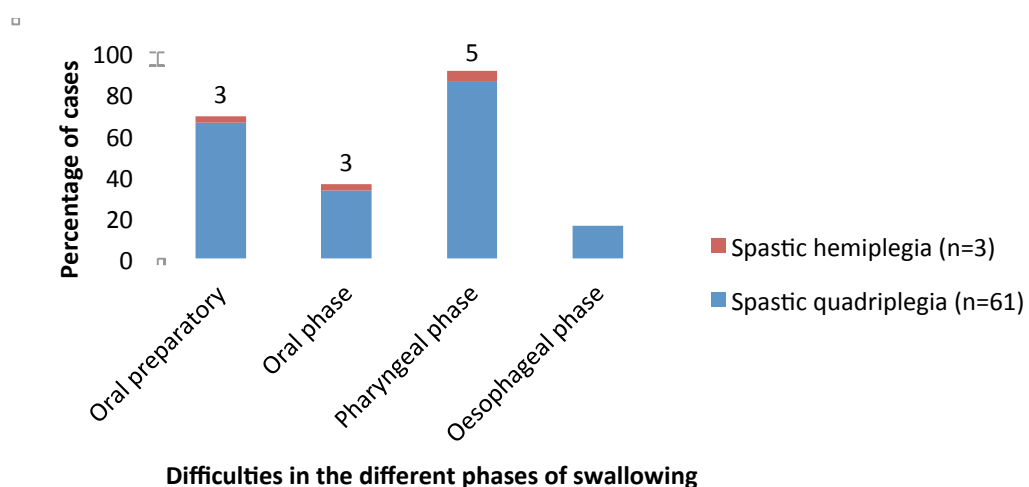


Figure 9. Difficulties in the different phases of swallowing for participants with spastic CP (N=64).

Note. Values reflected in Figure 9 are not mutually exclusive, difficulties in the different phases of swallowing for participants with spastic CP will therefore not add up to 100% as difficulties may have presented simultaneously in certain participants.

Participants with spastic CP demonstrated oral preparatory and pharyngeal phase difficulties more frequently than other phases of swallowing.

4.3.2. FSD in Participants Classified as Evolving CP

Twenty-eight participants (22.8%, N=123) were classified as evolving CP; 26 (93%, N=28) of whom demonstrated FSD. Difficulties were recorded in all phases of swallowing, with oral preparatory and pharyngeal phase difficulties noted more frequently. Oesophageal phase problems were noted least frequently of all phases, with two participants (8%, N=26) demonstrating an oesophageal phase disorder. Figure 10 reflects the difficulties in the different phases of swallowing for participants with evolving CP.

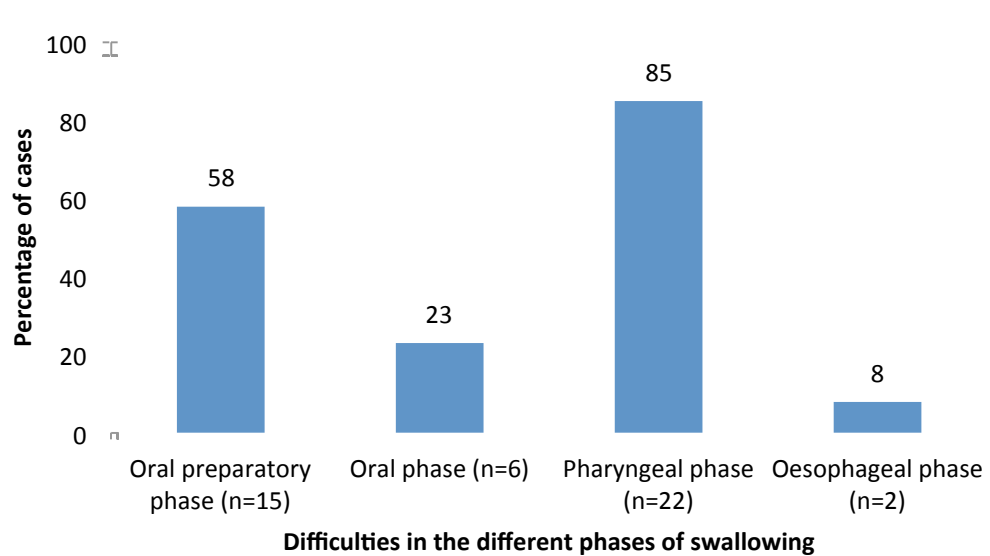


Figure 10. Difficulties in the different phases of swallowing for participants with evolving CP (N=26).

Note. Values reflected in Figure 10 are not mutually exclusive, difficulties in the different phases of swallowing for participants with evolving CP will therefore not add up to 100% as difficulties may have presented simultaneously in certain participants.

4.3.3. FSD in Participants Classified as Mixed CP and Dyskinesia

As the classifications of dyskinesia and mixed CP individually represented less than 10% of the total number of participants (n=12; N=123), the results of the difficulties in the different phases of swallowing for these classifications of CP are presented together in Figure 11.

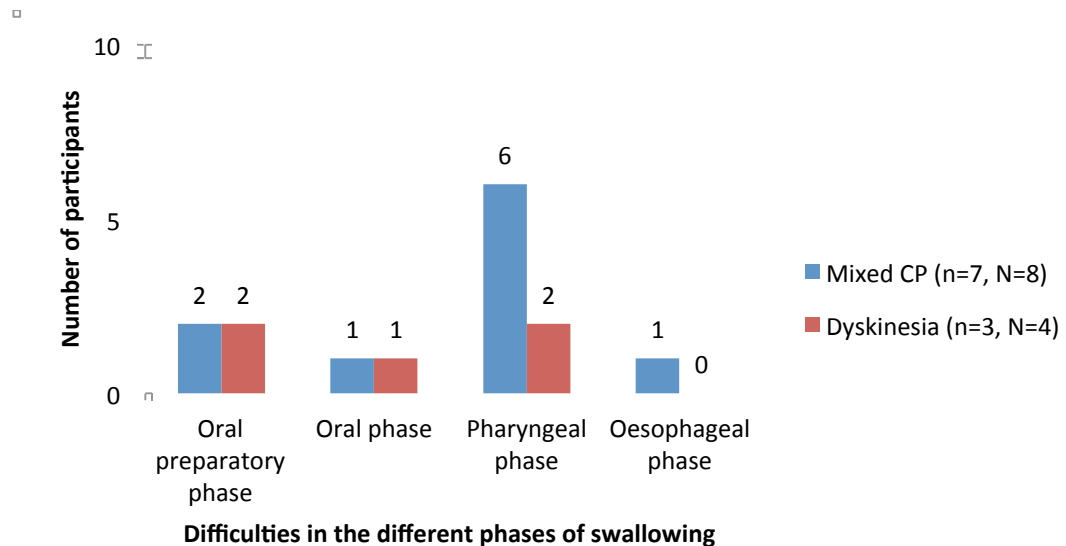


Figure 11. Difficulties in the different phases of swallowing for participants with mixed CP and dyskinesia.

4.3.3.1. Mixed CP

Eighty-eight percent (n=7, N=8) of participants with mixed CP demonstrated FSD. Pharyngeal phase difficulties were noted most frequently for participants with mixed CP. Oral and oesophageal phase difficulties were observed least frequently in this sample of participants with mixed CP.

4.3.3.2. Dyskinesia

Seventy-five percent (n=3, N=4) of participants with dyskinesia, demonstrated FSD. Participants with dyskinesia had equal difficulties in the oral preparatory and pharyngeal phases of swallowing. No problems were observed in the oesophageal phase.

4.3.4. Summary

Participants demonstrated FSD across all the different classifications of CP which were represented in the study. Pharyngeal phase difficulties were demonstrated most frequently in every classification of CP, except for participants diagnosed with dyskinesia (including athetoid and dystonic CP), who demonstrated oral preparatory and pharyngeal phase difficulties equally. Oesophageal phase problems were noted least frequently for all classifications of CP.

4.4. The Nature of Services Provided to Participants Subsequent to the VFSS.

4.4.1. The Team of Health Care Professionals Consulted

The SLT was one of a range of health care professionals who provided services to participants post a VFSS. Figure 12 reflects the different health care professionals who provided consultation or services to participants up to six months after participants' final VFSS.

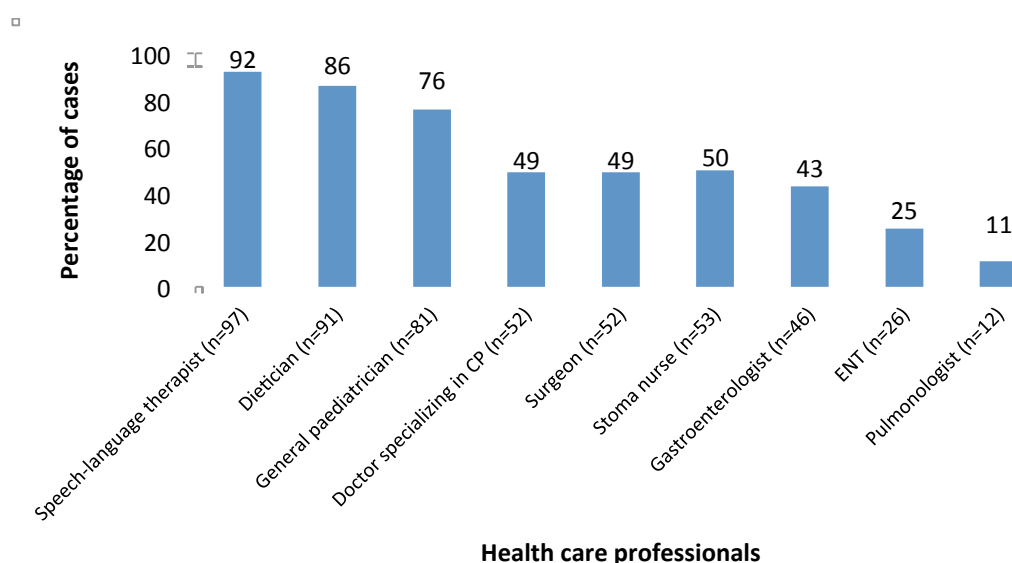


Figure 12. Health care professionals who provided consultation or services to participants up to six months post a VFSS (N=106).

Note. Values reflected in Figure 12 are not mutually exclusive, the different health care professionals who provided consultation to participants six months post a VFSS, will therefore not add up to 100% as participants may have had services simultaneously.

Post a VFSS, services by a SLT, dietician and general paediatrician were rendered more frequently than services by other health care professionals. Pulmonologists and Ear-nose-and-throat surgeons were least frequently consulted post a VFSS.

4.4.2. Nature of Speech-Language Therapy Recommendations and Interventions

Figure 13 reflects the recommendations and interventions which were provided by a SLT to participants.

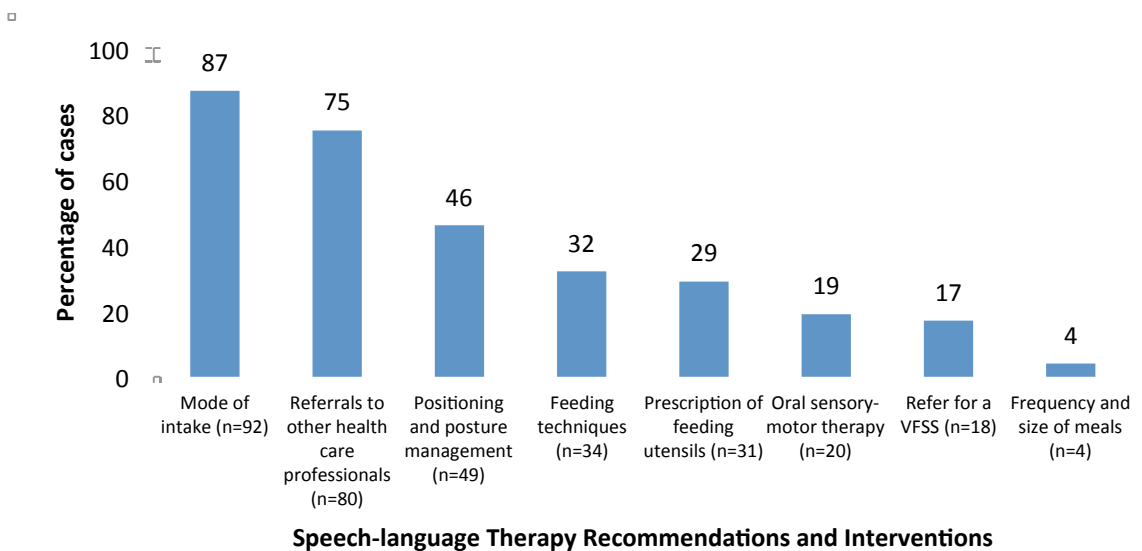


Figure 13. Specific speech-language therapy services provided to participants (N=106).

Note. Speech-language therapy recommendations and interventions were documented after the first VFSS and up to six months after a participant's last VFSS.

Values reflected in Figure 13 are not mutually exclusive, speech-language therapy services may have been provided simultaneously to participants, and therefore services provided will not add up to 100%.

Speech-language therapy recommendations and interventions relating to (i) the safest mode of intake (oral and non-oral), as well as the inclusion of consistency changes to oral feeds, (ii) referrals to health care professionals and (iii) positioning and posture management for feeding were observed more frequently than other speech-language therapy interventions. Feeding techniques such as (i) oral control, (ii) lateral feeding, (iii) pacing of feeds, (iv) repeat dry swallows to reduce oral

and/or pharyngeal residue and (v) smaller bolus sizes per offering, were also introduced for 32% of participants (n=34, N=106).

Feeding utensils were prescribed for 31 participants (29%, N=106) and included syringes to drink small volumes of liquids at a time, cut-out cups, spoons, specific bottles and pacifiers to aid in the clearance of oral and pharyngeal residue.

Forty-two percent (n=45, N=106) of participants discontinued with speech-language therapy services post a VFSS, as these participants were lost to follow up due to defaulting appointments. Speech-language therapy services continued for 46% of participants (n=49, N=106) at the institution, either through the SLT working at the CP clinic or the resident SLT. Speech-language therapy services were further provided to 1.9% of participants (n=2, N=106) in a private practice. Twelve percent of participants (n=15, N=123) were not referred to a SLT post a VFSS.

4.5. Changes in Health and Feeding Outcomes Following the VFSS.

4.5.1. Health Outcomes as Defined by a Comparison of the (i) Number of LRTI not Leading to Admission in a Period of Six Months Before and After the First VFSS and the (ii) Number of Admissions Relating to LRTI in a Period of Six Months Before and After the First VFSS

Thirty-five percent of participants (n=43, N=123) were diagnosed with LRTI before the first VFSS that were severe enough to warrant admission. The number of LRTI not leading to admission ($Z=2.018$; $p=.0436$) and admissions related to LRTI ($Z=3.592$; $p=.0003$) were significantly less, six months after the first VFSS, than six months before the first VFSS.

Although the number of LRTI not leading to admission and the number of admissions relating to LRTI were documented for the second to fourth VFSS, the before-after time period for these VFSS, differed considerably between participants (3 months to > a year), making comparisons difficult.

The participants who demonstrated aspiration on the first VFSS demonstrated fewer LRTI not leading to admission ($Z=1.722$; $p=.085$) six months

after the first VFSS than six months before the first VFSS. Participants who demonstrated aspiration on the first VFSS however demonstrated significantly fewer admissions related to LRTI ($Z=2.068$; $p=.0386$) six months after the first VFSS than six months before the first VFSS.

4.5.2. Feeding Outcomes as Defined by (i) the Changes From Participants' Initial Mode of Feeding (Directly Post the First VFSS) to Final Mode of Feeding (Up to Six Months After Participants' Final VFSS) and (ii) Consistency Changes to Oral Diets

4.5.2.1. Changes From Participants' Initial Mode of Feeding to Final Mode of Feeding

A significant change, when comparing participants' initial to final mode of feeding, was noted, except in the oral mode of feeding where the number of participants who fed orally at the initial mode of feeding did not change significantly at the final mode of feeding. Table 4 reflects the observed statistical change in comparing the initial to final mode of feeding.

Table 4.

Observed Statistical Change Noted for Participants' Initial to Final Mode of Feeding

| Mode of Feeding | Initial mode (n=104) | Final mode (n=105) | Test statistic (Chi-square) | p-value |
|------------------------|---------------------------------|-------------------------------|------------------------------------|----------------|
| Oral | 51 | 47 | 0.941 | .332 |
| NGT | 40 | 2 | 37.026 | <.0001 |
| NJT | 8 | 2 | 5.143 | .016 |
| Gastrostomy/PEG | 3 | 35 | 16.409 | <.0001 |
| Combined | 2 | 19 | 10.083 | <.0001 |

Note. One participant did not have a specified initial mode of feeding, however a final mode of feeding was indicated in the medical record; hence the difference in the n-value for the initial and final mode of feeding.

The specific changes noted from the first to final mode of feeding will be described in Table 5.

Table 5.

Specific Changes Noted for Participants' Initial to Final Mode of Feeding

| First (n=104) | Final (n=104) | | | | |
|------------------------------|---------------|-----------|-----------|------------------------|-----------------|
| | Oral (n=47) | NGT (n=2) | NJT (n=2) | Gastrostomy/PEG (n=34) | Combined (n=19) |
| Oral (n=51) | 40 | 1 | 0 | 4 | 6 |
| NGT (n=40) | 7 | 1 | 1 | 22 | 9 |
| NJT (n=8) | 0 | 0 | 1 | 6 | 1 |
| Gastrostomy/PEG (n=3) | 0 | 0 | 0 | 2 | 1 |
| Combined (n=2) | 0 | 0 | 0 | 0 | 2 |

Note. The one participant, who did not have a specified initial mode of feeding, was fed through a gastrostomy/PEG at the final mode of feeding. This particular participant's information is not reflected in this table, hence the difference between the total number of participants who received a gastrostomy/PEG (n=35) as reflected in Table 4 and reported in Table 5 (n=34). The participant's information which is not reflected in Table 5 also accounts for the difference in the final mode of feeding (n=105) as reported in Table 4 and reflected in this table (n=104).

NGT= nasogastric tube; NJT=nasojunal tube; PEG= percutaneous endoscopic gastrostomy

The number of participants who required short term enteral feeds (nasogastric tube (NGT) and nasojunal tube (NJT) feeds) at the final mode of feeding was less, relative to the number of participants who required short term enteral feeds at the initial mode of feeding. More than half of participants (58%) who were fed via short term enteral feeding initially, required a gastrostomy/PEG at the final mode of feeding. An increase in long term enteral feeding was therefore noted at the final

mode of feeding as 32 new referrals for a gastrostomy/PEG during the study period resulted in 35 participants being fed through a gastrostomy/PEG at the final mode of feeding (33%, n=105), in comparison to only 3 participants (3%, N=104) who initially fed via gastrostomy/PEG.

4.5.2.2. Consistency Changes to Oral Diets

Sixty-one percent of participants (n=65, N=106) who had FSD, had changes made to the consistency of their oral diet.

Fifty-six participants (86%, N=65) had consistency changes to their oral diet at the initial mode of feeding. Of these, seventy-nine percent (n=44, N=56), continued with the same consistency at the final mode of feeding as they had shown no improvement with consistencies aspirated previously. Twenty-one percent of participants (n=12, N=56) who had a consistency change at the initial mode of feeding did not require a consistency change at the final mode of feeding. These participants were either (i) able to tolerate an unrestricted consistency diet or (ii) required a gastrostomy/PEG and were therefore fed non-orally.

Six participants (12%, N=50) who did not require a consistency change at the initial mode of feeding, demonstrated regression in their ability to tolerate certain consistencies safely, therefore requiring consistency changes at the final mode of feeding.

4.5.3. Summary

Participants demonstrated an improvement in general health outcomes as demonstrated by fewer number of LRTI not leading to admission as well as fewer number of admissions related to LRTI six months post the first VFSS in comparison to six months prior to the first VFSS.

The participants who demonstrated aspiration on the first VFSS, had fewer LRTI not leading to admission six months after the first VFSS in comparison to six months prior to the first VFSS, although this was not found to be significant. However, these participants demonstrated significantly fewer admissions relating to

LRTI six months after the first VFSS in comparison to six months before the first VFSS.

A significant change was noted for each mode, except the oral mode of feeding, when comparing participants' initial to final mode of feeding. Short term enteral feeding was utilised less, relative to increasingly more patients requiring long term enteral feeds at the final mode of feeding.

A large number of participants who required a consistency change to their oral diets, did not show any improvement and continued with restricted consistency diets at their final mode of feeding.

4. DISCUSSION

The majority (86%) of participants with CP demonstrated FSD; therefore children with CP who present for a VFSS, are very likely to have FSD and should, for that reason, be referred to a SLT for appropriate assessment and management.

Participants with more motor and/or limb involvement demonstrated FSD more frequently as in the case of those diagnosed with evolving CP (93%), mixed CP (88%), spastic quadriplegia (87%) and dyskinesia (75%), in comparison to participants with spastic hemiplegia (60%). This finding suggests that there may be an association between motor involvement and the presence of FSD, which has been reported in other studies (Benfer et al., 2013; Kim et al., 2013; Salghetti & Martinuzzi, 2012).

Whilst the sample sizes for participants diagnosed with mixed CP (N=8) and dyskinesia (N=4) were small, many of the participants in these classifications of CP presented with FSD, suggesting that even though they may not be seen that frequently in the clinic setting, they are very likely to present with these difficulties as well. Although fewer participants with less motor involvement (60% in spastic hemiplegia) demonstrated FSD in the current study, FSD were still fairly common, suggesting that health care professionals should monitor all children with CP for FSD, irrespective of their classification of CP.

The participants in this study presented with FSD in all phases of swallowing, with oral preparatory (62%) and pharyngeal (88%) phase difficulties being noted more frequently; a finding consistent with other recent research (Kim et al., 2013). Participants' key difficulties in the oral preparatory phase included the anterior loss of the bolus due to reduced lip closure and inadequate bolus formation as a result of poor lingual control; these difficulties have also been described in other research (Kim et al., 2013; Rogers et al., 1994; Van den Engel-hoek et al., 2013; Wright et al., 1996). Oral preparatory phase difficulties may have a direct impact on the effectiveness of feeding and result in slow and effortful feeding (Adams et al., 2012; Benfer et al., 2012a), probably contributing the most to the strains that parents

and/or caregivers often report in feeding children with chronic FSD, including those diagnosed with CP (Hewetson & Singh, 2009).

The SLT plays a key role in the identification, assessment and management of oral preparatory phase difficulties, as poor nutrition and growth may result if these difficulties are not addressed (Adams et al., 2012; Salghetti & Martinuzzi, 2012). In this study the interventions used most frequently by the SLT to address oral preparatory phase difficulties, included either direct measures such as the use of feeding techniques (32%) and/or oral sensory-motor therapy (19%), as well as indirect measures such as positioning and posture management (46%). Oral preparatory phase problems may contribute to poor eating efficiency and long and difficult feeding, which may have a negative impact on parents/caregivers. The role of the SLT to address oral preparatory phase difficulties and train the parents/caregivers on how to assist their children in managing these difficulties, can therefore not be overemphasized.

In addition to oral preparatory and oral phase difficulties which are more overt (Otapowicz et al., 2010), the majority of participants in this study presented with pharyngeal phase difficulties, which are less likely to be visible to parents/caregivers (Colombo & Hallberg, 2012). The main pharyngeal phase difficulties as reported in this study were laryngeal penetration (87%) and aspiration (77%), with 20% of participants, aspirating silently.

Participants in this study aspirated on all consistencies (liquids and semi-solids), however aspiration was demonstrated more frequently with liquids (77%) in comparison to semi-solids (35%), a finding consistent with other research (Rogers et al., 1994; Van den Engel-hoek et al., 2013). Moreover, participants in this study demonstrated silent aspiration on both consistencies; almost a third of participants (26%) demonstrated silent aspiration with liquids, whilst a fifth (20%) aspirated silently with semi-solids.

All children with CP, but especially those who may be classified as evolving CP, mixed CP, spastic quadriplegia or dyskinesia, should therefore, when querying pharyngeal phase problems such as aspiration, be assessed objectively, e.g. using VFSS (Kim et al., 2013; Staiano & Martinelli, 2013) or fiberoptic endoscopy

(Arvedson, 2008; Bader & Niemann, 2010). Participants who demonstrated silent aspiration (20%) in this study, may have been missed clinically, if a VFSS had not been conducted. An instrumental assessment such as a VFSS may therefore prove invaluable to assess pharyngeal phase difficulties, especially to identify the presence of aspiration and in particular silent aspiration. It is recommended that an instrumental assessment should be considered as part of an assessment battery, particularly in children who have signs or symptoms that indicate a possible problem.

Parents/caregivers and health care professionals should therefore be educated regarding the possible presence of pharyngeal phase difficulties in children with CP, and health care professionals should be made aware of the appropriate referral pathways that are available. It is important to note that the main indicator for referring participants for a VFSS in this study, was actually to investigate the presence of aspiration (81%), a finding consistent with older literature (Mirrett et al., 1994). The request to investigate aspiration suggests an accurate referral from health care professionals, firstly as the identification of aspiration is considered a main benefit of the VFSS (Arvedson, 2008; Colombo & Hallberg, 2012; Weir et al., 2011), but secondly, as a large proportion of participants (77%) in this study, did in fact demonstrate aspiration on a VFSS.

Just over a third of participants with CP in this study (35%) had been diagnosed with a LRTI in the 6 month period immediately preceding the first VFSS which was deemed severe enough to warrant admission. The participants who demonstrated aspiration on the first VFSS however had significantly fewer admissions related to LRTI during the 6 months after the first VFSS in combination with feeding and swallowing intervention, in comparison to 6 months before the first VFSS. This finding suggests that appropriate management of aspiration resulted in fewer admissions for LRTI. As pharyngeal phase difficulties, especially the presence of aspiration and silent aspiration, is not always visible clinically, the VFSS allowed for the determination of the reasons for aspiration in a high number (77%) of participants. The results of the VFSS facilitated the implementation of trial therapy and/or determining the effectiveness of therapy strategies, resulting in

positive outcomes, in that participants demonstrated fewer LRTI and fewer admissions related to LRTI in the 6 months after the VFSS. Besides the fact that an instrumental assessment such as the VFSS, is valuable to assess for the presence of aspiration in children with CP, it has proven useful to identify possible intervention strategies for FSD, which when implemented, may prevent further aspiration and subsequent health problems.

The main emphasis during intervention and management of FSD in this study population, focused on addressing pharyngeal phase difficulties; the management of these difficulties centred mostly on the prescription of the safest mode of intake (87%), with the key focus being to eliminate aspiration, a finding consistent with recommendations to address FSD in other research (Arvedson, 2008; Salghetti & Martinuzzi, 2012). The safest mode of intake was achieved by either recommending consistency changes to a child's diet or by introducing an alternative to an oral mode of feeding.

More than half of the participants (61%) who demonstrated FSD, had consistency changes made to their oral diet; these consistency changes mostly consisted of a semi-solids diet which was introduced for those participants who demonstrated aspiration with liquids. Consistency changes are usually introduced as part of the management of FSD to eliminate aspiration (Gosa et al., 2011). The introduction of consistency changes to feeds to ensure safe and efficient feeding has also been suggested for children with CP who have FSD in other research (Araújo et al., 2012; Snider et al., 2011). The majority of participants (79%) who were placed on an altered diet of a changed consistency remained on this for at least 6 months; suggesting that swallowing difficulties had not resolved within that time frame. After 6 months, some participants (21%) however no longer required an altered diet, which may have been due to improvement and the ability to tolerate a normal diet, or a deterioration in feeding and swallowing skills, resulting in the need for a gastrostomy/PEG.

The majority of children with CP may therefore present with aspiration of liquids over a longer period of time. The persistent aspiration with liquids as described for participants in this study is consistent with the characteristics of CP; in

that it is a long-term disorder producing life-long consequences (Tan et al., 2005). Liquids further require a high degree of sensory-motor coordination (McPherson et al., 1992), which is a particular challenge in CP (Erasmus et al., 2012). It is therefore recommended that children with CP are monitored closely - they will need continued intervention as their FSD may resolve at varying rates; some children's FSD may "recover" and liquids may be introduced back into their diet, whilst other children may require continued intervention to progress their diet to as a normal consistency as possible.

Some participants in this study, who demonstrated aspiration, could not attain a safe mode of feeding by making consistency changes to their diets alone; these participants required enteral feeds to ensure safe and adequate feeding. During the 6 months after the initial VFSS, almost half of the participants (46%) received short term (NJT and NGT) enteral feeds; whilst a very small number of participants (n=3) were placed on long term enteral feeds (gastrostomy/PEG). However, 6 months after the final VFSS, the number of participants who required long term enteral feeds increased. A third of participants received a gastrostomy/PEG six months after the final VFSS, indicating that many participants may have demonstrated a regression in their feeding and swallowing abilities over a longer period.

The need for long-term enteral feeds for a third of participants in this study emphasizes the longstanding nature of FSD that some children with CP may encounter; it also confirms our understanding that associated difficulties (Hack & Costello, 2008) may exacerbate as the child becomes older (Erasmus et al., 2012; Kim et al., 2013), even though CP is a non-progressive disorder (Kim et al., 2013; Rosenbaum et al., 2007). Enteral feeds may therefore become a necessity for a group of children with CP at some stage in their lives. Previous research suggested that certain population groups, including children diagnosed with CP, may be more prone to require long term enteral feeds, based on their diagnosis and nutritional and feeding requirements (Ceriati et al., 2006; Sullivan, 2008).

As some children with CP may require long-term enteral feeding, proper planning around the budgeting, management and distribution of enteral feeds,

should be implemented. Local service delivery sites, such as day hospitals, should be aware that alternate nutrition may be a necessity for children with CP, therefore the purchasing of enteral feeds should be planned when budget allocation and expenditure are considered. It is important that information regarding the need for enteral feeds at community health care sites is clearly communicated between health care sites, to ensure that children with CP who require enteral feeds are able to obtain the necessary feeds once transferred to the local clinic from the tertiary site where they received their initial operation. As the transition from oral to enteral feeds, may be a traumatic experience for parents/caregivers (Hewetson & Singh, 2009), they may further require extensive counselling and orientation regarding tube feeding. Parent/caregiver support groups could act as a means through which assistance is offered (Hewetson & Singh, 2009) and may facilitate the process of providing information not only regarding the procedure of obtaining feeds when their child is placed on long-term enteral nutrition, but also on how parents/caregivers may deal with the transition from oral to tube feeds (Hewetson & Singh, 2009).

Whilst a third of participants in this study were placed on long term enteral feeds, the final outcome of their intervention and if they could ever return to oral feeds, are not known. As the presentation of FSD may change over time, it is recommended that children with CP, including those who are fed via gastrostomy/PEG, need ongoing monitoring over a long period as they continue to grow and receive therapy, to monitor for any regression or improvement in their feeding and swallowing abilities.

Children with CP, who demonstrate FSD, require, based on the complexity of their needs, intervention from health care professionals offering various services, who should ideally work together in a multidisciplinary or interdisciplinary team to provide coherent and holistic management (Andrew et al., 2012; Arvedson, 2008; Salghetti & Martinuzzi, 2012). Participants in this study, who had FSD, accessed many different services offered by a variety of health care professionals. It is not known whether the health care professionals in this study, necessarily worked

together to manage and treat a child holistically, or if services were provided on an individual basis to children and their families.

The SLT was consulted most frequently (92%) of all health care professionals by the participants and provided interventions with the main aim to establish safe and efficient feeding. The SLT requested input from other health care professionals for 75% of participants, suggesting that the SLT recognized the importance of the input various team members may provide to children with CP who have FSD, or that other team members had not yet been included in the management of the participants.

Health care professionals play an integral role in requesting early investigations to detect possible FSD. The second most frequent indicator (58%) for requesting a VFSS in this study, was to assess the presence of GOR. Although the VFSS is useful in the assessment of swallowing and aspiration, it is not considered beneficial in the assessment of GOR (Ceriati et al., 2006; Vandenplas et al., 2009) as the VFSS is neither sensitive nor specific in diagnosing GOR (Vandenplas et al., 2009). Sixty-two percent of participants in this study, were diagnosed with GOR based on the results of the VFSS, despite it not being an accurate measure of GOR. The presence of GOR is however common in children with CP (Campanozzi et al., 2007; Saadah, 2009) and associated with FSD (Campanozzi et al., 2007; Ceriati et al., 2006), which may provide a reason as to why GOR was a common indicator for a VFSS in this study.

Professional education regarding the rationale for requesting a VFSS and other assessment measures which may be considered more sensitive and specific in the diagnosis of GOR, such as the use of a pH-study (Vandenplas et al., 2009), is therefore recommended to ensure accurate diagnosis of GOR, which is necessary to guide management plans and interventions. It is further proposed that guidelines regarding appropriate indicators for a VFSS are developed and disseminated by the radiology and speech-language therapy team at RCWMCH, to assist health care professionals who form part of the team dealing with children with FSD, in appropriately requesting a VFSS.

The dietician (86%) was the second most frequent health care professional consulted after the VFSS. The dietician plays an important role in managing children with FSD, specifically monitoring growth and nutritional needs, especially when gastrostomy/PEG feeds are introduced (Arvedson, 2008; Barratt & Ogle, 2010; Norman et al., 2011). As children with CP may demonstrate poor growth (Wilson & Hustad, 2009), they need to be monitored by a dietician (Andrew et al., 2012). The dietician, together with the SLT, plays a central role when managing children with CP who have FSD and should collaborate with other health professionals, to ensure the best possible outcome for the child.

The majority of children who receive services at a tertiary hospital such as RCWMCH, have access to a team of health care professionals who offer specialized services. The question however arises regarding the availability of these services for children with CP at the community level in South Africa. Many of the children seen at the Speech-Language Therapy Department at RCWMCH, live in the greater Cape Town area (Red Cross War Memorial Children's Hospital, 2013) and have to travel long distances (Western Cape Government, 2013b) to receive long-term out-patient treatment at this tertiary hospital. As CP is a chronic condition, these children need ongoing intervention and should ideally be able to access therapeutic and health care services at the primary health care level within their local community; this will improve access as well as reduce transport costs for parents/caregivers.

Currently, government speech-language therapy services are not available in the areas around Cape Town (Western Cape Speech Therapy/Audiology Forum, 2013) and children therefore do not have easy access to these services. In the present study, 42% of participants discontinued speech-language therapy services after the VFSS as participants defaulted their appointments. If speech-language therapy services are offered at the primary health care level within their local community, attendance rates might improve and result in more efficient therapy, as parents/caregivers will have easier access to services without the need to incur costs to travel. The need for speech-language therapy services to be available at all service delivery levels, but especially the primary health care and district level, cannot be over emphasized, especially as community-based services may not only

improve the health outcomes of children with CP who have FSD (Western Cape Government, 2013a), but may also contribute to decrease the cost burden on the health care system (Western Cape Government, 2013a).

The provision of local services may facilitate the early identification and subsequent management of a child with chronic FSD who could be managed effectively at the community level. In the present study, the SLT (92%) was responsible for identifying, addressing and managing FSD in the paediatric population with CP. The development and establishment of SLT posts at all levels of care should therefore be an important priority for the Western Cape Department of Health, as well as the National Department of Health. In line with the proposed Health Care 2030 Plan (Western Cape Government, 2013a), speech-language therapy services requiring specialized equipment such as a fluoroscopy machine, as well as other specialized medical and surgical interventions such as the insertion of a gastrostomy /PEG, should be offered at a tertiary hospital. The SLT situated at the primary or district health care level, should however provide long-term therapeutic intervention and management for children with CP who have FSD within their local community, as well as provide training for parents/caregivers and other members of the health care team regarding the need to identify and refer when FSD is queried.

The post structure for SLTs in the Western Cape Department of Health (Western Cape Government, 2013c; Western Cape Speech Therapy/Audiology Forum, 2013), has not allowed for a SLT to be involved at community level, resulting in limited speech-language therapy support to children and their families within their home environment (Western Cape Government,2013d) . Speech-language therapy will be regarded as primary health care facility-based services in future (Western Cape Government, 2013a) and has therefore been excluded from the home-based care teams as stated in the Health Care 2030 Plan (Western Cape Government, 2013a). Considering that the results of this study suggested that a large number of children with CP who presented for a VFSS, have FSD, as well as the potential negative consequences associated with FSD, it is recommended that SLTs play a role in the education and training of rehabilitation workers and community

health workers (Western Cape Government, 2013a). These health care workers could then facilitate the implementation of the SLT plan with regards to FSD and support children with FSD, and their families, within the home environment.

Until South Africa's efforts to address the millennium development goals (South Africa & UNDP, 2013; Western Cape Government, 2013a), specifically reducing child mortality and improving maternal health, are realized, a high prevalence of children born with CP in this country may be inevitable. Although prevention and health promotion to prevent illness is better than providing rehabilitative care, South Africa still has the responsibility to provide rehabilitative care to the many children who will survive with disabilities (Clawson et al., 2007; Hack & Costello, 2008; Nelson, 2008). The services that are required to address the extensive needs of children with CP and their families, should therefore be identified, planned and implemented.

The main limitations of this study relate to the retrospective nature of the design, in that data were missing in some instances, specifically with regards to the severity/degree of motor impairment. The researcher was restricted to use the classification system (topography and nature of the movement disorder) which was adopted by the research site, instead of using a validated classification system (Rosenbaum & Rosenbloom, 2012). Researchers who have investigated FSD in children with CP, have also utilized many different CP classification systems (Calis et al., 2008; Erkin et al., 2010; Kim et al., 2013; Mirrett et al., 1994; Rogers et al., 1994; Van den Engel-hoek et al., 2013; Wright et al., 1996). As there is no single classification system for CP (Rosenbaum & Rosenbloom, 2012), it becomes very difficult to compare results of research which employ different classification systems. It is therefore recommended that prospective studies are utilized in future to allow researchers to eliminate the problem of missing data through the careful selection of specific information that should be collected, such as the use of a validated CP classification system. The use of a validated classification system, may enhance communication among health care professionals (Rosenbaum & Rosenbloom, 2012) and may be useful to improve validity across research in future studies who investigate the characteristics of FSD in children with CP.

The patient profile in this sample may not be representative of all classifications of CP, therefore limiting the ability to accurately quantify the frequency of and describe the nature of FSD in the different classifications of CP. Previous research has often reported on FSD in children with severe CP (Calis et al., 2008; Mirrett et al., 1994) and spastic quadriplegia (Erkin et al., 2010), which is considered one of the most common classifications of CP (Ceriati et al., 2006; Odding et al., 2006). Children with spastic quadriplegia were the largest group represented in this study, suggesting that children with spastic quadriplegia, might be more prone to demonstrate FSD. It is not clear whether children with other classifications of CP, who were not represented in this study (such as those with ataxia), are less prevalent as a group or whether they do not generally present with FSD.

Furthermore, the wider paediatric population with CP was not investigated in this study, with the focus being on children with CP who were referred for a VFSS. The results of this study cannot be extrapolated to the larger CP population, as participants of the present study, may have been referred for a VFSS with a suspected problem (Arvedson, 2008; Colombo & Hallberg, 2012; Lefton-Greif & Arvedson, 2008; Weir et al., 2011). The results however provide a starting point to contribute specific information regarding the nature of FSD in the paediatric population with CP who were referred for a VFSS and reside in the Western Cape. It is recommended that future research include multi-centred prospective studies to allow for a larger sample of children with CP, with the aim to establish the prevalence of FSD in the wider paediatric population with CP in South Africa.

As the Health Care 2030 plan (Western Cape Government, 2013a) is still in its second draft version and attainment is only planned by 2030, it is recommended that future research focuses on developing a standardized screening tool to screen for FSD in the general paediatric as well as the paediatric population with CP. Until speech-language therapy services are established at primary health care sites as recommended in the Healthcare 2030 plan (Western Cape Government, 2013a), an interim plan to address the service delivery needs of children with CP who have FSD, should be implemented. The screening tool could be used at community clinics

to assist doctors and other health care workers in early detection of children who have FSD and to refer these children for appropriate assessment and management to health care sites where SLTs are currently available. Future studies could also continue to investigate the relationship between aspiration and the presence or development of LRTI as this is still inconclusive (Wallis & Ryan, 2012; Weir et al., 2007a), as well as the impact of intervention to address aspiration, on the respiratory status of children with CP.

Children with CP who have FSD face various challenges in the current South African health care system. It is however hoped that the findings of this study will underline the importance of addressing FSD in the paediatric population with CP. The employment of key team members, such as the SLT, as part of the multidisciplinary or interdisciplinary community health care team, as well as the training of rehabilitation care workers and community health workers, may initially seem costly. The saving of costs for the Department of Health may however ultimately be achieved in the long-term as early identification and management of FSD may result in a lesser chance to develop LRTI or be admitted to hospital, as documented in the present study. The effective management of FSD in this population may further result in reduced labour requirements involving nursing staff, doctors and other health professionals as a result of fewer health consequences and hospital admissions. Further research should however be conducted to investigate the impact of managing FSD and any associated cost reduction on the South African health care system.

This study has demonstrated that children with CP who are referred for a VFSS, specifically those with classifications of evolving CP, mixed CP, spastic quadriplegia and dyskinesia are at risk of developing FSD. To address their FSD, participants required input from various team members, highlighting the need for appropriate services at all levels of care. Many participants required consistency changes to their oral diet or the introduction of non-oral feeds to ensure safe and optimal feeding. Based on the findings of this study, the SLT played an important role in the identification, assessment and management of FSD in the paediatric

population with CP, suggesting that the SLT needs to be involved in teams responsible for assessing and managing children with CP at all levels of care.

5. CONCLUSION

The present study has provided insight into the nature of FSD as it presents in children with CP who have been referred for a VFSS at a tertiary hospital in the Western Cape, South Africa. This information may assist and guide health care professionals to anticipate what FSD they might expect when assuming responsibility for children with CP in the clinical setting.

The results of the study demonstrates that a large proportion of children with CP, may present with FSD at some stage in their lives. These difficulties may be present across all phases of swallowing and may become more pronounced as motor involvement increases. However, the presence of FSD in children with different classifications of CP, suggests that all children with CP, irrespective of their classification, should be screened and monitored for FSD.

Oral preparatory and pharyngeal phase difficulties were noted most frequently for participants in this study. These findings should alert health care professionals to the possibility that children with CP may present with difficulties, especially in the oral preparatory and pharyngeal phases of swallowing. An instrumental assessment, such as a VFSS, should therefore be considered when FSD, and particularly aspiration or silent aspiration, is suspected.

The findings of this study have particular implications for service delivery within the context of South Africa. The current study suggested that appropriate management of aspiration, as identified on a VFSS, resulted in fewer admissions for LRTI. The finding suggests that the identification of aspiration and subsequent appropriate intervention, may result in positive respiratory outcomes for the child with CP. Managing FSD in children with CP may aid South Africa in addressing one of the millennium development goals (South Africa & UNDP, 2013), namely reducing child mortality, through the management of aspiration and subsequent prevention of LRTI, which is considered one of the leading causes of infant and child mortality in South Africa (Bradshaw et al., 2003).

The importance of an interdisciplinary or multidisciplinary team approach to identify and address FSD in this population has also been emphasized. The role of

the SLT to identify and manage FSD has furthermore been highlighted. The SLT was responsible for recommending the safest mode of intake and techniques to facilitate optimal feeding. A third of participants required long-term enteral feeds, suggesting that local health care sites should be aware that children with CP may require enteral nutrition and therefore, the planning and budgeting to purchase and stock enteral feeds, should take place.

It is recommended that SLTs should be included in all teams involved with children who have CP, at all levels of care, particularly at the primary health care level. The provision of speech-language therapy services to address FSD, especially at the primary health care level, may contribute to earlier identification of FSD, subsequently resulting in positive health outcomes for the child (Adams et al., 2012; Araújou et al., 2012; Calis et al., 2008; Prasse & Kikano, 2009) and thereby possibly reducing the cost burden on the Department of Health (Western Cape Government, 2013a).

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8. APPENDICES

APPENDIX A: 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

06 July 2009

REC REF: 282/2009

Ms L le Roux

Division of Communications Sciences & Disorders

Dear Ms le Roux

PROJECT TITLE: THE NATURE OF FEEDING AND SWALLOWING DIFFICULTIES IN THE PAEDIATRIC CEREBRAL PALSY POPULATION WHO HAVE HAD VIDEOFLUOROSCOPIC SWALLOW STUDIES.

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 06 July 2010.

Please submit an annual progress report if the research continues beyond the approval period.

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

Please quote the REC REF in all your correspondence.

Yours sincerely

pp 

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSE 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.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

lemjedi

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

lemjedi

APPENDIX B: Permission Letter to and From Medical Manager



School of Health and Rehabilitation Sciences

Faculty of Health Sciences

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

F45 Old Main Building, Groote Schuur Hospital,
Observatory 7925

5 August 2009

The Medical Superintendent

Red Cross War Memorial Children's Hospital

c/o Klipfontein Road and Milner Road

Rondebosch

7740

Dear Dr Thomas Blake

Re: Permission to conduct research study

I am a Speech-Language Therapist, currently a student at the University of Cape Town. I am registered for my Masters in Speech-Language Pathology and my research will focus on feeding and swallowing difficulties in the paediatric Cerebral Palsy population.

The primary aim of the study is to describe the nature of feeding and swallowing difficulties in the paediatric cerebral palsy population (0-12 years), who have had videofluoroscopic swallow studies (VFSS) at Red Cross War Memorial Children's

Hospital from January 2007 to December 2009. The study will be in the form of a retrospective folder review.

Ethics approval for the study was obtained from the University of Cape Town, Faculty of Health Sciences Research Ethics Committee (REC Ref 282/2009). Ethical principles governing health research (e.g. autonomy, justice) will be upheld during the research study. Every participant will receive a reference number and data that will be obtained from the medical folder will be delinked in order to ensure anonymity and confidentiality. Participants will also not be identified in any publication that arises from this research. As participants will not be directly involved in the research and medical records will be reviewed to obtain data, there is no evident risk or harm to participants or their families.

The results of the study will contribute to the knowledge that exists in the field of paediatric feeding and swallowing difficulties, especially in the CP population. It is envisaged that the specific findings will benefit children with CP who have feeding and swallowing difficulties, as well as clinicians who provide services to this population.

I hereby ask your permission to conduct the proposed study at Red Cross War Memorial Children's Hospital. Your favourable consideration would be greatly appreciated.

If you have any questions you are welcome to contact me at (021) 658 5264.

Yours Sincerely

Lezanne le Roux

Speech-Language Therapist



DEPARTMENT
of HEALTH

Provincial Government of the Western Cape

Red Cross War Memorial Children's Hospital

Tblake@pgwc.gov.za
Tel: +27 21 658 5788; fax: +27 21658 5166
Klipfontein Rd, Rondebosch, 7700
Private Bag X5, Rondebosch, 7701

REFERENCE:

ENQUIRIES: Dr. TA BLAKE

Dear Ms Le Roux

Permission for Masters Research to be conducted at Red Cross Hospital

Permission is hereby granted to conduct the research study entitled "The nature of feeding and swallowing difficulties in the paediatric Cerebral Palsy population who have had videofluoroscopic swallow studies" at Red Cross War Memorial Children's Hospital.

If you have any further enquiries, please feel free to contact me at above mentioned number.

Yours sincerely,

DR T A BLAKE

SENIOR MEDICAL SUPERINTENDENT

DATE: 14 August 2009

APPENDIX C: Data Collection Checklist

The Checklist for Feeding and Swallowing Difficulties in Children (0-12 years 11 months) with Cerebral Palsy

| | | | | | | | | |
|------|---|--|--------|-------------------------------|---|--------|----------|-----------------|
| 1 | Reference number | | | | | | | |
| 2 | Demographic data | | | | | | | |
| | Residential area: | | | | | | | |
| | Specify: In-patient or Out-patient at time of initial VFSS | | | | | | | |
| | Age at initial VFSS | | | | | | | |
| | Sex: | Male | Female | | | | | |
| 3 | Hospital admissions | | | | | | | |
| 3.1. | Number and date of documented general hospital admissions | | | | | | | |
| | State reason for admission: | Before VFSS (include 6 months prior to VFSS) | | | After VFSS (include 6 months post VFSS) | | | |
| 3.2. | Number and date of documented admissions related to LRTI/aspiration pneumonia | | | | | | | |
| | Specify dates | VFSS 1 | VFSS 2 | VFSS 3 | VFSS 4 | | | |
| | Six months prior to VFSS | | | | | | | |
| | Six months post VFSS | | | | | | | |
| 3.3. | Number of LRTI not leading to admission | | | | | | | |
| | Specify dates | VFSS 1 | VFSS 2 | VFSS 3 | VFSS 4 | | | |
| | Six months prior to VFSS | | | | | | | |
| | Six months post VFSS | | | | | | | |
| 4. | Classification of CP | Spastic | | Dyskinesia | | Ataxia | Evolving | Other (Specify) |
| | | Hemi | | Dystonia | | | | |
| | | Di | | | | | | |
| | | Quad | | Athetoid | | | | |
| | | Other | | | | | | |
| 5. | Severity of CP | Unspecified | Mild | Moderate | | Severe | | |
| 6. | Indication for VFSS Specify: | VFSS 1 | VFSS 2 | VFSS 3 | | VFSS 4 | | |
| 7. | Total number of VFSS within time period (Specify dates) | | | | | | | |
| 8. | Feeding and Swallowing Signs/Disorders | | | | | | | |
| 8.1 | Oral structure and function | | | | | | | |
| | Drooling | | | Presence of abnormal reflexes | | | | |
| 8.2 | Oral preparatory phase | | | | | | | |

| | | | | | | |
|------|---------------------------------------|--|--|---|---|--|
| | Oral sensory-motor difficulties | Reduced lip closure (food loss anteriorly) | Poor lingual function (unable to form bolus) | Hyposensitivity | Hypersensitivity | Oral aversion |
| | VFSS / A1 | | | | | |
| | VFSS / A2 | | | | | |
| | VFSS / A3 | | | | | |
| | VFSS / A4 | | | | | |
| 8.3 | Oral phase | | | | | |
| | | | Reduced labial tension, reduced lingual control and strength, reduced buccal tension (Oral residue in anterior or lateral sulcus, residue on tongue or floor of mouth) | | Apraxia of swallow, reduced oral sensation (Delayed onset /absent initiation of oral swallow) | |
| | VFSS 1 | | | | | |
| | VFSS 2 | | | | | |
| | VFSS 3 | | | | | |
| | VFSS 4 | | | | | |
| 8.4. | Pharyngeal phase (Liquids) | | | | | |
| | | Delayed trigger of the pharyngeal swallow (pooling in valleculae and pyriform sinuses prior to trigger of swallow) | Reduced velar-pharyngeal closure (nasal-pharyngeal backflow) | Reduced laryngeal elevation, reduced closure of laryngeal vestibule (laryngeal penetration / entry) | Reduced laryngeal closure (aspiration) SPECIFY if SILENT | Reduced tongue base posterior movement, reduced anterior laryngeal movement (residue in valleculae and pyriform sinuses) |
| | VFSS 1 | | | | | |
| | VFSS 2 | | | | | |
| | VFSS 3 | | | | | |
| | VFSS 4 | | | | | |
| 8.5 | Pharyngeal phase (Semi-solids) | | | | | |
| | | Delayed trigger of the pharyngeal swallow | Reduced velar-pharyngeal closure | Reduced laryngeal elevation, reduced closure of laryngeal vestibule | Reduced laryngeal closure (aspiration) | Reduced tongue base posterior movement, |

| | | | | | | |
|-------|---|--|---|--------------------------------|-------------------|--|
| | | (pooling in valleculae and pyriform sinuses prior to trigger of swallow) | (nasal-pharyngeal backflow) | (laryngeal penetration/entry) | SPECIFY if SILENT | reduced anterior laryngeal movement (residue in valleculae and pyriform sinuses) |
| | VFSS 1 | | | | | |
| | VFSS 2 | | | | | |
| | VFSS 3 | | | | | |
| | VFSS 4 | | | | | |
| 8.6 | Oesophageal phase | | | | | |
| | | Delayed/insufficient UOS opening | Structural abnormalities e.g. stricture, trache-oesophageal fistula | Oesophageal motility disorders | | |
| | VFSS 1 | | | | | |
| | VFSS 2 | | | | | |
| | VFSS 3 | | | | | |
| | VFSS 4 | | | | | |
| 9. | Gastro-oesophageal reflux | | | | | |
| | | Presence: Yes/No | Level | Aspiration of GOR? | | |
| | VFSS 1 | | | | | |
| | VFSS 2 | | | | | |
| | VFSS 3 | | | | | |
| | VFSS 4 | | | | | |
| | Elsewhere? Specify test with dates | | | | | |
| | Placed on anti-reflux medication? | Yes | No | | | |
| 10. | Nature of services and recommendations provided post VFSS (include up to six months post VFSS) | | | | | |
| 10.1. | MODE (mark in order; specify FINAL mode) | Oral | NGT | NJT | Gastrostomy /PEG | Combined Oral + tube |
| | VFSS 1 | | | | | |
| | VFSS 2 | | | | | |
| | VFSS 3 | | | | | |
| | VFSS 4 | | | | | |
| 10.2. | Consistency changes (Specify) | | | | | |
| | VFSS 1 | VFSS 2 | VFSS 3 | VFSS 4 | | |
| 10.3. | Utensils (Specify) | | | | | |

| | | | | |
|-------|---|-------------|-------------|-------------|
| | VFSS 1 | VFSS 2 | VFSS 3 | VFSS 4 |
| 10.4. | Oral sensory-motor therapy | | | |
| | VFSS 1 | VFSS 2 | VFSS 3 | VFSS 4 |
| 10.5. | Posture and position management | | | |
| | VFSS 1 | VFSS 2 | VFSS 3 | VFSS 4 |
| 10.6. | Frequency and size of meals | | | |
| | VFSS 1 | VFSS 2 | VFSS 3 | VFSS 4 |
| 10.7 | Other: Specify | | | |
| | VFSS 1 | VFSS 2 | VFSS 3 | VFSS 4 |
| 10.8. | No intervention: | | | |
| 10.9 | Team of health care professionals consulted post VFSS (include up to 6 months post VFSS) | | | |
| | | Post VFSS 1 | Post VFSS 2 | Post VFSS 3 |
| | Speech- Language Therapist | | | |
| | Dietician | | | |
| | GIT | | | |
| | Respiratory / Pulmonology | | | |
| | Surgeon (specify surgery) | | | |
| | Stoma sister | | | |
| | Paediatrician (specify) | | | |
| | Other: specify | | | |

APPENDIX D: Specific Signs and Disorders of Feeding and Swallowing Within Each Phase and Classification of Cerebral Palsy

| Phase | Sign/s | Disorder/s | Spastic CP (n=64) | | Evolving (n=26) | Mixed (n=7) | Dyskinesia (n=3) |
|-------------------------------|--|--|-------------------|----------------|-----------------|----------------|------------------|
| | | | Quad (n=61) | Hemi (n=3) | | | |
| ORAL PREPARATORY PHASE | | | 42 (69%) | 2 (67%) | 15 (58%) | 2 (29%) | 2 (67%) |
| | Anterior food loss | <i>Reduced lip closure</i> | 39 (93%) | 2 (100%) | 12 (80%) | 2 (100%) | 1 (50%) |
| | Inadequate bolus formation | <i>Poor lingual formation</i> | 34 (81%) | 1 (50%) | 10 (67%) | 2 (100%) | 1 (50%) |
| | Hypersensitivity | | 5 (12%) | 0 | 0 | 0 | 1 (50%) |
| | Oral aversion | | 2 (5%) | 0 | 0 | 0 | 0 |
| ORAL PHASE | | | 21 (34%) | 2 (67%) | 6 (23%) | 1 (14%) | 1 (33%) |
| | Oral residue (i) Residue in anterior sulcus (ii) Residue on tongue or floor of mouth | (i) Reduced labial tension (ii) Reduced lingual control | 5 (24%) | 1 (50%) | 1 (17%) | 0 | |
| | (iii)Residue in lateral sulcus | (iii) Reduced buccal tone | | | | | |

| | | | | | | | |
|-------------------------|--|---|-----------------|-----------------|-----------------|----------------|----------------|
| | Absent or delayed initiation of oral swallow | Apraxia of swallow, limited tongue movement, reduced oral sensation | 19 (91%) | 2 (100%) | 5 (83%) | 1 (100%) | 1 (100%) |
| PHARYNGEAL PHASE | | | 55 (90%) | 3 (100%) | 22 (85%) | 6 (86%) | 2 (67%) |
| | Pooling in the valleculae and/or pyriform sinuses | Delayed trigger of pharyngeal swallow | 38 (69%) | 1 (33%) | 13 (59%) | 5 (83%) | 1 (50%) |
| | Nasal-pharyngeal backflow | Reduced velar-pharyngeal closure | 15 (27%) | 0 | 7 (32%) | 1 (16%) | 0 |
| | Laryngeal penetration | Reduced laryngeal elevation, reduced closure of laryngeal vestibule | 47 (85%) | 3 (100%) | 19 (86%) | 5 (83%) | 2 (100%) |
| | Aspiration | Reduced laryngeal elevation, reduced laryngeal closure, delay in trigger of pharyngeal swallow | 44 (80%) | 3 (100%) | 15 (68%) | 5 (83%) | 1 (50%) |

| | | | | | | | |
|--------------------------|-------------------------------|--|-----------------|---------------|---------------|----------------|---------------|
| | Pharyngeal residue | Reduced tongue base posterior movement, reduced anterior laryngeal movement | 14 (25%) | 0 | 4 (18%) | 2 (33%) | 0 |
| OESOPHAGEAL PHASE | | | 10 (16%) | 0 (0%) | 2 (8%) | 1 (14%) | 0 (0%) |
| | Delayed UOS opening | | 1 (10%) | | 0 | 0 | |
| | Structural abnormality | | 3 (30%) | | 2 (100%) | 1 (100%) | |
| | Motility disorder | | 7 (70%) | | 0 | 0 | |

Note. Values reflected in this table are not mutually exclusive; difficulties in the phases of swallowing will therefore not add up to 100% as phase difficulties may have presented simultaneously in certain participants.

APPENDIX E: A Description of the Different Indicators for Participants Across VFSS 1 – 4

| Indications for VFSS | VFSS 1 (n=117) | | VFSS 2 (n=27) | | VFSS 3 (n=8) | | VFSS 4 (n=1) | |
|--|----------------|----|---------------|----|--------------|----|--------------|-----|
| | Frequency | % | Frequency | % | Frequency | % | Frequency | % |
| Investigations for aspiration | 89 | 77 | 14 | 52 | 2 | 25 | 0 | 0 |
| Investigation for GOR | 62 | 53 | 12 | 44 | 1 | 13 | 0 | 0 |
| Assessing effectiveness of feeding interventions | 3 | 3 | 16 | 60 | 3 | 38 | 1 | 100 |
| Weight loss / FTT | 16 | 14 | 1 | 4 | 0 | 0 | 0 | 0 |
| Documentation of Anatomy | 12 | 10 | 3 | 11 | 0 | 0 | 0 | 0 |
| Difficulty with feeding | 7 | 6 | 0 | 0 | 0 | 0 | 0 | 0 |

Note. Values reflected in this table are not mutually exclusive; indicators for participants will therefore not add up to 100% as different indicators may have been requested simultaneously for certain participants.

APPENDIX F: Pharyngeal Phase Signs (and Disorders) for Liquids (N=90) and Semi-solids (N=49).

| PHARYNGEAL PHASE | Sign | Disorder | Liquids (N=90) | | Semi-Solids (N=49) | |
|------------------|--|---|----------------|------------|--------------------|------------|
| | | | Frequency | Percentage | Frequency | Percentage |
| | Pooling in valleculae and pyriform sinus | Delayed trigger of the pharyngeal swallow | 48 | 53 | 43 | 88 |
| | Nasopharyngeal backflow | Reduced velar-pharyngeal closure | 23 | 26 | 5 | 10 |
| | Laryngeal penetration | Reduced laryngeal elevation; reduced closure of laryngeal vestibule | 78 | 87 | 18 | 37 |
| | Aspiration | Reduced laryngeal elevation; reduced laryngeal closure; delay in trigger | 69 | 77 | 17 | 35 |
| | Pharyngeal residue | Reduced tongue base posterior movement; reduced anterior laryngeal movement | 10 | 11 | 16 | 33 |

Note. Values reflected in this table are not mutually exclusive; different signs / disorders for both liquids and/or semi-solids will therefore not add up to 100% as the difficulties for each consistency may have presented simultaneously in certain participants.