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The aetiology and nature of paediatric dysphagia (0-18 months) in state hospitals Johannesburg, Gauteng.

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CHAPTER ONE

RATIONALE AND LITERATURE REVIEW

Chapter one provides an overview of the rationale for this research and includes a discussion of relevant literature in relation to the areas included in this study. This chapter will provide the reader with the basis from which this research developed. The literature presented relates not only to paediatric dysphagia; but provides information on South Africa, the context in which this research occurred.

Dysphagia is defined as "problems in a broad range of eating activities that may or may not be accompanied by a difficulty with swallowing food and liquid" (Arvedson, 2008, p. 118-119), and may present in a number of different ways including refusal to eat, poor growth and weight-gain, difficulty mastering developmentally-appropriate feeding skills and disruptive behaviour during mealtimes (Arvedson, 2008). Current research (Arvedson, 2008; Burklow, Phelps, Schultz, McConnell, & Rudolph, 1998; Manikam & Perman, 2000; Miller & Willging, 2003; Prasse & Kikano, 2009) indicates that as many as 40% of appropriately developing children and as many as 80% of children with developmental disabilities experience feeding difficulties. In the South African context very little is known about the aetiology and nature of these paediatric feeding difficulties and whether these differ from those reported internationally. The number of infants experiencing dysphagia is reportedly increasing (Arvedson, 2008) yet there is a dearth of knowledge surrounding the management and care of infants with such difficulties particularly within South Africa. This research therefore aims to investigate the

aetiology, nature and management of dysphagia in infants below the age of 18 months at three Government Hospitals in the Gauteng Province, South Africa.

1.1 Health in the Context of South Africa

Developing countries, including South Africa, have complex health, social and economic challenges, which differ from those in the developed world. One aspect, common to many developing countries is that many residents live in areas where poverty and unemployment is rife. This is particularly noted with regards to South Africa as a result of inequitable education and the rate of unemployment (Aliber, 2003). Poverty infiltrates all aspects of communities and affects adults and children alike. Poverty in developing countries has been linked to poor nutrition and sanitation resulting in stunting and an increase in infections in children (Grantham-McGregor, et al., 2007). Not only do poverty and social factors affect children and their families but they also influence the leading causes of mortality in children under the age of five years in South Africa. Examples of these mortality related conditions include HIV/AIDS, low birth-weight, diarrhoeal disease, lower-respiratory infections and protein-energy malnutrition (Bradshaw, Bourne & Nannan, 2003; Chopra, Daviaud, Pattinson, Fonn & Lawn, 2009). These five causes of mortality comprise 71.8% of all infant deaths in the country with HIV/AIDS accounting for 40.3% (Bradshaw et al., 2003).

Many of the patients utilising state hospitals in South Africa are unemployed and live in peri-urban settlements with poor access to amenities, such as sanitation, which results in an increase in communicable diseases (Benatar, 2004; Cameron, Nixon, Parnes & Pidsadny, 2005).

Furthermore, it has been determined that a higher number of children with disabilities live in low-income areas as opposed to those living in affluent, developed countries (Cameron et al., 2005). This higher number of children with disabilities and developmental delays has been linked to poor pre- and perinatal care (Walker, et al., 2007). It has been established that almost 11% of infants born at term in developing countries, have a birth-weight of less than 2500g (Walker et al., 2007). Furthermore, pregnant mothers exposed to poverty and low social standings are more susceptible to having low birth-weight infants and infants born premature (Emerson & Hatton, 2007). In studies conducted internationally (Eichenwald & Stark, 2008; Taylor, Klein, Drotar, Schluchter & Hack, 2006), low birth-weight infants have been found to have a higher prevalence of developmental disabilities and negative health correlates. Not only are infants at risk for developmental difficulties purely by being born into poverty stricken environments, but research (Kosek, Bern & Guerrant, 2003) determined that the leading cause of disability in African countries is infectious disease.

Infants in developing countries are not only more susceptible to disabilities but also infectious diseases (Benatar, 2004; Walker et al., 2007). Infections particularly prevalent are those related to gastrointestinal complications resulting in diarrhoea and subsequent dehydration (Walker et al., 2007), which due to poor health care and inadequate rehydration has been shown to have negative developmental and neurological consequences (D'Anci, Constant & Rosenberg, 2006). Furthermore, as developing countries have poor access to clean water and sanitation, the occurrence of gastroenteritis and the long term consequences of dehydration in young infants is still a concern.

As acknowledged by Bradshaw, et al. (2003) HIV/AIDS is the leading cause of mortality in children under the age of five years. Not only does HIV/AIDS have mortality consequences but it impacts the social, psychological and physical well-being of each child (Chopra, Daviaud et al., 2009). Research into the prevalence of HIV/AIDS within South Africa has estimated that 2.5% of the population of children between the ages of 2-14 years is infected with the virus (Shisana et al., 2009). However, there appeared to be a dearth of literature into the prevalence of the disease in infants under the age of 24 months. This may be attributable to the difficulty in accurately diagnosing infants below the age of 18 months with HIV/AIDS (World Health Organisation, 2007). Prior to 12 months the infants may retain the mother's antibodies due to breast feeding and transmission of antibodies in utero and during birth thereby resulting in a false positive on the standard antibody test (Layton & Davis-McFarland, 2000; World Health Organisation, 2007). However, research (Stevens, Sherman, Cotton, Gerntholtz & Webber, 2006) has suggested that rapid HIV testing in from six weeks of age is becoming more reliable. The dearth of literature is potentially related to the high mortality of infants with HIV under the age of 12 months (Stevens et al., 2006). HIV/AIDS has further been associated with not only a compromised immune system and susceptibility to infections but also to an increase in cognitive and motor delays (Cameron et al., 2005).

One of the communicable diseases typically found in South Africa and contributing to almost six percent of infant deaths is that of respiratory related conditions (Bradshaw et al., 2003). It has further been reported that the incidence and subsequent mortality from pneumonia is considerably higher in developing countries than in first world countries (Kirkwood, Gove, Rogers, Lob-Levyt, Arthur & Campbell, 1995; Owayed, Campbell & Wang, 2000). These are

typically pneumonia and tuberculosis which can result in respiratory complications and potentially death if not treated (Owayed et al., 2000) In addition to the illness mentioned above; a third of infants below the age of five years in developing countries were found to present with stunted growth as a result of persistent undernutrition (Walker et al., 2007), with almost 35% of pre-school children in sub-Saharan Africa experiencing stunting (Leenstra, Petersen, Kariuki, Oloo, Kager & ter Kulle, 2005). Particularly prevalent in developing counties are the malnutrition diseases marasmus and kwashiorkor (Walker et al., 2007). Marasmus is diagnosed when severe wasting is present whereas kwashiorkor is the severe wasting compounded with oedema, a severely compromised immune system and changes in the skin and hair (Müller & Krawinkel, 2005), These conditions are particularly noted when there is a deficiency in protein, energy rich food sources and nutrients (Müller & Krawinkel, 2005). This malnutrition results in structural and physiological changes in the brain negatively affecting the child's ability to learn (Kar, Rao & Chandramouli, 2008; Watanabe, Flores, Fujiwara & Tran, 2005). These structural changes can have far reaching negative cognitive, development and academic implications (Kar et al., 2008; Motion, Northstone, Emond & the ALSPAC Study Team, 2001; Rudolf and Logan, 2005).

In addition to all of the negative health correlates of the diseases mentioned above, these illnesses may impact either primarily on the infants feeding ability or on other systems that may secondarily affect the infants' ability to feed safely and effectively, for example the respiratory system. This begs the question as to whether the infants in developing countries, such as South Africa are experiencing feeding difficulties with different aetiologies and/ore presentations in comparison to infants in developed, well resourced countries.

In the context of inequities in service delivery and access to health care, the Department of Health in South Africa proposed a reform through the Primary Health Care (PHC) approach (Department of Health, 2000). This approach aimed to provide basic health care services to all and therefore reduced the inequities experienced by many people living in disadvantaged, rural areas (Chopra, Lawn, Sanders, Barron, Abdool Karim, Bradshaw et al., 2009; Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009). In addition, a number of district clinics were created and staffed in order to provide basic medical assistance; and free district health care for all, as well as free health care for children under the age of six years and pregnant women (Chopra, Lawn et al., 2009; Coovadia et al., 2009; Department of Health, 2000). Health services were identified as either district, regional or tertiary levels of care, with district centres dealing with common illnesses and concerns and those at a tertiary level dealing with the complex cases requiring specialised staffing and equipment (Department of Health, 2000). The Department of Health (2000) specified that the district and regional level centres should be concerned with early intervention for common communicable diseases affecting the community, for example, rehydration for infants suffering from acute gastroenteritis. Due to the HIV/AIDS and tuberculosis pandemic these district level centres were also created in order to assist in the provision of antiretroviral and tuberculosis medications. These district level clinics and centres are typically staffed by nurses with access to basic medical intervention and primarily focused on the prevention and reduction of the effects of illnesses through vaccination campaigns and the provision of long term medication such as antiretrovirals (Chopra, Lawn et al., 2009; Coovadia et al., 2009; Department of Health, 2000). The aim of the PHC approach was to minimise the load of common illnesses at a tertiary level of care and allow for improved access to health care

services for all South African people regardless of whether they reside in cities or rural areas (Department of Health, 2000).

1.2 Healthy Feeding and Swallowing

Adequate feeding is paramount to an infant's survival (Rommel, De Meyer, Feenstra & Veereman-Wauters, 2003), as it is the means in which an infant obtains nutrition and hydration. It has been shown that feeding also provides the basis for normal development, growth, communication and early mother-infant attachment (Arvedson & Brodsky, 2002, p. 3). As adequate feeding underpins many aspects of growth and development, it can be seen how impaired feeding may affect the infant's entire life and development.

Feeding development is a developmental process beginning when the infant is still in utero, through birth and onwards into childhood (Arvedson & Brodsky, 2002, p. 24). The developmental process of feeding will briefly be discussed below in terms of age progression. Many conditions that occur in utero or in the infant's early life can have long term consequences in respect to health and feeding (Arvedson & Brodsky, 2002, p. 34). Therefore, the progression of normal feeding has been included in this review as it is paramount for one to have an understanding of normal feeding development in order to comprehend dysphagia, the possible aetiologies thereof as well as the typical assessment and management strategies implemented.

Swallowing in healthy humans is a dynamic process that involves the complex integration of a number of neuromuscular and sensori-motor processes (Ertekin & Aydogdu,

2003; Prasse & Kikano, 2009) which are involved in the intricate coordination of the respiratory and gastrointestinal mechanisms (Arvedson & Brodsky, 2002, p. 3). In order for safe and effective feeding and swallowing to occur, infants require intact sensori-motor processing, adequate health and nutritional status as well as the integration of the infant's central nervous and skeletal-musculo systems (Arvedson & Brodsky, 2002, p. 4). The term 'feeding' refers to the complete eating experience including the environment, persons involved, foods eaten as well as the overall experience of eating (Delaney & Arvedson, 2008). Swallowing is concerned with the physiological aspect of transporting food from the mouth to the stomach (Delaney & Arvedson, 2008). As objective assessment measures are typically focused on swallowing, this will be the focus of the study. However, the term feeding will be used throughout this research to describe both the eating and swallowing experience.

Effective swallowing occurs as one complex process but is typically divided into three phases, namely the oral, pharyngeal and oesophageal phases of the swallow (Ertekin & Aydogdu, 2003). Each phase has a specific function in the overall swallowing mechanism (Ertekin & Aydogdu, 2003). The oral phase occurs in the oral cavity and is concerned with preparing the food to be swallowed (Arvedson & Brodsky, 2002, p. 41; Ertekin & Aydogdu, 2003; Winstock, 2005, p. 17). The pharyngeal phase of the swallow ensures that the airway is protected from food entering the lungs and directs the bolus from the oral cavity toward the stomach (Arvedson & Brodsky, 2002, p. 41; Ertekin & Aydogdu, 2003; Winstock, 2005, p. 18). The oesophageal stage of the swallow ensures that the food enters the stomach in order for the digestion process to begin (Arvedson & Brodsky, 2002, p. 46). Impairments at any stage in the

swallowing process may have negative consequences with regards to the child's health and development (Arvedson & Brodsky, 2002, p. 3).

Although the developmentally appropriate infant only requires oral feeding after birth, the development of these skills begins in utero (Arvedson & Brodsky, 2002, p. 24). The crucial aspects of development related to feeding, occurs between the fourth and fifth week of growth post conception (Arvedson & Brodsky, 2002, p. 24). It is at this time that the brachial apparatus begin to form resulting in the face, neck, pharynx nasal and oral cavities (Arvedson & Brodsky, 2002, p. 26). The development of the palate begins from the fifth week and between 10 and 11 weeks post-conception, pharyngeal swallows may be observed (Arvedson & Brodsky, 2002, p. 30; Arvedson & Lefton-Greif, 1996; Garg, 2003). However, only between 32-36 weeks does the infant have the maturity and coordination required to feed orally (Arvedson & Brodsky, 2002, p. 30; Arvedson & Lefton-Greif, 1996; Dusick, 2003; Garg, 2003).

Infants that are born prior to thirty-seven weeks of gestation are considered to be born premature (Eichenwald & Stark, 2008). In conjunction with prematurity many infants also experience low (2500g or less), very low (1500g or less) and extremely low (1000g or less) birth weights (Eichenwald & Stark, 2008). Due to advances in neonatal care, a higher number of premature and low birth weight infants are surviving (Miller & Willging, 2003). These infants, as a result of their lack of full development often exhibit health and feeding difficulties (Eichenwald & Stark, 2008). They are particularly susceptible to respiratory, gastrointestinal, cardiac and neurological difficulties all of which may affect the infants feeding abilities (Eichenwald & Stark, 2008).

1.2.1 Birth to Eighteen Months

In the neonatal period, an infant's feeding is governed by hunger and satiety (Arvedson & Brodsky, 2002, p. 61). Through growth, development and the establishment of stable sleep-awake cycles the infant begins to develop a pattern of self regulation (Arvedson & Brodsky, 2002, p. 61). This self-regulation is fundamental in the coordination and synchrony of sucking, swallowing and breathing required for safe and effective feeding (Arvedson & Brodsky, 2002, p. 61).

During the infancy period (three to six months), caregivers may begin transitioning the infant to soft foods that may be fed from a spoon (Arvedson & Brodsky, 2002, p. 69; Hall, 2001, p. 37). Literature (Arvedson & Brodsky, 2002, p. 69; Northstone, Emmett, Nethersole & the Avon Longitudinal Study of Pregnancy And Childhood Study Team, 2001) has suggested that a critical period exists between five and six months for the introduction of soft foods. It is at this age that an infant is developmentally ready to chew. It is proposed that if infants are not exposed to chewable foods at this age they may develop adverse reactions to subsequently eating soft foods (Arvedson & Brodsky, 2002, p. 69; Northstone et al., 2001).

During the period of six to twelve months of age the infant experiences a burst of physical and neurological development (Arvedson & Brodsky, 2002, p. 70). Infants have the neuromuscular and postural ability to sit independently with their hands free, enabling exploration and grasping of new objects (Arvedson & Brodsky, 2002, p. 70; Carruth & Skinner, 2002). As a result of this development and increased independence, infants acquire four predominant feeding abilities, including oral-motor ability and coordination required for

effective spoon feeding (Arvedson & Brodsky, 2002, p. 70; Carruth & Skinner, 2002; Hall, 2001, p. 20); the ability to begin eating solid foods that may require more advanced chewing skill (Arvedson & Brodsky, 2002, p. 70). With further autonomy and independence and increased fine motor abilities the infants begins the transition to self-feeding (Arvedson & Brodsky, 2002, p. 71; Carruth & Skinner, 2002). This fine-motor ability further lends itself toward effective cup and independent bottle drinking (Arvedson & Brodsky, 2002, p. 71).

By 18 months of age infants have developed gross and fine motor movements required for independent sitting, eating and chewing (Carruth & Skinner, 2002). A critical period for the acquisition of the skills required for chewing solid foods exists at this age (Clark & Laing, 1990; Northstone et al., 2001). It is thought that if this critical period lapses without introduction to this new skill, the infants will experience adverse feeding effects such as vomiting, food refusal and an inability to develop the skill required (Northstone et al., 2001). According to the principles of normal development, by 18 months of age infants should have been exposed to multiple feeding skills (Carruth & Skinner, 2002), such as chewing, and any difficulties with related to feeding or swallowing should be evident.

1.3 Disordered Swallowing

Disordered swallowing can be observed during a clinical observation but can only be confirmed with a videofluoroscopic swallowing study (Hiorns & Ryan, 2006), which will be discussed at a later stage in this review. As discussed previously, normal swallowing can be categorised into three phases, namely the oral, pharyngeal and oesophageal phase (Ertekin &

Aydogdu, 2003). Difficulties can occur at any stage in the stage of swallowing and on any consistency of food. Examples of disorders in each phase of swallowing have been outlined below.

1.3.1 Oral phase swallowing disorders

Impairments in the oral phase of swallowing are related to the preparation of the food for swallowing, formation of a bolus and the propulsion of the bolus into the pharynx. An impairment in this phase of swallowing may be seen during the clinical observation. Infants with an oral phase swallowing difficulty may present with anterior spillage of food out of the mouth, residue in the anterior and lateral sulci, and food pushed forward out the mouth (Arvedson & Brodsky, 2002, p. 320; Norman, Louw & Kritzinger, 2007). If an infant has oral phase difficulties they also may have difficulty with sucking, drinking and/or chewing.

1.3.2 Pharyngeal phase swallowing disorders

Pharyngeal phase swallowing disorders cannot definitively be determined without the use of an objective assessment measure although some of the signs of dysphagia, such as coughing or a gurgly voice may be indicative of a pharyngeal phase swallowing disorder (Arvedson & Brodsky, 2002, p. 320; Norman et al., 2007; Stoeckli, Huisman, Seifert & Martin-Harris, 2003). Impairments in this phase of swallowing may result in pooling or residue in the valleculae and pyriform sinuses or a delayed swallow mechanism (Arvedson & Brodsky, 2002, p. 320). One of the most concerning aspects of dysphagia, aspiration, is classified as a pharyngeal phase disorder (Arvedson & Brodsky, 2002, p.320).

1.3.3 Oesophageal phase swallowing disorders

Impairments in the oesophageal phase of swallowing are typically related to gastro-oesophageal reflux (GOR), delayed emptying into the stomach and oesophageal motility impairments (Arvedson & Brodsky, 2002, p. 46; Norman et al., 2007). These conditions have multiple aetiological bases and have been discussed at a later stage in this review.

These aspects of disordered swallowing can typically be seen on a VFSS and provide the health professionals involved in dysphagia with a picture of the infant's swallowing difficulties. If the disordered phase of swallowing can be determined, appropriate intervention can be provided. In addition an understanding of the impaired swallowing may provide insight into the possible aetiological factors underlying the feeding difficulty.

1.4 Consequences of Feeding Difficulties

Feeding difficulties can result in a magnitude of problems both for the infant and his/her caregivers and family. The most life-threatening consequence of a feeding disorder is that of aspiration, pneumonia and possible death (Calis, Veugelers, Sheppard, Tibboel, Evenhuis & Penning, 2008; Manikam & Perman, 2000; Prasse & Kikano, 2009; Schwartz, 2003; Schwartz, Corredor, Fisher-Medina, Cohen & Rabinowitz, 2001). Aspiration pneumonia is reported to have the highest rate of mortality of nosocomial infections (Prasse & Kikano, 2009).

Infants with feeding difficulties often have nutritional difficulties due to the reduced amount and variety of foods eaten (Kirby & Noel, 2007). Research conducted on 100 children

with disabilities in England (Sullivan, Juszczak, Lambert, Rose, Ford-Adams & Johnson, 2002) revealed that 80% of the children consumed an energy-deficient diet. Furthermore, the children were found to have micronutrient, and in particular, iron deficits (Sullivan et al., 2002). This decreased energy and micronutrient consumption has resultant long term negative health, development and growth correlates (Sullivan et al., 2002). This reduction in intake may result in the infant being underweight (Kirby & Noel, 2007; Schwartz, 2003), or small for his/her gestational age and/or height (Kirby & Noel, 2007) making these infants susceptible to opportunistic infections and diseases. Other consequential nutritional factors in infants with feeding difficulties include constipation, decreased energy, nutrient and mineral deficiencies, dehydration and anaemia (Kirby & Noel, 2007). Research (D'Anci et al., 2006; Liu, Raine, Venables, Dalais & Mednick, 2003) has also shown that malnutrition and dehydration can result in cognitive impairment furthermore affecting development, growth and feeding.

A large (n=14138), longitudinal study, of infants born in the United Kingdom between 1991 and 1993 conducted by Motion, et al. (2001) determined that a large proportion of infants with feeding difficulties in the first 16 months of life experienced language, motor and behaviour delays. This indicates that the long-term consequences of poor feeding may be far-reaching and affect many key developmental areas. However, this study failed to acknowledge the possible underlying causes of the feeding difficulties. Therefore the study could not conclusively discern whether it was the feeding difficulty that resulted in the poor developmental outcomes, or in fact the underlying condition that may have caused the feeding problems to begin with. However, it appears that negative developmental consequences and dysphagia are related.

Feeding is also the earliest form of bonding and attachment with his/her caregiver as well as a means to explore the environment (Rommel et al., 2003). If feeding is in-effective or absent, these early bonding experiences can result in poor social abilities and attachment difficulties at a later stage in life (Arvedson & Brodsky, 2002, p. 3). A lack of exposure and exploration of the infant's environment may result in a delay in subsequent neuromuscular milestones such as cognition, speech and language (Arvedson & Brodsky, 2002, p. 3). A semi structured interview-based, qualitative study conducted in South Africa (Hewetson & Singh, 2009) determined that mothers of children with feeding difficulties, expressed feelings of disempowerment, loss of a dream, as well as a loss of ability to fully participate in social activities and family routines. This highlights that not only does dysphagia impact the health and development of the child, but also the caregiver and family involved. This overall impact indicates that paediatric dysphagia is not only a health concern but also a social, welfare and community one.

As literature indicates, dysphagia can result in serious consequences which should not be ignored. Feeding difficulties have both short-term and long-term consequences with severity ranging from undernutrition to death. Infants with feeding difficulties and their caregivers need immediate attention and intervention to try and minimise these effects and consequences. Therefore, it is pertinent that infants with feeding difficulties are identified early in order for intervention to be provided and the long term effects of the dysphagia minimised (Gisel, 2008). Therefore, the disorders experienced by children in which dysphagia is frequently associated are presented below.

1.5 Signs and Symptoms of Dysphagia

There are multiple signs and symptoms that an infant may present with if he/she is having difficulty with feeding. An infant may present with signs and symptoms related to the infant's physiological response to feeding. Examples of these include vomiting, nasal regurgitation, drooling, delayed or multiple swallows, poor weight gain and dehydration (Arvedson, 2008; Hall, 2001, p. 84; Manikam & Perman, 2000; Prasse & Kikano, 2009). A physiological response typically associated with acute aspiration and possible dysphagia is that of an increase in the infant's body temperature during feeding times or in the absence of another infection (Arvedson & Brodsky, 2002, p. 472).

In addition to physiological markers many infants with dysphagia may present with signs of respiratory distress. Examples of these include coughing, choking, tachypnoea and apnoea, changes in colour particularly around the nose and mouth as well as changes in posture and tone (Arvedson, 2008; Hall, 2001, p. 84; Manikam & Perman, 2000; Prasse & Kikano, 2009). These infants often present with multiple lower respiratory tract infections such as pneumonia which if left untreated, or occurs recurrently, may ultimately result in chronic lung disease (Calis et al., 2008).

With regards to behavioural signs and symptoms of feeding difficulties, some infants and young children may display food selectivity with regards to taste and texture, prolonged and difficult mealtimes as well a poor motivation to feed (Manikam & Perman, 2000). Feeding difficulties with primary behavioural signs and symptoms may be due to adverse social and

psychological factors or an underlying disorder such as autism (Arvedson & Brodsky, 2002, p. 450). Signs and symptoms of a secondary behavioural feeding difficulty refer to those infants that refuse to eat and are possibly selective about the type of food due to underlying factors that make feeding difficult (Manikam & Perman, 2000). Examples of this includes refusal to eat to avoid discomfort as a result of GOR.

1.6 The Detection of Dysphagia in Infants

In order to obtain a clear understanding of the nature and presentation of infants' feeding difficulties a number of procedures are required. In an ideal clinic setting the infant would be assessed by a team of professionals in order to ensure holistic management of the infant and his/her family (Arvedson & Brodsky, 2002, p. 5). The primary health professional involved in paediatric dysphagia is the speech-language therapist (Arvedson, 2008; Arvedson & Brodsky, 2002, p. 8).

Upon initial assessment, an interview is typically conducted with the infant's caregivers to establish information related to the presenting complaint, the infant's medical history as well as the infant's current mode of feeding (Arvedson, 2008). Due to the language diversity within South Africa (Mesthrie, 2002) this information may be obtained through the use of an interpreter or through the hospital records. The second assessment protocol is an assessment of the infant prior to feeding (Arvedson, 2008). This includes an assessment of the infant's tone, posture and whether or not he/she is receiving any medical support such as supplemental oxygen (Arvedson, 2008). In addition, Bernard-Bonnin (2006) recommends a comprehensive physical assessment,

including anthropometric, developmental and neurological tests, be undertaken by a paediatrician or medical doctor. Once the medical professionals and speech-language therapist are satisfied that the infant is medically stable, the clinical assessment begins. This assessment includes an examination of the infant's oral structures including determining whether or not the reflexes required for feeding are present or not (Arvedson, 2008).

Once the pre-feeding assessment has been conducted, the speech-language therapist observes the infant's current mode of feeding. Observations during this period include the positions used by the care-giver during feeding, the types of food being fed to the child as well as the manner of feeding (Arvedson, 2008; Dusick, 2003; Prasse & Kikano, 2009). The time taken for the infant to feed is also an important factor in the assessment process as this may indicate fatigue on the part of the infant during feeds (Arvedson, 2008). It is during this period that the speech-language therapist should note any difficulties experienced by the infant such as coughing, choking, food refusal or any other of the signs of a feeding difficulty as previously discussed. Following this, a subjective feeding assessment should be conducted. This involves the assessment of the infant's ability to swallow various age-appropriate consistencies and whether any difficulty with feeding and/or swallowing is noted (Arvedson, 2002). Furthermore, the subjective assessment provides the speech-language therapist with the opportunity to implement any intervention strategies such as consistency or positioning changes, external feed pacing or altering the mode of food presentation to determine what improves the infant's ability to feed safely and effectively. The subjective assessment is only able to conclusively assess the oral-phase of the swallow and from physiological signs and symptoms make clinical judgements

on the pharyngeal and oesophageal phase of swallowing, however, an objective assessment measure is often required to confirm these suspicions.

At present the gold-standard objective measure for assessing dysphagia in both infants and adults is the videofluoroscopic swallow study, otherwise known as VFSS (Arvedson, 2008; De Matteo, Matchovich & Hjartarson, 2005; Hiorns & Ryan, 2006; Zammit-Maempel, Chapple & Leslie, 2007). This procedure observes the swallow via X-ray that allows a dynamic view of the oral, pharyngeal and oesophageal phases of the swallow (Arvedson, 2008; Hiorns & Ryan, 2006). The VFSS has been found to be sensitive to both overt and silent aspiration and can effectively assess airway protection in the infant concerned (Hiorns & Ryan, 2006). The VFSS also provides the speech-language therapist with the opportunity to visually evaluate therapy techniques such as consistency or postural changes and to determine the safety of these techniques in reducing or eliminating aspiration (Arvedson, 2008; Hiorns & Ryan, 2006). Although VFSS provides a dynamic view of swallowing of various consistencies it has been criticised for only providing a brief time-frame into a feeding experience (Hiorns & Ryan, 2006). The use of VFSS in all hospital settings has also been criticised as the equipment required to conduct a VFSS is expensive and specialised and is not necessarily feasible for all hospitals or health centres (De Matteo et al., 2005). There is also an ongoing debate regarding the amount of radiation exposure during the VFSS. In a study conducted by Zammit-Maempel et al. (2007) on 203 adult patients in the United Kingdom it was found that the radiation dose during a VFSS was minimal compared to the radiation each person is exposed to naturally on a daily basis. However, the effect of the radiation on infants and young children has yet to be examined. Recently concern has been raised with regards to relevance of gastrointestinal imaging in the form of

VFSS and upper gastrointestinal series (DiSantos, 2008). This argument was made in relation to the high quality imaging techniques currently available in the form of magnetic resonance imaging (MRI) and computer topographic (CT) scans (DiSantos, 2008). However, it was determined that at present there is no other imaging procedure that provides a real-time, accurate evaluation of swallowing; or a procedure that allows for the implementation of management strategies during the imaging procedure (DiSantos, 2008).

In response to the debate surrounding the VFSS, the use of fibre-optic endoscopic evaluation of swallowing (FEES) has been proposed (De Matteo et al., 2005; Prasse & Kikano, 2009). FEES involves the insertion of a fibre-optic camera via the nose in order to obtain direct visualisation of the hypopharynx and larynx during swallowing (De Matteo et al., 2005). This procedure often requires the infant to be restrained and does not necessarily mimic an optimal feeding posture (De Matteo et al., 2005).

In some instances when the advanced radiological videofluoroscopy equipment is not available a barium oesophagram, otherwise known as a barium swallow series, oesophagography or upper gastrointestinal series may be used (Hall, 2001, p. 79). This is an x-ray procedure that is employed predominantly to determine the integrity of the anatomy of the gastrointestinal tract (Hall, 2001, p. 79). The procedure is typically used to evaluate oesophageal anatomy, motility disorders and on a gross scale, gastro-oesophageal reflux (Allen, Baker & Falk, 2009; Hall, 2001, p. 79; Levine, Rubensin & Laufer, 2009). During this assessment the patient drinks liquid barium whilst lying in various positions including supine, prone and side lying whilst x-rays are taken as the liquid passes through the gastrointestinal tract (Baker, Einstein, Herts, Remer,

Motta-Ramirez, Ehrenwald, Rice et al., 2007). The barium oesophagram is focused on the oesophageal and gastric phase of swallowing and not typically employed for the evaluation of oral and pharyngeal based swallowing disorders (Hall, 2001, p. 79). In the instances whereby a oesophagram is used to evaluate oral-pharyngeal swallowing function the results may not always be accurate due to the unnatural feeding postures employed during the study as well as the predominant focus on the oesophageal and gastric phases of swallowing (Hall, 2001, p. 79).

Objective assessments such as VFSS, FEES and barium oesophagrams require expensive equipment that may not necessarily be available at all medical facilities in developing countries. Therefore, the use of cervical auscultation has been proposed (Dusick, 2003; Stroud, Lawrie & Wiles, 2002). Cervical auscultation involves the use of a stethoscope, placed on the thyroid cartilage during swallowing (Stroud et al., 2002). The clinician employs this technique as the patient swallows and listens to the sounds of swallowing and respiration (Stroud et al., 2002). The primary goal of cervical auscultation is to detect aspiration (Stroud et al., 2002). It has been argued that cervical auscultation may be a useful non-invasive tool to assess the suck-swallow-breathe sequence and aspiration that cannot always be easily observed. However, this is not standard protocol with the sensitivity ranging between 73-90% and specificity approximately 80% (Stroud et al., 2002). A study investigating the inter- and intra-reliability of cervical auscultation to detect aspiration by Stroud, et al. (2002) revealed that there was only a fair reliability (0.28, kappa) when used in isolation and a high prevalence of false positives with regards to aspiration. Therefore, it was proposed that cervical auscultation may be used in conjunction with the other assessment procedures and if refined and intensive training conducted be used as part of a screening tool. This assessment measure should be further researched as with

further investigations and regulations may become an inexpensive, easily accessible tool for detecting dysphagia in developing, resource-poor countries.

1.7 Aetiologies and Incidence of Feeding Difficulties

Literature (Arvedson, 2008; Burklow et al., 1998; Manikam & Perman, 2000; Miller & Willging, 2003; Prasse & Kikano, 2009) has suggested the incidence of feeding disorders is between 25-40% in normally developing children; and 80% in children with disabilities. Furthermore, it has been suggested that the incidence of dysphagia is increasing (Arvedson, 2008). Due to the recent advancements in medical technology, infants with conditions previously considered fatal such as severe prematurity and infants with very low birth weight are surviving (Arvedson, 2008; Miller & Willging, 2003; Newman, Keckley, Petersen, & Hamner, 2001; Vincer, Allen, Joseph, Stinson, Scott & Wood, 2006). The incidence of dysphagia in the paediatric population as a whole has very limited research both within South Africa and internationally. There is a lack of a standardised, consistent classification system for paediatric dysphagia has made comparisons between studies difficult and unreliable.

The aetiology of dysphagia in children is often complex and varied and may be affected by one or multiple systems. The only literature that reported multiple aetiological factors was by Silverman (2010), who reported that up to 85% of cases of dysphagia contain mixed aetiology. Silverman (2010) indicated that the majority of the additional aetiological factors were behaviourally related. Therefore, the profile of dysphagia with multiple aetiologies has not fully been described. In no particular order the most frequently reported aetiologies of dysphagia both

internationally as well as in South Africa have been discussed below. Where applicable, research into the incidence of dysphagia with regards to the specific aetiologies has also been presented.

Dysphagia with a neurological basis can refer to difficulties acquired prenatally, perinatally as well as later in the infant's life (Hall, 2001, p. 56). The most common neurological disorder with subsequent dysphagia is cerebral palsy (Arvedson & Brodsky, 2002, p. 35). Prevalence rates of cerebral palsy in developed countries range from 1.5 to 3.6 children per 1000 live births (Andersen, Irgens, Haagaas, Skranes, Meberg & Vik, 2008; Kupermine & Stevenson, 2008; Krägeloh-Mann & Cans, 2009). There are differing opinions in research as to whether the prevalence of cerebral palsy in developing countries is higher than in developed countries. A study conducted in Turkey (Serdaroğlu, Cansu, Özgan & Tezcan, 2006) reported a prevalence of cerebral palsy to be 4.4 per 1000 live births, whereas van Toorn, Laughton, van Zyl, Doets and Elsinger (2007) argue that the rates between developed and developing countries have no differences. However what was noted in a study conducted in the Western Cape, South Africa (van Toorn et al., 2007), is that the incidence of cerebral palsy as a result of an acquired condition (21.1.%) was higher than that in developed countries. This was attributed to the higher number of communicable diseases such as tuberculosis meningitis and cerebral vascular insults typically seen in developing countries (van Toorn et al., 2007).

Literature (Arvedson & Brodsky, 2002, p. 85; Calis et al., 2008) suggests that the prevalence of dysphagia in infants with cerebral palsy is between 85-90%. Infants with cerebral palsy often have difficulty with the neuromuscular aspect of feeding including sucking and chewing (Hall, 2001, p. 60). Oral-motor difficulties, including poor lip closure and drooling, may

also contribute to the infant with cerebral palsy's difficulty with feeding (Calis et al., 2008). Infants with cerebral palsy also frequently present with gastro-oesophageal reflux, oesophageal dysmotility and oesophagitis (Arvedson & Brodsky, 2002, p. 136). Within developing countries one of the primary causes of morbidity and mortality in infants is dehydration secondary to diarrhoea and gastroenteritis (Kosek et al., 2003). Within South Africa, diarrhoeal disease is the third leading cause of death in children below the age of five years (Bradshaw et al., 2003). When the infant experiences severe dehydration, the chemical levels in the blood alter and the infant becomes hypernatraemic (Kosek et al., 2003; Laing & Wong, 2002). This hypernatraemia has multiple health and neurological correlates, including seizures, intracranial haemorrhage and hydrocephalus (Laing & Wong, 2002). Although the more severe, permanent neurological impairment may occur when the infant is rehydrated too quickly and the neurological correlates are exacerbated leading to long term, permanent brain damage (Laing & Wong, 2002).

A larger study investigated dysphagia in 166 children from the Netherlands with severe cerebral palsy (Calis et al., 2008) as classified by level four or five on the Gross Motor Function Classification System (Palisano, Rosenbaum, Walter, Russell, Wood & Galuppi, 1997). The dysphagia was rated according to a severity scale created by the researchers based on the Dysphagia Disorders Survey (Sheppard, 2002). The dysphagia was classified in terms of mild, moderate-severe, profound or no dysphagia (Calis et al., 2008). Almost all of the infants (99%) experienced some form of dysphagia, with the majority (76%) of the infants' experiencing moderate-severe dysphagia with 15% profound dysphagia receiving no food orally. Furthermore, it was reported that 91% of these infants had signs of pharyngeal phase involvement. However, the assessments used to determine the severity of dysphagia were based on subjective tools and

no objective measures were conducted. Therefore, the accuracy of the pharyngeal phase involvement in particular is questionable and may have been assessor dependent. In addition, only children with severe cerebral palsy were included in the study. Therefore, the incidence of dysphagia in children with any degree of cerebral palsy may not be as high as 99%.

Schwartz et al. (2001) conducted a study in New York, where the feeding difficulties in 79 children with developmental disabilities were analysed through the use of multiple objective assessment measures. The sample comprised of children with cerebral palsy, prematurity, chromosomal abnormalities, central nervous system malformations, congenital infections and other developmental disabilities (Schwartz et al., 2001). The children's swallowing was categorised into gastro-oesophageal reflux without aspiration; with aspiration; oropharyngeal dysphagia and aversive feeding behaviour (Schwartz et al., 2001). The focus of the study was on the effect of intervention on the nutritional and clinical response to the management related to the child's specific disorder. Findings revealed that management should be aetiology and infant specific and nutritional interventions reduced the length of hospitalisation in all of the infants. What was not determined in this study was the type of dysphagia specific to the child's underlying disorder. Therefore, one could not discern whether the children with cerebral palsy where more likely to experience, oropharyangeal dysphagia, gastro-oesophageal reflux with or without aspiration or a combination of factors.

Within South Africa, Barratt and Ogle (2010) reviewed the records of 100 children between birth and fourteen years of age attending a neurodevelopmental clinic in a Government Hospital. This research investigated the disorder and type of dysphagia experienced by children.

The conditions experienced by the children as outlined in the records included developmental delay, genetic syndromes, cerebral palsy and autism spectrum disorder, to name a few (Barratt & Ogle, 2010). Of the files reviewed, 29% contained reports of feeding difficulties, with 14% referred for a feeding assessment. What was interesting to note is that even in a neurodevelopmental clinic many of the children with reported feeding problems were not referred for a feeding assessment even though 79% of the files reviewed revealed that the children did receive intervention from an allied health practitioner (Barratt & Ogle, 2010). This indicates that the allied health services, particularly with regards to feeding assessments and intervention, are not being fully utilised.

Dysphagia as a result of anatomical or structural difficulties can affect any stage of the feeding and swallowing process. A common anatomical impairment with associated feeding difficulties is that of cleft-lip and/or palate (Arvedson & Brodsky, 2002, p. 528). According to Arvedson and Brodsky (2002, p. 528) cleft lip and palate deformities occur in approximately 1 in 750 live births in the United States of America. These infants present with difficulty in sucking and maintaining an adequate lip seal against the bottle or teat (Arvedson & Brodsky, 2002, p. 529). Other anatomical abnormalities that have been known to affect feeding are those involving the oropharynx, larynx, trachea, oesophagus, stomach and bowel (Arvedson, 2008; Prasse & Kikano, 2009). Examples of oropharyngeal structural abnormalities include micrognathia and glossoptosis (Baudon, Renault, Goutet, Biran-Mucignat, Morgant, Garabedian & Vazquez, 2009). Laryngeal and tracheal structural abnormalities may include tracheal stenosis, a tracheo-oesophageal fistula or laryngeal webs (Arvedson & Brodsky, 2002, p. 176). The concern with regards to oro-facial and laryngeal anomalies is the potential affect of respiration (Miller &

Willging, 2007). In some instances it is in fact the structural abnormality affecting respiration that is impairing the infant's feeding ability and not the oral-motor or swallowing itself (Miller & Willging, 2007). In terms of oesophageal and gastric structural anomalies, oesophageal atresia, bowel rotation, pyloric stenosis and volvulus may occur at birth (Arvedson & Brodsky, 2002, p. 198). As mentioned above the aetiologies of dysphagia are not static and may overlap. This is often seen when the structural abnormality may be a result of a genetic condition such as Pierre-Robin Sequence, thereby including both the genetic and structural aetiologies of dysphagia.

Research conducted in France by Baudon, et al. (2009) analysed dysphagia in 42 infants with facial malformations. It was determined that regardless of the specific facial anomaly, many infants experienced respiratory and nutritional impairments (Baudon et al., 2009). The infants' dysphagia was analysed through electromyography and oesophageal manometry. Electromyography involves the placing of surface electrodes onto the muscles, in this case on the face, and analysing the muscle activation at rest as well as movement (O'Kane, Groher, Silva & Osborn, 2010; Vaiman, Segal & Eviatar, 2004). Oesophageal manometry was used to determine the contraction and relaxation of the upper and lower oesophageal sphincters at rest and during swallowing (Lacy, Paquette, Robertson, Kelley & Weiss, 2009). In the study conducted by Baudon, et al. (2009) the most common facial malformation included micrognathia, cleft palate, high arched palate and glossoptosis. The dysphagia was characterised as absent or ineffective sucking movements, choking, vomiting as well as apnoeas and oxygen desaturation during feeding (Baudon et al., 2009). It was further determined that in the sample analysed, many of the infants experienced oral and oesophageal phase swallowing difficulties. However, this study only analysed facial malformations and not tracheal, laryngeal, oesophageal or gastric structural

anomalies. Furthermore, the sample size in this study was relatively small and all of the infants had predetermined dysphagia therefore the prevalence of dysphagia in a population of infants with facial malformations is still in question.

Infants with oral anatomical conditions such as a cleft lip and/or palate typically present with oral phase feeding difficulties (Arvedson & Brodsky, 2002, p. 529). A prospective observation study conducted by Reid, Reilly and Kilpatrick (2007) analysed the sucking abilities of 40 infants with cleft palates. It was determined that infants with a cleft lip only, presented with adequate sucking but difficulty latching to the nipple. Whereas those infants with a cleft lip and palate, had difficulty with sucking regardless of the nipple used or the placement of the nipple in the mouth (Reid et al., 2007). What was further noted is that the infants' sucking ability was dependent on the infants' type, classification and position of the cleft and therefore specific to each individual child. This study did not include children with genetic syndromes with concomitant cleft lip and/or palates and therefore the results cannot be generalised to all infants presenting with a cleft lip and/or palate.

As mentioned, an additional aetiology related to dysphagia is with regards to genetic syndromes and disorders. The features and feeding correlates of genetic syndromes are specific to each disorder and the individual manifestation in each infant. Unlike neurological difficulties, all genetic syndromes have their own specific pathologies and associated conditions. The nature of the feeding difficulties for each syndrome is therefore varied and disorder specific. Examples of genetic syndromes which result in feeding difficulties include Prader-Willi, Down syndrome

and Pierre-Robin Sequence (Arvedson, 2008; Arvedson & Brodsky, 2002, p. 550; Cooper-Brown, Copeland, Dailey, Downey, Petersen, Stimson & Van Dyke, 2008; Hall, 2001, p. 72).

Dysphagia as a result of a systemic illness is a very broad classification that encompasses any medical condition that may result in a feeding difficulty. In a study conducted in Belgium by Rommel, et al. (2003) with 700 infants, it was revealed that more than 80% of infants with dysphagia had an underlying medical condition causing the feeding difficulty. However, very few studies have been conducted elsewhere into the prevalence of the various aetiologies within paediatric dysphagia. Examples of aetiologies that fall within this category include cardiovascular, gastrointestinal and metabolic related abnormalities (Arvedson, 2008; Miller & Willging, 2003).

Within the classification of dysphagia secondary to systemic illness is HIV/AIDS. This disease has multiple dysphagia correlates including odynophagia due to oral and pharyngeal candida (McNeilly, 2000), encephalopathy (World Health Organisation, 2007) and gastrointestinal difficulties such as gastro-oesophageal reflux disease (Rabie, Marais, van Toorn, Nourse, Nel, Goussard, Sellers, et al., 2007). There is a dearth of research into paediatric feeding and HIV/AIDS and therefore a study conducted by Halvorsen, Moelleken & Kearney (2003) into adults with HIV/AIDS was included in this review. It was revealed through VFSS findings of 17 adults with HIV/AIDS, that nine showed oral dysfunction and four experienced oesophagitis. The pharyngeal phase of swallowing was also impaired with delays in the pharyngeal swallowing, inadequate laryngeal elevation as well as aspiration. Although comparisons cannot be made between the Halvorsen et al. (2003) study and infants with HIV/AIDS one can extrapolate that HIV/AIDS has direct feeding and swallowing correlates.

Within Africa, a study conducted in Tanzania (Cameron et al., 2005) found that the social factors may also contribute to an infant's health and development. Cameron, et al. (2005) found that the primary cause of disability in a low income area within Tanzania was infectious diseases for example gastroenteritis and pneumonia. Due to lack of amenities and resources, infectious diseases spread rapidly within communities with resultant long term consequences. Infants from impoverished areas are also typically undernourished and underweight (Cameron et al., 2005). These factors may not only have health and growth but also feeding correlates.

A retrospective study conducted in Tennessee, reviewing the videofluoroscopic swallow studies (VFSS) of 43 infants under the age of 12 months determined that 49% of the infants were diagnosed with pneumonia (Newman et al., 2001). Pneumonia has been determined to account for almost five million deaths in children under the age of five years in developing countries (Owayed et al., 2000). In children, it is often difficult to determine whether the dysphagia resulted in the pneumonia or whether the pneumonia has resultant feeding difficulties. The most common causes of pneumonia include viral and bacterial infections as well as aspiration pneumonia (Weir, McMahon, Barry, Ware, Masters & Chang, 2007). Pneumonia also presents with similar symptoms to that of dysphagia in that coughing, breathing difficulties and food refusal are common symptoms in both disorders (Gessman & Rappaport, 2009). Therefore, discerning which condition presented first is often a conundrum. A retrospective review of the records of 150 infants that underwent a VFSS in Brisbane, Australia, determined that a similar number of children with aspiration as well as those without aspiration developed pneumonia

(Weir et al., 2007). Significantly, there was an association between pneumonia and children that presented with residue after the swallow.

A similar, larger study (N=238) conducted in Toronto, Ontario, examined the records of infants with recurrent pneumonia (Owayed et al., 2000). The most prevalent disorder determined in these infants was that of aspiration secondary to oro-pharyngeal inco-ordination (n=114). In response, to the debate regarding which illness came first, Owayed, et al. (2000) determined that only four of the infants with aspiration, were diagnosed with pneumonia prior to the aspiration diagnosis. The remaining 110 infants were diagnosed with pneumonia following an aspiration diagnosis.

A smaller study (N=19) analysed the VFSS results in children with oropharyngeal dysphagia without evident risk factors (Lefton-Greif, Carroll & Loughlin, 2006). This study investigated the swallowing physiology of infants with unexplained respiratory symptoms. All of the children that underwent the VFSS had silent aspiration. This silent aspiration appeared to be the district reason as to why dysphagia was not considered in the differential diagnosis of the recurrent respiratory difficulties (Lefton-Greif et al., 2006). However, this was a very small study and therefore this cannot be generalised to all children with recurrent respiratory difficulties. The significance of this study is that it provides evidence for the consideration of dysphagia as part of a differential diagnosis in children with recurrent respiratory difficulties.

Gastrointestinal conditions have been well documented to have feeding correlates. The two main gastrointestinal conditions that will be discussed include diarrhoeal disease and gastro-

oesophageal reflux. Structural gastrointestinal abnormalities will not be discussed in this section as they have been covered previously.

Within South Africa, diarrhoeal disease has been identified as the third leading cause of mortality in children under the age of five years (Bradshaw et al., 2003). A study conducted in the Limpopo and KwaZulu-Natal provinces of South Africa established that out of the 1357 children assessed, 22.8% were reported to have diarrhoea (Horwood, Butler, Vermaak, Rollins, Haskins, Nkosi, Neilands, et al., 2011). The negative effects of dehydration and subsequent hypernatraemia (D'Anci et al., 2006; Laing & Wong, 2002) as discussed previously, have negative neurological complications as discussed above, and may lead to feeding difficulties. Therefore, appropriate early intervention for children presenting with diarrhoeal disease and dehydration is vital to not only ensure life but also to combat the risks of additional complications including neurological and feeding difficulties as well as long term cognitive development and learning.

Gastro-oesophageal reflux (GOR), although not an infectious disease is the cause of feeding difficulties in many children (Duca, Dantas, Rodrigues & Sawamura, 2008). As a result of the GOR many infants will experience vomiting and regurgitation during or following feeds (Duca et al., 2008). These consequences may result in odynophagia due to trauma to the pharyngeal wall, food refusal as a result of oesophagitis, respiratory difficulties caused by food entering the larynx, and irritability during feeding (Duca et al., 2008; Putnam, 1997. A small (n=18) retrospective review of infants that underwent a VFSS at the North Western Memorial Hospital, USA, revealed that most of the infants in the control (no GOR) and GOR group had

normal swallow physiology (Mendell & Logemann, 2002). However, what was noted was that the infants with GOR displayed some hesitancy prior to the swallow and two of the infants indicated the feeling of something being stuck in their throats during swallowing (Mendell & Logemann, 2002). In addition, the infants with GOR presented with more repeated swallows, increased residue and more frequent laryngeal penetration, albeit no aspiration, than the control group. Duca, et al. (2008) studied the swallowing of 37 children with vomiting after feeding and a control group of 15 children. This study also determined that laryngeal penetration, without aspiration, was evident in the infants with GOR. Furthermore, 78.4% of mothers of infants with GOR reported crying during feeds, choking, poor sucking and increased time needed for feeding (Duca et al., 2008). This indicates that not only is feeding a negative experience for the child with GOR but al so for the caregivers and family involved.

Although these studies had small sample sizes, they highlight the fact that infants with GOR appear to have many symptoms of feeding difficulties. In addition, even though aspiration was not evident in either of the studies, the presence of frequent penetration indicates that the safety of the swallowing mechanism might be compromised in infants with GOR. This constant exposure of the larynx and oesophagus to GOR may result in decreased laryngeal sensation further emphasises that the infant's ability to swallow safely may be compromised (Arvedson & Brodsky, 2002, p. 163). Therefore, GOR should be considered as part of the differential diagnosis in children with apparent food refusal, respiratory difficulties and irritability during feeding. Furthermore, intervention should be provided early on to avoid long term respiratory and swallowing difficulties.

Conditions associated with complications in-utero and during the early neonatal period may also have negative feeding consequences. The conditions that will be discussed below include prematurity and low birth weight. Prematurity is a condition associated with multiple medical and feeding problems (Hawdon, Beauregard, Slattery & Kennedy, 2000). In the United States of America it is estimated that 12.5% of live infants are born prematurely (Eichenwald & Stark, 2008). The effects of prematurity vary from infant to infant and depend largely on their gestational age, birth weight, overall medical status and the medical care which they have received (Manikam & Perman, 2000). A study conducted into the swallowing dysfunction in infants in the United States of America (Mercado-Deane, Burton, Harlow, Glover, Deane, Guill et al., 2001) determined that 56.4% of infants that were born prematurely experienced swallowing dysfunction on upper gastrointestinal imaging.

Therefore, dependent on these factors the infants may present with varied feeding difficulties and needs. Typically, infants that are born prematurely have underdeveloped respiratory systems and ineffective suck-swallow-breathe coordination (Lau, Smith & Schanler, 2003). This results in ineffective feeding abilities and places the child at risk for aspiration and therefore pneumonia. Premature infants have been found to have oral motor difficulties both at birth and at ten months corrected age indicating that premature infants may experience feeding difficulties that extend into early childhood (Buswell, Leslie, Embleton & Drinnan, 2009). Furthermore, Thoyre (2007) reported that 19-80% of premature infants experience dysphagia following discharge in particular fatigue during feeding and low caloric intake. In addition to the prematurity, infants may experience a multiple complex medical conditions as a result of their underdevelopment. In conjunction to prematurity, infants may also be born with below optimal

birthweight. The conditions experienced by children with low birth weight and those born prematurely are similar in nature and include respiratory difficulties such as bronchopulmonary dysplasia; gastrointestinal difficulties such as necrotising enterocolitis; cardiac difficulties such as patent ductus arteriosus; and neurological complications such as intraventricular haemorrhage, periventricular white-matter injury as well as retinopathy or prematurity (Eichenwald & Stark, 2008). As a result of the underdeveloped respiratory system, poor suck-swallow-breath synchrony and the multiple aetiologies that may influence the child, feeding difficulties are common and varied between infants, therefore the exact nature of dysphagia in infants born prematurely or with a below optimal birth weigh are infant specific.

Failure to thrive (FTT) generally refers to infants who have poor weight gain and has associated social and developmental deficits (Drewett, Kasese-Hara & Wright, 2002; Emond, Drewett, Blair & Emmett, 2007). Typically, FTT is classified as organic, when an illness or impairment is found and non-organic when no underlying aetiology could be found (Arvedson & Brodsky, 2002, p. 234). However, it has now been argued that FTT may be a result of poor maternal education, infant temperament, social demographics including family size as well as physical conditions that may affect weight gain (Emond et al., 2007; Wright & Birks, 2000). Infants with FTT have been found to have poor sucking and when compared with infants with adequate weight gain, it was determined that infants with FTT were found to refuse feeds more often than their non-FTT controls (Emond et al., 2007). However, only infants with overt conditions such as cleft palates and those born prematurely were excluded from the study and infants with underlying conditions that may influence feeding such as GOR or neurological impairments were not considered. In infants with FTT it is important to exclude any underlying

conditions that may affect weight gain and feeding in order to provide accurate and appropriate intervention.

Infants may also have feeding difficulties with a psychological or behavioural aetiology. This may be related to oral deprivation due to long term tube feeds (Arvedson & Brodsky, 2002, p. 415) or underlying behavioural difficulties such as those associated with Pervasive Developmental Disorders or a history of adverse feeding conditions such as force-feeding (Hall, 2001, p. 74).

1.8 Classification of Feeding Difficulties

Throughout history, literature has presented diverse opinions as to the manner in which dysphagia should be classified. Initially, literature classified feeding difficulties in a dichotomous manner as having either an organic or non-organic aetiology (Burklow et al., 1998; Rommel et al., 2003). Feeding difficulties related to structural, neuromuscular, nutritional or medical conditions where considered organic in nature (Burklow et al., 1998; Rommel et al., 2003), whereas all feeding difficulties related to behaviour, social or psychological factors were considered to be non-organic in nature (Burklow et al., 1998; Rommel et al., 2003). More recently, an argument has been presented (Miller & Willging, 2003; Rommel et al., 2003) against this dichotomy. It has been argued that the dichotomy does not account for those feeding difficulties with multiple factors and aetiologies or the possibility that the underlying aetiology may have a combined organic and non-organic component (Miller & Willging, 2003; Prasse & Kikano, 2009; Rommel et al., 2003). Due to this overlap, a classification system acknowledging

that multiple factors may influence the feeding difficulty has been suggested (Miller & Willging, 2003; Prasse & Kikano, 2009). However, universal categories for classification have not yet been agreed upon and subsequently varied categories are used. In addition, operational definitions for the terminology used in the field of paediatric dysphagia have not been agreed upon (Piazza, 2008). Due to these differences in terminology the comparison between studies in literature is unreliable and needs to be considered in isolation. Examples of some of the categories have been outlined in this discussion.

A study of 700 infants with feeding problems conducted by Rommel, et al. (2003), classified the aetiologies of the dysphagia into three categories: medical, oral or behavioural. It was argued that this classification system was employed for intervention purposes. Medical diagnoses were based on specific medical conditions and were confirmed through disorder specific investigations, examples of medical aetiologies include gastrointestinal, neurological, genetic, cardiac, oro-facial, metabolic, nephrologic and combinations of these pathologies (Rommel et al., 2003). Oral feeding problems related to oropharyngeal conditions such as oral motor and oral sensory dysfunction, sucking, pharyngeal dysphagia and combinations thereof. Behavioural aetiologies where assigned when certain behaviours did not meet expected norms. This included psychological conditions such as Munchausen by proxy (Rommel et al., 2003). Although this classification allowed for combinations of aetiologies it did not provide insight into the exact systems and conditions that were involved. Furthermore, complications in classifications occurred whereby conditions overlapped. For example, oral motor difficulties as a result of neurological involvement may be classified as oral or medical conditions.

Burklow, et al. (1998) reviewed the records of 103 children presenting with feeding difficulties. Five categories were then created by the research team and the infants' dysphagia was classified according to the categories created. These included structural abnormalities (e.g. cleft palate, oesophageal stricture), neurological (e.g. CP, developmental delay), cardio-respiratory (e.g. bronchopulmonary dysplasia), metabolic (e.g. fructose intolerance), and behaviour conditions (e.g. food refusal, poor child-feeder interaction). These categories were not exclusive and combinations thereof were described in the research by Burklow, et al. (1998). The same classification system was later acknowledged in a review of literature by Miller and Willging (2003). Although operational definitions are defined for each category (Burklow et al., 1998) not all aetiologies contributing to dysphagia have been acknowledged, for example, gastro-oesophageal reflux.

Manikam and Perman (2000) reported that dysphagia can be caused by a number of factors including medical, nutritional, behavioural, psychological and environmental conditions. Although this classification includes the influence of environmental factors, not otherwise taken into consideration, it fails to encompass all of the conditions that may result in dysphagia such as anatomical or genetic conditions.

The classification proposed by Arvedson and Brodsky (2002, p. 5) included dysphagia as a result of neurological (e.g. CP, brain injury), anatomical and structural (e.g. cleft palate, tracheo-oesophageal fistula), genetic (e.g. Down syndrome), secondary to systemic illness (e.g. respiratory or gastrointestinal conditions), psychological or behavioural (e.g. lack of oral intake), and secondary to resolved medical condition (e.g. iatrogenic). Although this classification system

does not take into consideration the environmental aspects that may result in feeding difficulties, it appears to include many of the aetiological conditions.

Bernard-Bonnin (2006) reported that paediatric feeding should be classified according to three domains namely structural abnormalities, neurodevelopmental disabilities and/or behavioural feeding conditions. Dysphagia as a result of medical conditions is classified as a behavioural based feeding condition. This classification system is somewhat limited as well as confusing and reinforces the need to create operational definitions and the need for a universally agreed upon classification system.

Recently, it has been proposed that feeding disorders should be classified in line with the International Classification System of Functioning, Disability, and Health (ICF) (Lefton-Greif & Arvedson, 2007; Miller 2009). As the ICF has established definitions and acknowledges all facets of the infants' life, it may provide a holistic, comprehensive outlook on dysphagia (Threats, 2007). However, although the ICF may be beneficial in clinical settings, it describes the specific factors associated with each infant and therefore makes comparisons and classification of broad aetiologies such as anatomical and secondary to systemic illness, problematic.

Other classifications are related to the stage of the swallow affected (Calis et al., 2008; Schwartz, 2003). This classification is primarily focused on swallowing and does not account for any feeding difficulties related to social or psychological factors.

From this overview it can be seen that there are many varied classification systems that attempt to account for all of the aetiological factors. However, at present there is no one classification system that encompasses or adequately describes the complex nature of paediatric dysphagia. It is felt that a more comprehensive classification system acknowledging the time of presentation of the underlying cause; the biological system involved and the progression of the aetiology may be helpful in classifying paediatric dysphagia.

1.9 Health Professionals Involved in Dysphagia

As mentioned earlier the primary health professional involved in the assessment and management of paediatric dysphagia is a speech-language therapist (Arvedson, 2008; Putnis, 2008). A paediatrician is typically involved for those infants with medically based conditions and conducts the physical examinations and other investigations that are deemed appropriate (Lefton-Greif & Arvedson, 1997). However, the exact team members involved in the assessment and management of feeding problems is dependent not only on the infant's needs but also the staffing of the facilities where the infants are being managed (Lefton-Greif & Arvedson, 1997). Other health professionals that are typically involved in the management of infants with dysphagia include nurses, dieticians and specialist physicians and surgeons (Arvedson, 2008; Arvedson & Brodsky, 2002, p. 8; Lefton-Grief & Arvedson, 1997). Internationally, occupational and physical therapists are also associated with dysphagia (American Speech and Hearing Association (ASHA), n.d.). However, within South Africa, dysphagia does not currently fall within the scope of practice of these two professions (Health Professions Council of South Africa (HPCSA), n.d.(a); HPCSA, n.d.(b)). However, VitalStim (Freed, Freed, Chatburn, & Christian 2001), an

electro-stimulation based procedure for the management of dysphagia has been training both speech-language therapists and physiotherapists in South Africa in this method. At present the training is only offered to physiotherapists and speech-language therapists. An extensive review of the literature and the professional bodies of physiotherapy and speech therapy South Africa was conducted and it appeared that currently there are no policies or protocols with regards to scope of practice and the use of VitalStim by physiotherapists within South Africa. In addition, at present there is no conclusive evidence based research indicating the efficacy of VitalStim in treating dysphagia.

The key element of the feeding team however is the inclusion of the caregivers and family members of the infants with dysphagia (Lefton-Greif & Arvedson, 1997). The family should be involved in all aspects of the decision making process both in terms of assessment and intervention.

Within African countries a need has risen for additional specialist services due to the increased number of children affected by life-threatening illnesses such as HIV/AIDS (Liben, Papadotou & Wolfe, 2008). Therefore, specialist paediatric palliative care teams have been developed to assist in maintaining quality of life for patients and families affected by life-threatening illnesses as well as providing relief from pain and other difficulties faced by the children or their families (Harding, Karus, Easterbrook, Raveis, Higginson & Marconi, 2005). A study conducted in Malawi, determined that children with HIV/AIDS had social problems not typically experienced by children facing other life-threatening diseases and therefore paediatric palliative care provided not only the medical and pain support needed but social and familial

support (Lavy, 2007). Due to the high prevalence of HIV/AIDS, respiratory complications and other life-threatening illnesses associated with paediatric dysphagia it begs the question as to whether paediatric palliative care may be able to assist in the management of infants with dysphagia and lessen the load on other health professionals involved.

1.10 Dysphagia Intervention

A number of management options are available in the realm of paediatric dysphagia. The management options are specific to the type of dysphagia, underlying aetiology and the individual needs of the family and child (Manikam & Perman, 2000). The type of management required for each infant should be decided on by the multi-disciplinary team involved in dysphagia as well as the family (Arvedson & Brodsky, 2002, p. 5). The management options available will be discussed below.

1.10.1 Food and Utensil Modification

In many cases, an infant's dysphagia can be resolved or improved by modifying the presentation of the food they eat. The most common modification is with regards to consistencies. This is typically seen in infants presenting with GOR (Carroll, Garrison & Christakis, 2002; Nel, 2007; Wenzl, Schneider, Scheele, Silny, Heimann & Skopnik, 2003). Thickening of feeds is considered to be first line intervention for GOR in conjunction with positioning and family counselling (Saedon, Gourgiotis & Germanos, 2007). Thickening feeds was determined to both reduce the number of episodes of GOR as well as the volume regurgitated (Carroll et al., 2002; Vandenplas, Salvatore & Hauser, 2005). However, this method

is controversial as it does not eliminate the GOR, it only makes the symptoms less overt. Therefore, the damage to the pharynx and oesophagus as a result of the stomach acid continues and the infant is still at risk for developing respiratory complications (Vandenplas et al., 2003). Furthermore, the thickened feeds may mask the symptoms of GOR complicating the diagnostic process if any additional difficulties, such as food aversion are noted (Vandenplas et al., 2003). However, in a placebo-controlled crossover study, Wenzl, et al. (2003) determined that thickening feeds is an effective, fairly safe first line treatment in the management of GOR. The responsibility of modifying food typically falls within the scope of the speech-language therapist and the dietician, whereby the dietician monitors the nutritional intake of the infant and the speech-language therapist monitors the infant's ability to tolerate the thickened feeds. It is important that the infant's feeding abilities are monitored throughout the food modification process as silent aspiration of thicker foods may still occur.

Other management options involving the modification of the food include changing the taste, temperature or size of the bolus (Hall, 2001, p. 136). An infant may have reduced oral sensory awareness of the bolus in the mouth, resulting in a delayed triggering of the neurological swallow trigger placing the infant at risk for aspiration (Siktberg & Bantz, 1999). By increasing the sensory elements of the bolus, for example, by using a cold and sour bolus, the infant's awareness of the bolus may improve resulting in a more efficient, safe swallow (Siktberg & Bantz, 1999). Modification of the utensils used to present food may assist in correcting or reducing the effects of the dysphagia. For example, if an infant has a poor sucking ability due to a cleft palate, one may use a specialised bottle whereby the caregiver squeezes the bottle

providing the negative pressure required to remove the liquid from the bottle (Arvedson & Brodsky, 2002, p. 539).

Many hospitals in South Africa adopt the Baby Friendly Hospital Initiative whereby exclusive breastfeeding and breast milk is promoted and the use of bottle feeding and pacifiers excluded (Pérez-Escamilla, 2007). This was initially proposed by the World Health Organisation (WHO) and the United Nations Children's Fund (UNICEF) in 1991 whereby a ten step program was recommended (Marais, Koornhof, du Plessis, Naude, Smit, Hertzog, Treurnicht, et al., 2010). The initiative promotes exclusive breastfeeding and no use of artificial teats or pacifiers (Marais et al., 2010). Therefore those infants that are unable to breastfeed regardless of the reason are encouraged to cup-feed expressed breast milk (Flint, New & Davies, 2008). In a review of literature on the benefits and efficacy of cup-feeding versus bottle feeding in premature infants no significant differences were found with regards to weight gain, time spent feeding and length of hospital stay (Flint et al., 2008). However, cup feeding does allow the exact monitoring of the amount of milk consumed by the infants as well as provide a more hygienic as sterilisation of bottles and teats was no longer necessary (Dowling, Meier, DiFore, Blatz & Martin, 2002; Dowling & Thanattherakul, 2001).

1.10.2 Positioning modifications

Many infants, particularly those with neurological difficulties, have difficulty swallowing due to poor postural tone, instability and poor positioning (Arvedson & Brodsky, 2002, p. 301). The ideal position of an infant for feeding is where the infant's head is in the midline position with a slightly flexed trunk and neck (Dusick, 2003). These positional changes may be achieved

by the feeder or through adaptive seating and positioning devices (Dusick, 2003). One may also alter the position not only during feeding but afterwards too. By placing an infant with GOR in a more upright feeding position, one uses the effects of gravity to promote gastric emptying, thereby reducing the risk of the acid reflux (Arvedson & Brodsky, 2002, p. 217; Nel, 2007).

1.10.3 Oral Motor Stimulation/Therapy

Oral motor therapy is provided for infants with predominantly oral-phase feeding problems. This intervention may require the caregiver to provide jaw-support to reduce spillage of the liquids or facilitate more effective graded chewing (Siktberg & Bantz, 1999). Other aspects or oral-motor therapy may include intervention outside of feeding time, such as providing oral stimulation with a finger or pacifier to improve the strength of the infant's suck needed during feeding (Arvedson & Brodsky, 2002, p. 423). For those infants that have a poor suck-swallow breathe synchrony or respiration difficulties, external pacing of the feed by the care-giver may allow the infant to feed safely and effective (Hall, 2001, p. 128). At present there is a dearth in literature into the efficacy of oral-motor stimulation in infants and also with regards to whether or not the stimulation programs are being complied with post-hospital discharge.

Research, has shown that providing infants with non-nutritive sucking experiences, such as with a pacifier, showed a decrease in the time needed for non-oral feeds and decreased hospital stay compared to those infants that were not provided with non-nutritive sucking opportunities (Gisel, 2008; Mason, Harris & Blissett, 2005; Pinelli & Symington, 2005). A review of research (Pinelli & Symington, 2005) into the effects of non-nutritive sucking on weight gain reflected varied results. Many of the studies reviewed found no difference in weight

gain between those infants provided with non-nutritive sucking opportunities compared to those without (Pinelli & Symington, 2005). Only one study, conducted by Bernbaum, Pereira, Watkins and Peckham (1983) indicated that non-nutritive sucking increased weight gain although this study had a small sample size (N=30) and is twenty-seven years old and therefore may no longer be relevant.

1.10. 4 Medical and Surgical Intervention

In some instances the underlying aetiology of the dysphagia is a medical or anatomical one, requiring medical and/or surgical intervention for example, GOR or a cleft lip/palate (Arvedson & Brodsky, 2002, p. 533). Once the child has received medication or the surgical procedure conducted, this may resolve the underlying condition and subsequently allow the child to feed successfully. Examples of these surgeries include cleft lip and palate repair, nissen fundoplicatoin and dilatation of the oesophagus. Particularly in these instances, the collaboration of multiple professionals is a necessity.

1.10.5 Alternative Feeding

When the dysphagia is severe, and other intervention options have been unsuccessfully implemented, alternative feeding options may need to be considered. In some cases alternative feeding is the primary intervention particularly if the child is respiratory compromised or too ill for treatment (Mason et al., 2005). The most common short-term alternative feeding option is the use of a naso-gastric (NG) feeding tube (Prasse & Kikano, 2009; Rommel et al., 2003). The duration of the use of a naso- or oro-gastric feeding tube should be considered as infants experiencing long term use of a feeding tube may display oral hypersensitivity, predisposition to

GOR, vomiting and inflammation of the oesophagus and subsequent refusal to transition to oral feeding (Mason et al., 2005). It has been suggested that in infants requiring non-oral feeding for a period of six weeks (42 days) or longer, the insertion of a permanent feeding tube should be considered (Gisel, 2008). For these infants where the chance of the dysphagia resolving in less then six weeks is slim, a permanent gastrostomy tube is typically inserted (Manikam & Perman, 2000). The most frequently inserted gastrostomy tube is a percutaneous endoscopic gastrostomy (PEG) tube (Munro, 2003).

The effects of the insertion of alternative feeding tubes need to be considered not only with respect to the infant but also to the family and their cultural beliefs (Craig & Scambler, 2006). As feeding is a social aspect that is entrenched in culture, society and mother-infant relationships, an inability to perform the task of feeding one's child may lead to depression, increased stress and anxiety on the part of the caregiver (Craig & Scambler, 2006; Hewetson & Singh, 2009). The insertion of tubes for feeding may surface feelings of inadequacy of the caregiver and associated stigma from the community not being able to provide her child with the most basic form of life (Craig & Scambler, 2006). Therefore, it is pertinent that all health professionals be mindful and empathetic to caregivers of children with feeding tubes and that the family be considered in the decision making process.

All of the intervention options discussed above are to ensure that the infant has the ability to swallow safely with minimal risk of aspiration or to provide adequate nutrition in the presence of an inadequate swallowing mechanism. The intervention should be tailored to suit each infant's

specific needs and include all health professionals involved in the management as well as the infants family.

1.11 Policies and Protocols for Paediatric Dysphagia in South Africa

Due to the complex nature of paediatric dysphagia and the multiple aetiological and intervention options, there is a need for a universal protocol with regards to the assessment and management of dysphagia. Within South Africa, the unpublished Gauteng Provincial Paediatric Dysphagia guideline (Gauteng Paediatric Dysphagia Workgroup, 2007) was developed. This protocol discusses the role of the speech-language therapist in dysphagia as well as provides guidelines for the assessment and management of paediatric dysphagia. The document was compiled from current literature and was designed by therapists for therapists working in the field of paediatric dysphagia (Gauteng Paediatric Dysphagia Workgroup, 2007). The extent to which this protocol has been implemented has not yet been researched. As a result of this, there is a need for an evidence based protocol to highlight the management of paediatric dysphagia in the South African health context. This protocol should highlight the responsibilities of staff and services provided at the three levels of care within the state health system as well as those working in the private sector. In line with the PHC approach (Department of Health, 2000) the protocol should include the responsibilities of the health professionals at a district and regional level in order to address the communicable diseases, improve prenatal and birth practices to reduce the risk of paediatric dysphagia and subsequently the burden of care on the tertiary levels of care.

A concern with regards to practices followed within the South African context is that the protocols and policies are based on international, first world practice where staff and resources are typically available. As discussed, this is not the case in many of the medical facilities in South Africa and therefore these protocols may not be applicable and appropriate. Therefore, there is a need or further research into the implementation and efficacy of such a guideline. This will assist in policy making within the South African Health system that is aligned paediatric dysphagia assessment and management internationally.

1.12 Conclusion

From this review it can be seen that paediatric dysphagia is an condition with multiple negative growth, health, nutrition, hydration and developmental correlates. However, the majority of research conducted into paediatric dysphagia has focused on developed countries and is related to either the phase of swallowing or specific conditions that may result in feeding impairments. There is limited research into the paediatric dysphagic population as a whole.

In addition, there is a dearth of research into paediatric dysphagia. As discussed there are many social factors, health correlates and diseases that are prevalent in developing countries and have described negative consequences in terms of growth, health and development. However, the profile of paediatric dysphagia in developing countries has not been fully explored. This research therefore aims to provide insight into the dysphagia experienced by infants in developing countries and whether this differs to that of developed countries. In order to provide a

comprehensive profile of paediatric dysphagia this research therefore aims to determined the aetiology and nature of dysphagia in infants in state hospitals.

Furthermore, as presented above, research provides information into the assessment procedures, health professionals and management strategies recommended for infants with dysphagia. This literature again is in reference to developed countries and little information into the practice of dysphagia in terms of assessment and intervention in developed countries is available. Therefore, this research aims to provide an overview of the state hospitals' practice of paediatric dysphagia and whether this is similar to that described in literature.

This research therefore aims to provide insight into paediatric dysphagia with regards to the nature, aetiology, health professionals involved and management strategies implemented in state hospitals, Johannesburg, Gauteng, South Africa.

CHAPTER TWO

METHODOLOGY

Chapter two outlines the methodology of this research including the aims and objectives of the study. It provides an overview of the research design and population sample as well as descriptions of the hospitals employed in this research. Chapter two further delineates the data procedures and forms a basis from which the results (Chapter three) were derived.

2.1 Aims and Objectives

This research aimed to describe the aetiology, nature and management of dysphagia in infants[1] below the age of 18 months at three Government hospitals in the Gauteng Province, South Africa.

The following objectives were implemented to assist in obtaining the above-mentioned aim:

- To determine the nature of dysphagia present
- To determine which aetiologies may contribute to feeding difficulties
- To determine the caregiver's primary complaint with regard to the infant's feeding difficulties
- To determine the health professionals involved in the assessment and management of infants with feeding difficulties
- To describe the intervention strategies employed to manage paediatric dysphagia

Infants[1]: in the context of this research infant refers to the infant's file and not the specific infant his/herself.

The null and alternate hypotheses for this research are as follows:

Null hypothesis (H_0): The profile of paediatric dysphagia in South Africa is consistent with what is reported internationally.

Alternate hypothesis (H_1): The profile of paediatric dysphagia in South Africa differs to that in other countries.

2.2 Research Design

A retrospective record review as described by Gearing, Mian, Barber and Ickowicz (2006) was employed for this research. This research design allowed for the description of the phenomenon (Terre Blanche, Durrheim & Painter, 2006); namely the nature and aetiologies of feeding difficulties present in infants below the age of 18 months at three Gauteng Government Hospitals. Information related to the infants' feeding difficulties was obtained from medical records from 263 infants attending three state hospitals in Johannesburg, Gauteng. The medical records of the infants were obtained from the radiology and speech therapy departments at each of the hospitals. A retrospective design was chosen to minimise the impact of the research on vulnerable caregivers and children. A cross-sectional design (Babbie & Mouton, 2001, p. 92) could have been employed for this research. This would have however required the active participation of caregivers and infants (Babbie & Mouton, 2001, p. 92). Caregivers of infants with feeding difficulties are typically vulnerable due to their infant's poor health. It was felt that conducting research on such a vulnerable population would have been invasive and provided more stress on the part of the caregiver than necessary. A retrospective research design ensured that the researcher was unbiased to the research process as the researcher was not employed at

any of the hospitals and therefore did not conduct the assessments or provide intervention for any of the infants' whose records were included in the research.

Retrospective research allows for the analysis of easily accessible data that is inexpensive and potentially provides a hypothesis that may then be tested through prospective studies (Gearing et al., 2006). However, there are some disadvantages to employing a retrospective record review. Medical records are not typically created for research purposes and therefore one has to rely on the accuracy of the health professionals reporting (Gearing et al., 2006; Jansen, van Aalst-Cohen, Hutten, Büller, Kastelein & Prins, 2005). Furthermore, medical records may have missing information that is unrecoverable and may contain jargon that is specific to that health professional or environment, thus making analysis and comparisons between records difficult (Gearing et al., 2006). However, in the event of a vulnerable population, such as infants with dysphagia, a retrospective record review allows the description of a sample population of infants with dysphagia that may otherwise not have been described (Gearing et al., 2006).

2.3 Hospitals included in this research

The three Gauteng Government Hospitals selected for this study included tertiary hospitals namely Chris Hani Baragwanath (CHBH), and Charlotte Maxeke Johannesburg Academic (CMJAH) Hospitals and a regional level hospital, Rahima Moosa Mother and Child Hospital (RMMCH). These three hospitals were selected as they service a large proportion of Johannesburg's residents. The patients attending these hospitals are from various areas within Johannesburg and therefore this assisted in establishing a demographically representative

sample. The three hospitals were approached for permission to conduct the study, whereby an information letter (Appendix A) detailing the nature of the research as well as a consent form (Appendix B) was sent to the Chief Executive Officer as well as the heads of the radiology and speech therapy departments within the hospitals. Permission to conduct the research at the three hospitals was obtained and the signed consent forms are attached as Appendix C to K. Permission from the University of the Witwatersrand Ethics Committee was then applied for and obtained, clearance certificate M091041 (Appendix L).

2.4 Hospital Records

The records selected for this study pertain to infants below the age of 18 months who presented with feeding difficulties at the three Gauteng Government Hospitals mentioned above.

2.4.1 Inclusion Criteria.

The following criteria were required for the records of paediatric patients with feeding difficulties to be reviewed:

- Only records of infants below the age of 18 months were included in the research. The age of 18 months was chosen as the maximum age as between birth and 18 months a number of critical periods have been proposed (Arvedson & Brodsky, 2002, p. 69; Clark & Laing, 1990; Northstone et al., 2001). It is suggested that if children are not exposed to new feeding skills such as soft foods (6-7 months) or chewable foods (9-12 months), they may experience adverse reactions to the introduction or not acquire the feeding skill at all (Arvedson & Brodsky, 2002, p. 69; Clark & Laing, 1990; Northstone et al., 2001).

- The infant must have undergone a videofluoroscopic as well as a subjective evaluation at the Chris Hani Baragwanath, Rahima Moosa Mother and Child or Charlotte Maxeke Johannesburg Academic Hospitals. The videofluoroscopic evaluation was selected as the objective measure of assessment as it is currently the gold standard for the assessment on paediatric dysphagia and is available at the three selected hospitals (Arvedson, 2008; De Matteo et al., 2005; Hiorns & Ryan, 2006; Zammit-Maempel et al., 2007).
- The videofluoroscopic evaluation should have been conducted in the period following January 2005. This five year period has been selected in order for the study to be relevant and current.
- In order for a record to be included in this research and analysed information pertaining to the nature and aetiology of dysphagia had to be present. If the results has missing information with regards to the health professionals involved, the caregivers' primary complaint and the management provided the records were still included in the research and analysis process. As the aim of this study was to determine the nature and aetiology of paediatric dysphagia it was felt that the information pertaining to the objectives was not vital.

2.5 Sample Size and Strategy

Three hundred records were initially selected as the sample size for this study. In order to obtain three hundred records, the files of one hundred infants were attempted to be obtained from each hospital. According to Terre Blanche et al. (2006) an ideal sample size is calculated as 1% of a moderately large population. According to Statistics South Africa (2001), in the

Johannesburg central municipality there are 116104 infants below the age of 2 years. The prevalence of feeding difficulties is 25-40% in normally developing children (Arvedson, 2008). Due to the lack of research into the prevalence of paediatric dysphagia the conservative estimate of 25% was employed during the calculation process for the calculation of an ideal sample size for this particular research. Therefore, 29026 infants in the Johannesburg Central Municipality should theoretically have some type of feeding difficulty and is the population for this research. The sample size was therefore calculated at 1% of this figure with a resultant sample size calculated at 290 infants. For ease of research and statistical analysis this figure was rounded up and 300 records were therefore determined to be the optimal sample size for this research. The records between 31 October 2004 and 31 October 2009 were considered for analysis during this research. The researcher obtained the records in a reverse fashion starting with those closest to 31 October 2009 and worked backwards until either one hundred records were obtained from each hospital or if the records exceeded past the five year period. This number was divided between each hospital and therefore 100 records from each hospital were attempted to be collected.

Difficulties were faced with regards to the collection of 300 records. These were attributed to missing files, destroyed records and in some cases missing data. The missing data pertained either to the nature or the aetiological factors affecting the infant. This information was considered paramount to this research and constituted one of the criterion for inclusion. Therefore, files without this specific information were excluded from this study. The specific details pertaining to the records collected from each hospital have been outlined in section

The records used in this study were recruited through purposive sampling. This sampling procedure allowed the researcher to recruit the records that suited the research topic and met the inclusion criteria (Babbie & Mouton, 2001, p. 166). The videofluoroscopic evaluation records were obtained from either the radiology or speech therapy departments at the relevant hospitals depending on the filing system at each hospital. In order to decrease the possibility of trends in the type of dysphagia present, initially every third record was analysed. However, it was determined that if every third record was analysed the researcher would not be able to obtain 100 records within the allotted time frame and therefore the record of every second infant having undergone a videofluoroscopic evaluation was reviewed.

2.6 Data Collection Tools

The pilot data collection tool (Appendix M) was created by the researcher and divided into a number of sections that correlated with the aims of this study. The sections included patient demographics, nature of dysphagia, aetiology of dysphagia, caregiver's primary complaint, health professionals involved and management strategies employed. The nature of dysphagia was classified in terms of phase of swallowing impaired therefore either oral, pharyngeal or oesophageal phase. If present in the file, the phase of swallowing impaired was recorded as indicated by the file. In many cases the clinical presentation of the feeding, for example, spillage of liquids, was recorded and therefore the researcher recorded the symptom as well as the phase of swallowing impaired.

In terms of the aetiological factors affecting the infant's feeding a classification system as described by Arvedson and Brodsky (2002, p. 5) was employed. Therefore the aetiological

factors were classified as neurological, anatomical and structural, genetic, secondary to systemic illness and psychological or behavioural (Arvedson & Brodsky, 2002, p. 5). This classification system was selected as it appeared to encompass the most factors that may influence feeding including dysphagia secondary to systemic illness regardless of the system which was not present in any of the other classification systems.

The caregivers' complaints were recorded according to common signs and symptoms of feeding difficulties as highlighted by Prasse and Kikano (2009). The health professionals involved in the research included those that are typically involved in dysphagia as well as those involved in the VFSS (Arvedson & Brodsky, 2002, p. 7). In addition to these elements, broad management strategies (Prasse & Kikano, 2009) that are typically employed in infants with dysphagia were included in the data collection tool.

All of these were incorporated in order to provide a comprehensive overview of paediatric dysphagia in infants within South Africa. Once ethical clearance has been obtained (Appendix L) the pilot study was conducted in order to determine the efficacy of this data collection tool.

2.7 Pilot Study

Once ethical clearance had been obtained from the respective hospitals as well as the University of the Witwatersrand Medical Ethics Committee, a pilot study was conducted by the researcher on 5% of the intended sample population. Thus, fifteen records of infants having

undergone videofluoroscopic evaluation (five from each hospital) were obtained for the pilot study. The pilot study data has not been included in the study. Once the fifteen records' had been collected and input into the data collection form; the pilot data collection form (Appendix M) was revised to ensure improved ease of data collection and accuracy of recording of required information. No changes were made to the data collection procedure however a number of changes were made to the pilot data collection form (Appendix M). The changes made to the form are outlined below:

- Participant demographics: The gender of the infants was included
- Type of dysphagia: the type of dysphagia was narrowed. Initially the data collection form included the oral, pharyngeal and oesophageal phases of swallowing as well as all of the aspects of these phases that may be disordered. Following the pilot study the type of dysphagia was condensed into only the oral, pharyngeal and oesophageal phases with a salient feature of the dysphagia identified as opposed to outlining all the possible dysphagia consequences. This information was condensed in order to provide an overview of the dysphagia and for ease of recording as many of the files from CMJAH and RMMCH did not have specific details pertaining to each aspect of swallowing that may be impaired. The presence or absence of aspiration was also included in this section. The specific aspects of disordered swallowing were then delineated to ensure consistency during the data collection process (Appendix N).
- Aetiology of dysphagia: the description of the aetiology was grouped into one section as opposed to specifying the aetiologies for each classification. The classification "other" was also included in the data collection form.

- Care-giver's primary complaint: it was identified in the pilot study that many caregivers cited breathing difficulties as a primary complaint. Therefore this category was included in the form as well as providing a description when "other complaints" were identified
- Health professionals involved: a column whereby a description of the other professionals involved could be recorded was included
- Management: the section, "alternative feeding" was delineated into naso-gastric (NG) tube, percutaneous endoscopic gastrostomy (PEG) and total parental nutrition (TPN) as well as the duration of these alternative feeding options. A description of other management strategies employed was also included in the data collection form.
- An additional section related to the records available for each infant was also included for ease of data recording and analysis.

Once the changes had been made to the pilot data collection form, the final data collection form (Appendix O) was created and utilised during the data collection process.

2.8 Ethical Considerations

2.8.1 Autonomy

All of the CEOs and heads of radiology and speech therapy departments at the three respective hospitals were provided with the information letter detailing the research and the involvement of the hospital in the research process. They were encouraged to ask questions to ensure that clarification was ensured prior to consent. The hospitals were also given the option to

decline involvement if they did not wish to participate. The CEO, head of radiology and head of speech therapy at all three hospitals signed the consent forms provided (Appendices C to K).

2.8.2 Confidentiality

Confidentiality was considered at every stage of the research. The infants' identifiable data including their name, date of birth and hospital number, was recorded for data collection purposes and then destroyed immediately once the infants' records had been obtained. This identifying information was not recorded with the data collected and was kept separately during the research process. To further ensure anonymity a coding system related to the respective hospitals was implemented to protect the identities of the infants whose records were analysed. During the research process all written data collected remained in a locked cupboard at the researcher's residence. During the inter-rater reliability process the research assistant signed a confidentiality agreement (Appendix P) prior to her reliability data collection to ensure that the inter-rater did not divulge any of the infants' information.

2.8.3 Non-maleficence and Beneficence

As neither the infants, nor their families actively took part in any element of the research process no physical harm came to the infants or their families. The researcher had access to the medical records and therefore confidential information. As a result of this there was always a risk of a breach in confidentiality. However, as detailed above, the researcher implemented a number of strategies to minimise this risk. It is subsequently felt that there was no breach of confidentiality during the research process and therefore non-maleficence and beneficence were upheld. As the videofluoroscopic evaluation contains radiation and may be considered harmful to

the infant, informed consent had to be obtained by the hospital from the infant's caregiver prior to the evaluation being conducted.

2.9 Reliability and Validity

Reliability is concerned with the replicability of a study, implying that a study conducted repeatedly would yield the same results (Babbie & Mouton, 2001, p. 119). The reliability of a study may be affected by a number of factors including whether if conducted repeatedly, the study would result in similar findings, this is known as the test-retest method (Johnson & Christensen, 2012, p. 138). This determines whether if placed under the same circumstances another researcher may obtain the same results. In order to address this issue of researcher bias, a second rater (researcher) was employed to verify 10% of the data captured; therefore 30 records were verified by the rater. At the time of the reliability measures, the rater was a final year Speech Pathology and Audiology student at the University of the Witwatersrand. The rater collected the data in the same manner as the researcher without knowledge of the initial diagnoses or findings. This was to ensure that the assistant researcher was not biased to the results. This allowed for an accurate and unbiased analysis of the data collected by the researcher and the assistant to ensure that there was no inter-rater bias and that the methodology was replicable. The records to be verified were selected randomly to reduce the effect of researcher bias. The two transcripts were subsequently analysed by the researcher using a Phi correlation. Correlations for all of the data collection subsections were calculated. An average correlation co-efficient of 0.7 with $p<0.05$, was calculated. This indicates a high correlation with a significant relationship and the data collection process was therefore deemed as having a high level of inter-

rater reliability (Tredoux & Durrheim, 2002, p. 184). The rater received remuneration for her time and travelling expenses as stipulated by the University of the Witwatersrand's guidelines of paying research assistants.

Reliability was further ensured by the researcher sampling three separate hospitals within the Gauteng area. This ensured that the results were representative of the paediatric population throughout Gauteng and not only limited to one hospital and area in Gauteng. Even though the tertiary and regional hospitals included in this research cater to different needs of the community, the objective of this research was to profile paediatric dysphagia in Gauteng. Therefore, reliability in terms of the sample population was ensured. Therefore the results can be deemed reliable as the population of infants with dysphagia analysed in this study is varied.

Validity is concerned with whether the research process is actually investigating the phenomenon in question (Babbie & Mouton, 2001, p. 122). One specific type of validity, construct validity, is concerned with whether the measures employed by the researcher to investigate the phenomenon effectively encompassed all of the areas under investigation (Babbie & Mouton, 2001, p. 123). For example, whether the data capture form (Appendix O) employed by the researcher was able to assess all areas necessary to fulfil the aims of the study. This was determined through the pilot study. Once the data collection form had been modified it was determined that the tool had a high level of construct validity as it was able to accurately retrieve all of the information required from the files for the purposes of this research. Validity was further ensured as the researcher reviewed not only the infants' hospital files but when available, pertinent records from the speech therapy and radiology departments too.

2.10 Research and Data Collection Schedule

The following timeline delineates the research project;

August 2009: The information and consent forms (Appendix A and B) were submitted to the CEO, radiology and speech therapy departments at the three hospitals.

October 2009: The research proposal was submitted to the University of the Witwatersrand Medical Ethics Committee and the Faculty of Humanities Higher Degrees Committee for approval.

October 2009: The research was approved by the University of the Witwatersrand Faculty of Humanities Higher Degrees Committee

November 2009: The research was approved by the University of the Witwatersrand Medical Ethics Committee

February 2010: The pilot study was conducted at the three hospitals included in the study.

April to July 2010: The data collection process commenced at the three hospitals. During this period the research assistant was employed to conduct the inter-rater reliability procedures.

August 2010: The data analysis procedure began.

January 2011: Statistical analysis of data commenced.

February to April 2011: The final research document was written.

April 2011: The final Masters document was submitted.

2.11 Recording and Management of Data

The information obtained from the medical records of each infant was captured on an electronic version of the data collection form (Appendix O). All of the data was captured electronically on the researcher's personal computer at each hospital respectively. The data was saved to a password protected file on the researcher's computer as well as a password protected external USB disc after every entry to ensure that there was a duplicate copy of the data throughout the research process. At the end of every day the data was transferred to a second password protected USB disc. This ensured that data was not lost at any stage during the research process. During the inter-rater reliability procedures, the research assistant employed the same recording and data management procedures.

2.12 Data Analysis

The data has been analysed using quantitative measures. Descriptive statistics including percentages and measures of central tendency (Howell, 2004, p. 60) were employed to quantify the prevalence of various aetiological factors related to feeding difficulties in this sample. Histograms and percentage calculations were employed to describe the professionals involved and the management provided. This allowed for comparisons between the hospital samples.

Statistical analyses in the form of phi correlations and logistical regressions were employed to further analyse and determine the significance of these results. Phi (φ) correlations were employed to analyse the correlations between dichotomous categorical variables and are a

variation on Pearson's *r* correlation (Howell, 2004, p. 190). A phi correlation determines the relationship between variables but does not consider the relationship of those variables on the other variables. An alternate statistical analysis that may have been employed was that of chi-square (Gravetter & Wallnau, 2007, p. 602). However, chi-square only calculates whether or not a relationship exists between variables but not the significance of this relationship. A phi correlation determines whether or not a relationship exists as well as the significance of that relationship. The interpretation of the phi coefficients are as follows:

0.0-0.3: weak association

0.3-0.7: moderate association

0.7-1.0: strong association

(Tredoux & Durrheim, 2002, p.184).

These coefficients may be positive or negative based on the relationship between the variables.

The second statistical measures employed for the analysis is logistical regression, a predictive model where the target variable is dichotomous (Azen & Walker, 2011, p. 181). The differences between a logistical and linear regression is that a logistical regression has absolute, dichotomous values, such as present (1) or absent (0) whereas there is no limit on values predicted by a linear regression (Azen & Walker, 2011, p. 181). Logistic regression considers the relationship between the variables and which dependent variable is the most predictive.

2.13 Description of Settings

2.13.1 Chris Hani Baragwanath Hospital

Chris Hani Baragwanath Hospital (CHBH), the largest acute hospital in the world contains 2964 beds and serves approximately 3.5 million people in the Soweto, South-West area in Gauteng (Chris Hani Baragwanath Hospital, n.d.). Although CHBH serves a specific region within Gauteng patients come from all over South Africa as well as neighbouring countries to receive specialised care. The data collection procedure at CHBH began at the speech therapy department where all of the videofluoroscopy records are kept. Once potential files had been identified from these videofluoroscopy records, information pertaining to the relevant hospital numbers and dates of birth were obtained. The VFSS records also provided information pertaining to the age of the infant at the time of VFSS, aetiology as well as information regarding the nature of the infant's dysphagia. The staff at the speech therapy and radiology departments utilise a specific VFSS form which was created by the staff of both departments respectively. An example of this form has been included as Appendix Q. Once the relevant hospital numbers had been identified, the hospital records data base was utilised to draw the infants' files. CHBH keeps the records only of those participants that were admitted to hospital as those that attend out-patient clinics take their records with them when they leave. Infants that were born at CHBH they are initially given their mother's hospital number for administration and then subsequently given a number of their own. For many of the files this new number was not linked to the mother's file and therefore these in-patient hospital files could not be located. Of the infants identified (N=100) only 44 hospital, in-patient files could be located. These files were retrieved from the filing department whereby the staff retrieved and returned the files to minimise loss of

files and incorrect filing. The researcher collected the data within the filing department and none of the files were removed from the department.

Once the records department verified that the remainder of the files were not accessible, the speech therapy department's out and in-patient records were analysed. Although a speech-language therapist and radiologist are present at every VFSS not all of the infants' undergoing the assessment are followed up at the speech therapy department as some of the infants' dysphagia did not require therapeutic services and were treated through medical and surgical interventions alone. As a result of this only 38 speech therapy records pertaining to the files identified were allocated. Therefore, out of the participants that were identified (N=100), 39 files had no other record apart from the VFSS record held at the speech therapy department.

2.13.2 Charlotte Maxeke Johannesburg Academic Hospital

Charlotte Maxeke Johannesburg Academic Hospital (CMJAH) a tertiary state hospital in central Johannesburg contains 1088 beds and serves a large number of patients from within Johannesburg as well as surrounding cities and provinces within South Africa and neighbouring countries (Johannesburg Hospital, n.d.). The data collection procedure at CMJAH began at the gastro-radiology department. The record book containing the dates pertaining to the VFSS conducted had been displaced and therefore the researcher obtained the information for potential infant records from the VFSS reports kept in a box in gastro-radiology. The hospital uses a standard x-ray form to record the results for the VFSS, an example of this x-ray form is included as Appendix R. Every second record that met the inclusion criteria, as per the data collection procedure was obtained and analysed. The researcher was able to obtain the information of 100

records between 31 October 2004 and 31 October 2009 that met the inclusion criteria. Once the relevant hospital numbers and dates of birth were obtained the hospital files were retrieved from the filing department. The researcher was shown how to draw the files and return them in the correct place. The researcher collected the data required from the files in the filing department and the files therefore did not leave the department.

The records of all patients attending CMJAH regardless of whether they are in- or out-patients are stored at the filing department. Eight of the records were excluded from the study as they did not have information pertaining to the infants' nature and/or aetiology of dysphagia. Therefore, 92 records were identified and analysed from CMJAH. The radiologists and radiographers at CMJAH indicated that multiple terminologies were used in the hospital with regards to VFSS including video swallow, hexabrix swallow, hexabrix video swallow, gastrograffin swallow or modified barium swallow. Therefore all records pertaining to these procedures were considered for inclusion in the research.

The HOD of the speech therapy department at CMJAH informed the researcher that the speech therapy records were contained in the hospital files. Therefore, information from the speech therapy records, as found in the hospital file was included in the data collection process. It was determined that of the 92 records analysed, 40 infants received speech therapy. There was no indication as to whether the VFS studies were attended by a speech-language therapist and no record of this was found at the speech therapy department.

2.13.3 Rahima Moosa Mother and Child Hospital

Rahima Moosa Mother and Child Hospital (RMMCH) is situated in the central suburbs of Johannesburg. RMMCH services 20 000-30 000 patients annually either for gynaecological, obstetric or neonatal services. The hospital services approximately 3000 infants in the four paediatric wards and 2000 infants in the six bed neonatal intensive care unit annually (Wits Paediatric Fund, n.d.). The potential infants' information was obtained from the log book in radiology between 31 October 2009 and 31 October 2004. One hundred infants were identified as meeting the inclusion criteria. The infants' hospital files were then accessed from the filing department. The filing department stores the files for both in- and out-patients attending the hospital. However, only seventy-three files were able to be accessed as it was indicated that at the time of the data collection process (June 2010) many of the files older than five years (June 2005-October 2004); as well as the files for infants that are deceased had been destroyed. One record was excluded as it did not contain information pertaining to the infant's nature of dysphagia as no VFSS report was contained in the file. The staff in the filing department retrieved and re-filed the files to ensure correct re-filing and to reduce the risk of loss of files. The files were not at any stage removed from the filing department. As with CMJAH, a standard x-ray form (Appendix R) was used to record the results from the VFSS.

The infants' medical information was contained in the hospital files and held at the main filing department. The speech therapy records were also contained in the hospital records. Of the 72 records collected for analysis, only 18 files had records indicating that they had received speech therapy. When the speech therapy department at RMMCH was contacted it was

determined that no specific filing system was employed within the department and that any infants seen by speech therapy would have duplicate notes written in the hospital file.

Therefore, from the three hospitals included in the study, 263 records were obtained and analysed. This was lower than the expected 300 record. As discussed previously, 290 records would have constituted a representative sample. RMMCH was the hospital where the least records were collected as a result of fewer VFSS conducted as well as poor record keeping procedures. Furthermore, the information received from Statistics South Africa (2001) regarding the population statistics included children up until two years of age. As there were no specific population statistics for infants between birth and 18 months of age, as those researched in this study, it was hypothesised that this figure would therefore be less, however the extent of which is unknown. Therefore it was determined that the 263 records analysed would be sufficient for this research process.

2.14 Demographics of Infants Receiving Dysphagia Intervention at the Three Sites

The infants analysed (N=263) reside in a number of areas in and around the Johannesburg area. As seen in *Figure 1* the majority of infants (n=191) reside in the central, south, east and south-western areas within Johannesburg. It was noted that only eight infants reportedly resided outside of the Johannesburg area, yet 57 had unspecified residential addresses. It should be noted that this number may not be accurate as parents that reside outside of Johannesburg may not stipulate their actual address for fear of not receiving care and/or treatment. It was noted that the infants (n=44) that attended CHBH in the south-western areas mainly resided in the south and

south-western regions and those that attended centrally located hospitals, CMJAH and RMMCH, resided predominantly in the central areas (n=62). Of the infants that were analysed in this research, 143 infants were males, 100 were females and 20 had unspecified gender in the hospital, VFSS and speech therapy records.

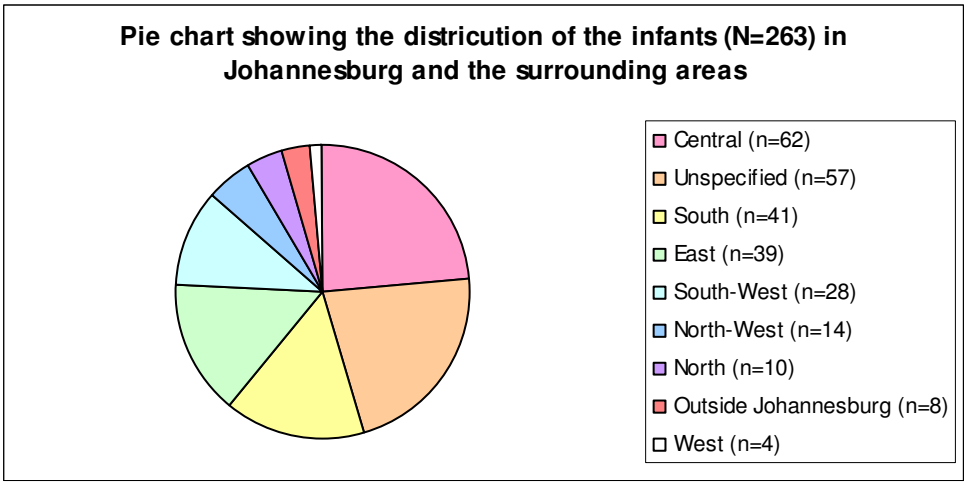


Figure 1. Areas of residence of infants attending the Chris Hani Baragwanath, Charlotte Maxeke Johannesburg Academic and Rahima Moosa Mother and Child Hospitals (N=263)

A detailed description of the infants' ages is found in *Table 1.* From the mode, the most frequently occurring age (Howell, 2004, p. 60) it can be seen that infants with feeding difficulties were identified early on in life. Thus, indicating that early detection and subsequent early intervention was provided. In contrast, some infants (n=50) were only identified after their first year of life, this constituted nineteen percent of the sample population. The infants that underwent a VFSS after their first year of life may have been due to the aetiological factors underlying the dysphagia. The mean related to the average age that infants underwent the VFSS. The mean provides a more comprehensive overview of the time of assessment indicating that

taking into account all of the ages at which the infants underwent the VFSS, on average they presented to the hospitals at six months of age.

Table 1

Age (months) at time of VFSS

Hospitals	CHBH	CMJAH	RMMCH	TOTAL
Mean	6.8	7	5.4	6.8
Mode	2	1	1	1
Range	1-18	0-18	0-18	0-18

CHAPTER THREE

RESULTS

Chapter three provides a detailed description of the results from this research. The results are presented in line with the aims and objectives of this study. Chapter three includes an overview of the results followed by a detailed analysis of aspects of the research that pertained to the specific aims of this study. The results from all three hospitals as well as for each individual aim of the study have been detailed below. Chapter three includes both descriptive and statistical representation of the results.

3.1 Overview of results

The findings of this study are discussed below in relation to the objectives of this research. The primary finding of this research is that although the type of dysphagia experienced by infants in this research was similar to that in seen in international research, the aetiological factors where significantly different. The most striking aspect noted was that the infants in this research experienced 214 different aetiological combinations which may have influenced their feeding ability. What was further noted was that the majority of the infants presented with dysphagia secondary to a systemic illness (n=175). It was determined that the primary conditions that typically afflicted the infants were communicable diseases such as pneumonia (n=89), HIV/AIDS (n=40), tuberculosis (n=22) and gastroenteritis (n=20). Furthermore, conditions such as failure to thrive (n=54) and prematurity (n=52) were prevalent in this sample. Thus, it appears that infants with paediatric dysphagia in South Africa may present with a different aetiological

basis than those in developed countries, where the primary causes of feeding impairments are neurological and gastrointestinal (Rommel et al., 2003).

3.2 Objective one: To determine the nature of dysphagia present

As outlined in *Chapter two*, the nature of dysphagia was classified as oral, pharyngeal, oesophageal phase or a combination of these phases (all phases of swallowing). The nature of dysphagia was retrieved from the VFSS results alone as the objective measure of swallowing. Clinical, subjective evaluation results were not recorded as these could not be substantiated. The VFSS forms used at CHBH delineate the dysphagia according to phases, whereby the radiologist and/or speech-language therapist ticks the presence of a disordered aspect of swallowing such as nasal regurgitation. Therefore, the nature of dysphagia from the records at CHBH was analysed according the recording methods of those conducting the VFSS. However, at CMJAH and RMMCH a standard x-ray form requiring a written summary of the findings was employed by the radiology department to record the VFSS findings. Therefore, Appendix N delineating the signs and symptoms of dysphagia in the three phases of swallowing was used to organise, analyse and subsequently determine the nature of dysphagia

Table 2

Nature of dysphagia at Chris Hani Baragwanath, Charlotte Maxeke Johannesburg Academic and Rahima Moosa Mother and Child Hospitals (N=263)

Nature of dysphagia	CHBH (n=99)	CMJAH (n=92)	RMMCH (n=72)	Total (N=263)
All phases of the swallow	16	2	1	19
Normal swallowing	14	22	21	57
Oral phase	13	1	0	14
Pharyngeal phase	8	7	1	16
Oesophageal phase	7	46	45	98
Oral and pharyngeal phase	19	3	0	22
Oral and oesophageal phase	13	1	0	14
Pharyngeal and oesophageal phase	9	10	4	23

From the results in *Table 2*, it can be seen that the nature of dysphagia experienced differed quite noticeably between the hospitals. It can be seen that 50% (n= 46) of infants at CMJAH and 63% (n=45) of infants at RMMCH experienced oesophageal phase dysphagia. However, at CHBH only 7% (n=7) of the infants experienced oesophageal phase dysphagia. This may have been attributable to the objective measures employed at the hospital. A discussion of these possibilities is found in *Chapter Four*. From *Table 2* above it appears that CMJAH and RMMCH had a fairly similar distribution of the nature of dysphagia experienced by the infants. Furthermore, it appeared that the infants that attended CHBH experienced a wider variety of dysphagia than those at the other two hospitals.

Initially RMMCH was analysed separately to CHBH and CMJAH as it is a regional level hospital and does not have the same level of experience and staffing the other two tertiary hospitals. Furthermore, RMMCH provides services to a different paediatric population that is less severe and less acute than those seen at the tertiary hospitals. Therefore, it was assumed that with regards to the nature of dysphagia, RMMCH would differ significantly in comparison to the

tertiary level hospitals. However, when a phi (φ) correlation coefficient was run it was determined that there were no significant differences between the nature of dysphagia experienced at each hospital and therefore the nature of dysphagia at the three hospitals have been presented together. When the nature of dysphagia experienced by the infants was descriptively analysed it was surprising to note that the data collected from CMJAH was more similar to that from RMMCH than CHBH, as originally expected. This was interesting as CHBH and CMJAH are both tertiary level of hospitals that typically see more complex paediatric dysphagia cases whereas RMMCH, a regional hospital, would see the less complex cases. The fact that the nature of dysphagia experienced by infants at CMJAH was more similar to those at RMMCH than CHBH may be attributed to the administration of the VFSS, staff present at the VFSS and perhaps the recording process of the VFSS conducted at these hospitals. This will be further explored in *Chapter Four*.

In comparison to CHBH and CMJAH, an analysis of the nature of dysphagia experienced by infants at RMMCH indicated that 92% of the infants experienced either oesophageal phase swallowing difficulties or normal swallow physiology. In contrast to CHBH and CMJAH, none of the infants experienced oral phase difficulties apart from one infant that experienced dysphagia in all three phases of swallowing. Furthermore, as the terminology relating to VFSS at CMJAH and RMMCH was varied (hexabrix swallow, gastrograffin swallow, oesophagram, etc) there may have been confusion with regards to the exact procedure conducted. Therefore, the procedures at these hospitals may have similar to that of a barium swallow which is traditionally employed to determined gross anatomy and the presence of GOR (Hall, 2001, p. 79). In addition the fact that a speech-language therapist is not present at every VFSS may result in a higher

number of pharyngeal phase elements not identified and only the oesophageal phase elements recorded.

What was interesting to note is that across all three hospitals 14-30% of the infants presented with normal swallowing physiology and therefore the apparent feeding impairments were not dysphagia related. This indicates that although the infants presented with dysphagia-like symptoms they had intact swallowing physiology. This indicates that the VFSS procedures conducted are sensitive to those infants with normal swallowing physiology.

Aspiration, was found to be present in 19% (n=49) of infants during the VFSS. What was interesting to note is that of the infants that presented with aspiration, 55% (n=27) attended CHBH while only 8% (n=4) underwent the VFSS at RMMCH. This may have been due to the nature in which the VFSS is conducted at RMCCH or alternatively, as the hospital is a regional level facility it may be attributable to the fact that more complex feeding cases may have been referred to one of the tertiary hospitals with specialised staff and care facilities. The records from CHBH, reflected that ten infants experienced laryngeal penetration during the VFSS. However, when the therapist responsible for these infants was contacted she indicated that she had used aspiration and penetration as interchangeable terms. Penetration during swallowing is defined as "when material enters the laryngeal area to the level of the true vocal folds," (Smith Hammond & Goldstein, 2006, p. 156S) whereas aspiration is defined "when material moves below the true vocal folds and enters the trachea," (Smith Hammond & Goldstein, 2006, p.156S).

From the results related to the nature of paediatric dysphagia at the three hospitals it was noted that oesophageal phase dysphagia was the most prevalent nature of dysphagia at CMJAH and RMMCH, although this was not the case at CHBH. The reasons for the differences between the hospitals will be fully explored in *Chapter Four*. In addition, initially it was hypothesised that there would be discrepancies between the regional and tertiary level hospitals. However, once the data was analysed it became evident that in terms of phases of swallowing affected, the infants presenting to CMJAH and RMMCH were more similar to each other than those presenting to CHBH. This was not was not was expected.

3.3 Objective 2: To determine which aetiologies may contribute to feeding difficulties

The data from the three hospitals was analysed according to both the aetiological categories that the infants that underwent VFSS presented with, as well as the specific conditions that the infants experienced. As mentioned in Chapter two, during the data collection process it was determined that there was a need for the creation of a sixth category, this was subsequently labelled "other". The conditions that did not fall into one of the specified categories were placed in "other". This will be discussed further below.

The most noticeable factor related to the aetiologies experienced by the infants with dysphagia was the number of aetiological combinations identified. Across the hospitals, 214 different aetiological combinations were identified. This comprises 81% of the infants and ranged from infants presenting with one diagnosis to those with eight diagnoses.

The data from the three hospitals were analysed according to the co-morbidities and the various aetiologies that may result in dysphagia. It was found that 67% (n=175) of the infants had aetiological factors secondary to a systemic illness. Some examples of these illnesses included pneumonia (n=89); HIV/AIDS (n=40); respiratory distress syndrome (n=27); tuberculosis (n=22); as well as gastroenteritis (n=20). The infants that were identified as being HIV/AIDS exposed in the files were not recorded as this did not indicate confirmed presence or absence of the disease.

In addition to many of the infants experiencing dysphagia secondary to systemic illness, 52% (n=136) had aetiological factors pertaining to the "other" category. Examples of these conditions included failure to thrive (n=54), prematurity (n=52), birth-weight below 2500g (n=28), gastro-oesophageal reflux disease (n=28) and nutritional impairments including kwashiorkor and marasmus (n=23). These disorders were classified in the "other" category as they did not fit into any of the categories as described by Arvedson and Brodsky (2002, p. 5).

Table 3

Aetiology of dysphagia at Chris Hani Baragwanath, Charlotte Maxeke Johannesburg Academic and Rahima Moosa Mother and Child Hospital (N=263)

Aetiology of dysphagia	Number of infants
Secondary to systemic illness and "other" aetiologies	56
Secondary to systemic illness	54
Three or more aetiological factors	41
"Other" aetiology	26
Neurological	24
Neurological and secondary to systemic illness	17
Neurological and "other" aetiologies	12
Anatomical	10
Anatomical and secondary to systemic illness	6
Anatomical and "other" aetiologies	6
Genetic and secondary to systemic illness	4
Neurological and genetic	2
Anatomical and genetic	2
Genetic	1
Neurological and anatomical	1
Psychological/behavioural and "other" aetiologies	1

From *Table 3* it can be seen that there were a number of aetiological combinations (for example secondary to systemic illness with "other") that influenced the infants' feeding difficulties. Due to these aetiological combinations it could not be discerned which of the conditions were the main contributing factor to the infants' feeding difficulty as well as whether the dysphagia was a result of the condition, or, whether the condition was a result of the dysphagia.

As the nature of dysphagia and aetiological factors are related, an analysis into the relationship between these aspects was required. Therefore the results related to the nature of dysphagia in relation to the aetiology have been presented below.

Furthermore, 30% (n=80) of the infants presented with neurological aspects of dysphagia including cerebral palsy (n=26), birth asphyxia (n=14), hydrocephalus (n=8) and HIV encephalopathy (n=8).

3.3.1 Nature of dysphagia in relation to the aetiological factors

An analysis of the data with regards to the nature and aetiology of dysphagia was conducted to determine whether a relationship exists between these two aspects. In order to analyse this relationship a logistic regression analysis was employed, that initially determined whether a relationship exists between the different phases of swallowing and the aetiological categories. The initial analysis was inconclusive as the "other" category was too large to be analysed in its entirety. Therefore, for all of the comparisons, the "other" category was delineated into the three main aetiologies that fell into this category. These aetiologies included prematurity, failure to thrive (FTT) and gastro-oesophageal reflux disease (GORD).

3.3.1.1 Oral phase dysphagia in relation to the aetiological factors

A significant relationship between oral phase dysphagia and neurological aetiology was determined ($r = 0.0004$, $p < 0.5$). Furthermore, a logistic regression determines the probability of a variable occurring based on another, implying that an infant with a neurological aetiology is 68.5% more likely to have an oral phase dysphagia, than not.

In addition, a significant relationship was found between infants with oral phase dysphagia and those with genetically-based aetiologies ($r = 0.0399$, $p < 0.05$) although the sample size for this was small (n=3). Therefore, the prediction of a relationship between a

genetically-based aetiology and oral phase dysphagia may not be exact and appropriate to another sample and population. In addition, genetically-based aetiologies are quite varied and dependent on the type of genetic aetiology therefore the features and affect on feeding may differ from disorder to disorder.

It was also determined that an infant with FTT is 1.495 times less likely to present with oral phase dysphagia ($r = 0.018$, $p < 0.05$). In addition to FTT, the analysis also reflected that infants with GORD are 4.939 times less likely to present with oral phase dysphagia.

No relationship between oral phase dysphagia and any other aetiological categories could be determined for the infants in this sample.

These results are therefore in line with literature presented internationally that infants are more likely to have oral phase dysphagia than not. This was further reinforced by the descriptive statistics where 47.8% (n=33) infants with an oral phase dysphagia component (n=69) presented with a neurological aetiology. This included all infants with oral phase dysphagia in conjunction with another swallowing phase dysfunction as well as those infants with oral dysphagia alone.

3.3.1.2 Pharyngeal phase dysphagia in relation to the aetiological factors

A logistical regression analysis determined that infants with pharyngeal phase dysphagia are 6.88 times less likely to present with GORD. In addition it was determined that 46.3% of infants with a pharyngeal phase component (n=80) presented with a respiratory based aetiology.

3.3.1.3 Oesophageal phase dysphagia in relation to aetiological factors

The logistical regression analysis reflected that infants with GORD are 61.7% times more likely to present with an oesophageal phase dysphagia (r = 0.0375, $p < 0.05$). A descriptive analysis determined that 56.3% (n=148) of infants presented with oesophageal phase dysphagia either as the only phase involved or as one of the disordered phases of swallowing. An analysis into the oesophageal phase dysphagia and aetiological factors determined that 18.2% (n=27) had an oesophageal based aetiology for example GOR or oesophageal atresia; whereas 53.4% (n=79) presented with a respiratory based aetiology for example, pneumonia or respiratory distress syndrome. However, from the data in the records it could not be determined whether the respiratory difficulties were a primary aetiology with concomitant oesophageal phase dysphagia; or whether the respiratory difficulties are perhaps due to secondary aspiration of reflux material into the airway. Aspiration during the VFSS was only evident in 16.5% (n=13) of the infants with a respiratory based aetiology and an oesophageal component to the dysphagia; however, the aspiration was only found to be present in multiple phase dysphagia and not in any of the infants with an oesophageal phase dysphagia (n=98) without the involvement of the other phases of swallowing.

From this analysis it can be seen that relationships between aetiological factors and phases of swallowing exists. However, due to the number of different aetiological combinations (n=214), an analysis of the phase of dysphagia in relation to specific conditions could not be determined as the sample size for each disorder was too small. In addition, as the infants experienced multiple aetiologies, in this context it is not possible to determine which condition was the main contributing factor to the paediatric dysphagia.

3.3.2 Dysphagia in relation to aetiologies common to developing countries

Infants born and living in developing countries, such as South Africa, are exposed to many communicable diseases that may have resultant negative health consequences for example, pneumonia, HIV/AIDS and gastrointestinal diseases (Boutayeb, 2006). It was further determined that these three diseases account for 56.3% of deaths to infants under the age of five years (Bradshaw et al., 2003). During the analysis of the data it was determined that the most prevalent disorder experienced by the infants with paediatric dysphagia was pneumonia (n=89) with 79.8% (n=71) presenting with disordered swallowing on VFSS. However, only eight of the infants presented with pneumonia as the only aetiological factor. Thus, similarly to the other aetiological combinations, in the remaining eighty-one infants with pneumonia, it could not be determined which disorder was the primary factor contributing to the paediatric dysphagia. Therefore, the pneumonia may have been either the primary factor resulting in the dysphagia, or it may have been a result of the dysphagia due to aspiration. However, aspiration was only evident on VFSS in 19% (n=49) of the infants of which only two of the infants presented with aspiration and pneumonia as the only aetiological condition.

According to Bradshaw, et al. (2003), HIV/AIDS is the leading cause of mortality of infants under the age of five years in South Africa. In relation to this research it was determined that 15.2% (n=40) of the infants were diagnosed with HIV/AIDS. As not all of the infants had confirmed diagnoses, this value may have in fact been higher as those infants who had been exposed to HIV/AIDS but no diagnosis confirmed were not included as having HIV/AIDS as an aetiological factor. This indicates that not only does HIV/AIDS have negative health correlates (World Health Organisation, 2007) but it also affects the infant's ability to feed effectively and

swallow efficiently. These findings are similar to research conducted into adults with HIV/AIDS (Halvorsen et al., 2003).

A consequence of HIV/AIDS is HIV encephalopathy, a neurological encephalopathy that manifests in stage four of the illness with one of the diagnostic criteria including nasal regurgitation during swallowing (World Health Organisation, 2007). When HIV encephalopathy in relation to the nature of dysphagia was analysed it was determined that of those infants that experienced nasal regurgitation as a component of the dysphagia (n=11) only three were diagnosed as having HIV encephalopathy. This indicates that although nasal regurgitation is associated with HIV encephalopathy it is also evident in paediatric dysphagia with other aetiologies. Thus it may be worthwhile to include testing for HIV encephalopathy during a differential diagnosis if an infant is presenting with nasal regurgitation during feeding, when no other obvious causes of nasal regurgitation are evident.

In terms of gastrointestinal disease, 8.7% (n=23) of infants presented with concomitant feeding impairments and gastrointestinal illness, in the form of acute gastroenteritis or hypernatraemia (Laing & Wong, 2002). As previously noted, gastrointestinal disease did not occur alone in the aetiology of this dysphagic population. However, as there are documented negative health correlates for infants experiencing gastrointestinal disease is can be extrapolated that there may be associated feeding impairments too. This is clearly seen from these results.

Growth abnormalities in the form of kwashiorkor and marasmus were evident in 8.7% (n=23) of the infants in this research. These disorders are not typically related to dysphagia and

are present in infants with poor protein and energy intake that results in poor growth and inadequate development and place the infants at risk for acquiring illnesses as a result of a compromised immune system secondary to the malnutrition (Alberda, Graf & McCargar, 2006; Pawellek, Dokoupil & Koletzko, 2008). Kwashiorkor and marasmus are linked to poor social circumstances and poverty (Müller & Krawinkel, 2005). What was interesting to note is that these infants appeared to have dysphagia in addition to their poor nutritional status.

This highlights the fact that communicable diseases associated with developing countries and potentially infant mortality, appear to affect an infant's ability to feed safely and effectively. The effect of this on the health professionals involved and management provided to the infants will be dealt with further in *Chapter Four.*

3.4 Objective three: To determine the caregiver's primary complaint with regard to the infant's feeding difficulties

The caregivers' complaint as recorded in the hospital file was analysed and compared both in relation to the nature of dysphagia and the aetiological factors experienced by the infants. When the records were analysed it was determined that 46 records did not have information pertaining to the caregiver's primary complaint. This was particularly noted with regards to CHBH where 42 of the records had missing information. When the caregivers' complaints were analysed it was determined that 33.2% (n=72) of the caregivers reported only one complaint. However, some caregivers reported up to four different complaints. This may have been due to the fact that the majority of infants presented with multiple aetiological factors each which may

have resulted in different symptoms and therefore different complaints. *Figure 2* illustrates the complaints reported by caregivers at the three hospitals although 51 of the results have not been displayed as the caregiver complaint combinations had less than five infants per combination. Some examples of these included coughing, vomiting and fever (n=3); coughing, breathing difficulties, poor weight gain and poor appetite (n=2); poor weight gain, coughing, choking and vomiting (n=1).

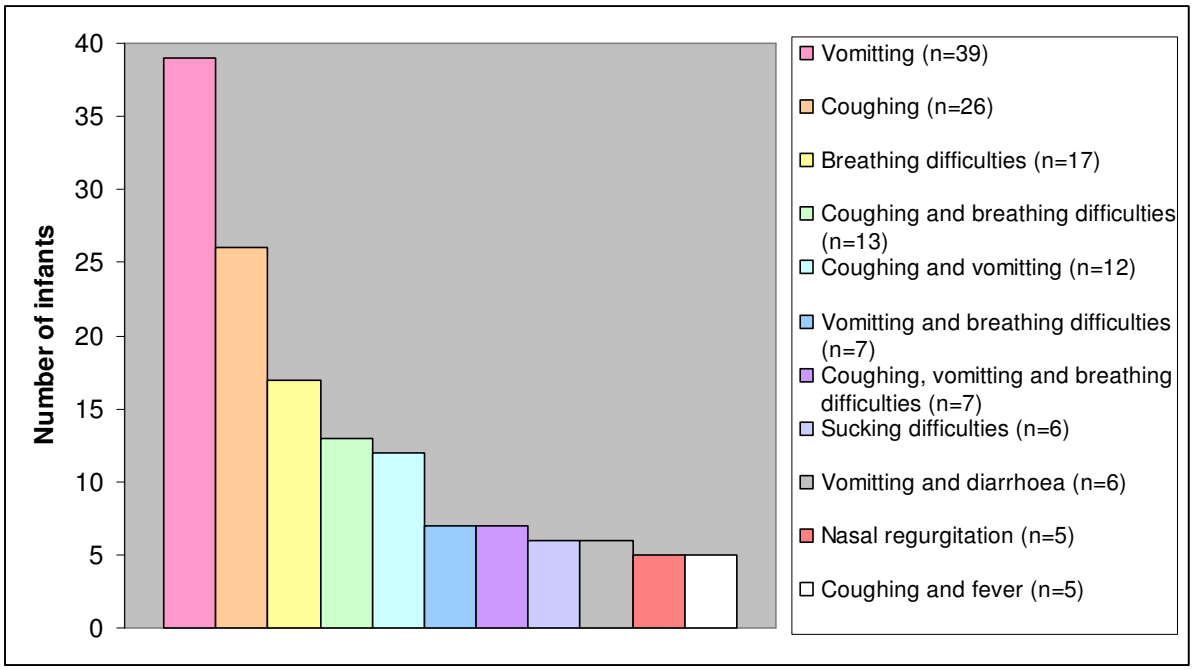


Figure 2. Caregivers' complaints at Chris Hani Baragwanath, Charlotte Maxeke Johannesburg Academic and Rahima Moosa Mother and Child Hospitals (n=143).

From *Figure 2* it can be seen that the primary complaints were with regards to vomiting, coughing and breathing difficulties. The data also indicated that although multiple combinations of complaints were reported, 100 caregivers reported vomiting, 96 caregivers reported coughing and 61 caregivers reported breathing difficulties.

The caregivers' complaints were analysed in relation to both the nature of dysphagia as well as the aetiologies influencing the dysphagia. Logistical regression analysis was computed to determine whether relationships existed between the caregivers' complaint and nature of dysphagia. The only significant relationship that occurred was between vomiting and pharyngeal phase dysphagia. During the computation, every record with vomiting as a complaint was included regardless of whether vomiting was the only complaint. Therefore, 100 records with a complaint of vomiting were analysed. It was determined that an infant with a pharyngeal phase swallowing difficulty is 1.058 times ($r = 0.0464$, $p < 0.05$) less likely to present with vomiting as a complaint. This was what was expected as vomiting is related to the stomach and pharyngeal phase dysphagia the pharynx and larynx. Therefore, one would not expect vomiting with a pharyngeal phase dysphagia.

When the caregivers' complaints were analysed in relation to the aetiologies experienced by the infants, it was determined that infants with dysphagia secondary to systemic illness are 59.9% ($r = 0.0098$, $p < 0.05$) more likely to present with coughing. This is what was expected and relates to the descriptive information whereby in terms of aetiology, 48.2% (n=127) of the infants presented with respiratory based conditions in the form of pneumonia, respiratory distress or tuberculosis. No other significant relationships between the caregivers' complaint and the nature of dysphagia or aetiology were determined from this set of data.

When the caregiver complaints and aetiology of dysphagia for the infants with normal swallow physiology (n=37) were analysed, it was found that the caregivers reported complaints of vomiting (n=8); no complaint (n=4); coughing (n=3); breathing difficulties (n=3) and a

combination of coughing and breathing complaints (n=3). Therefore, in a similar manner to the profile of the conditions experienced by the infants with normal swallowing, the caregivers' complaints for infants with normal swallowing were no different to those with disordered swallowing.

The concern with the results from the caregivers' district complaints is the large number of records that had missing information. This may indicate that the profile of complaints may be specific to this sample as the proportion of missing results may have influenced the overall pattern. A further concern is with regards to the record keeping and potential indication that the caregivers' complaints may not be considered to be part of the assessment procedure in paediatric dysphagia.

3.5 Objective four: To determine the health professionals involved in the assessment and management of infants with feeding difficulties

Of the records evaluated at the three hospitals, it was determined that 38 records at CHBH and six records at CMJAH did not have information pertaining to the health professionals involved in paediatric dysphagia. All of the records at RMMCH contained the required information.

At CHBH, as per departmental policy, a speech-language therapist is required at every VFSS. However, as 39 infants only had VFSS and no hospital or speech therapy records, it could

not be determined whether these infants received a subjective assessment or intervention from a speech-language therapist.

Table 4

Health professionals involved in the care of infants presenting to Chris Hani Baragwanath, Charlotte Maxeke Johannesburg Academic and Rahima Moosa Mother and Child Hospitals

Health professionals involved	CHBH (n=61)	CMJAH (n=86)	RMMCH (n=72)	Total (n=219)
Radiologist	61	92	72	225
Paediatrician	54	86	71	211
Speech-language therapist	61	39	17	117
Dietician	39	19	32	90
Other health professionals	38	32	14	84
Physiotherapist	26	28	11	65
Occupational therapist	27	8	7	42
General surgeon	8	19	5	32
Social worker	1	4	1	6
Gastrointestinal tract specialist	4	1	0	5

The concerning aspect with regards to CMJAH and RMMCH was that only 35.4% (n=56) of the infants received a consultation from a speech-language therapist during either the subjective assessment, VFSS or management decisions.

What is further noted from *Table 4* with respect to RMMCH; is that 44.4% of infants were seen by a dietician whereas only 23.6% were attended to by a speech-language therapist. This is a concern as the paediatric dysphagia team member particularly concerned with the assessment and management process is the speech-language therapist (Arvedson, 2008; Putnis, 2008). Therefore, it can be extrapolated from the data that the dieticians at RMMCH may be more involved in paediatric dysphagia than the speech-language therapists.

The 84 "other" health professionals, as seen in *Table 4*, involved in the infants' assessment and management included a HIV/AIDS specific team (n=23); ear nose and throat specialists (n=21); cardiologists (n=15); genetic counsellors (n=12) and paediatric palliative care (n=13). Those infants that were seen by a general surgeon (n=27) were seen for procedures other than the insertion of a percutaneous endoscopic gastrostomy feeding (PEG) tube.

3.6 Objective five: To describe the intervention strategies employed to manage paediatric dysphagia

The records analysed at CHBH and CMJAH indicated that eight records from each hospital did not have information pertaining to the management of the infants presenting with feeding difficulties. All of the records at RMMCH had information pertaining to the management strategies implemented. The most common form of management was that of medical intervention (71.1%) which involved medication; followed by positioning (34.4%) and food modification (32.4%). The most common example of food modification recorded was thickening of feeds.

Table 5

Management strategies used in the care of infants presenting to Chris Hani Baragwanath, Charlotte Maxeke Johannesburg Academic and Rahima Moosa Mother and Child Hospitals

Management strategies	CHBH (n=91)	CMJAH (n=84)	RMMCH (n=72)	Total (n=247)
Medical	40	74	63	177
Positioning	41	26	18	85
Food modification	44	11	25	80
Other	42	9	15	66
Naso-gastric feeding tube	35	19	8	62
Surgical	8	24	7	39
Oral-motor therapy	20	10	3	33
Percutaneous endoscopic gastrostomy tube	13	5	0	18
Utensil modification	13	4	1	18
Total parental nutrition	3	4	2	9

Table 5 indicates that 25.1% of infants received a naso-gastric feeding tube as an aspect of the dysphagia intervention. The infants received naso-gastric feeding for a time period ranging from one day to seventy-two days where the mean length in days was 18 days. Four infants received naso-gastric feeding tubes for a period longer than 42 days with only one of these infants receiving long term non oral feeds, with the other three returning to oral feeds. Of these 54 infants that received naso-gastric feeding, four, received a long term percutaneous endoscopic gastrostomy (PEG) tube, whereas, the remainder of the infants (n=50) returned to oral feeds. The further 14 infants that were fed via a PEG tube remained on non-oral feeds as noted in the hospital records.

The management area termed “other”, as seen in *Table 5*, included management strategies that did not fall into any other category specified. Examples of strategies that were included in this section was pacing of feeds (n=19), referrals to other professionals (n=19), a

repeat VFSS (n=4) and dual feeding whereby the infant is simultaneously oral and NGT/PEG fed (n=3). The surgical intervention provided (n=39) did not pertain to the insertion of PEG tubes. Examples of these surgeries include a nissen fundoplication, cleft lip and/or palate repairs, oesophageal dilatation and tracheo-oesophageal fistula repairs. The utensil modification (n=18) including cup drinking was provided for infants that were born prematurely (n=5) and those that presented with a neurological aetiology (n=5). It was further noted that six of the infants that received utensil modification intervention had an underlying aetiology of pneumonia.

Phi correlations were computed to determine whether relationships existed between the phase of dysphagia or aetiological factors in relation to the management strategies employed. The data revealed a small, albeit significant relationship between food modification and oral phase dysphagia ($r = 0.157$, $p < 0.05$). In addition, correlations in terms of oral phase dysphagia was found with regards to utensil modification ($r = 0.16$, $p < 0.05$); positioning strategies ($r = 0.189$, $p < 0.05$); oral motor therapy ($r = 0.165$, $p < 0.05$) and the insertion of a nasogastric feeding tube ($r = 0.251$, $p < 0.0001$).

When the relationship between pharyngeal dysphagia and the management of dysphagia was computed, it was determined that a small but significant relationship was found to exist ($r = 0.251$, $p < 0.0001$). In addition, pharyngeal dysphagia had a slight but significant correlation to positioning strategies ($r = 0.127$, $p < 0.05$); the insertion of a NGT ($r = 0.203$, $p < 0.05$) as well as the need for a PEG ($r = 0.262$, $p < 0.0001$), although this had a relatively small sample size and therefore may have only been applicable to this specific sample population.

Oesophageal phase dysphagia was not positively correlated to any of the management strategies implemented. When the aetiologies of dysphagia were computed in relation to the management strategies implemented, it was determined that positioning strategies had a small but significant relationship to a neurologically based aetiology ($r = 0.242$, $p < 0.05$). In addition the insertion of both NG ($r = 0.155$, $p < 0.05$) and PEG ($r = 0.153$, $p < 0.05$) tubes were correlated to a neurological aetiology.

All of these correlations were what was expected and are discussed in *Chapter Four*.

A correlation between surgical intervention and anatomical aetiology ($r = 0.365$, $p < 0.0001$) was found in this sample population. This is in line with literature (Miller & Willging, 2007) in that infants with anatomical aetiologies typically have structural abnormalities that may be rectified with surgical intervention.

In terms of intervention strategies in relation to systemic illness, the most prevalent aetiology experienced by this sample population, a small but significant relationship was found between medical intervention and systemic illness ($r = 0.201$, $p < 0.05$). This indicates that the intervention strategies required for paediatric dysphagia in the South African context may require dysphagia intervention secondary to medical intervention. This correlates with literature in that pneumonia, HIV/AIDS, tuberculosis and other systemic illnesses respond well to medical intervention (World Health Organisation, 2007). A relationship was also found with respect to systemic illness and the need for a NGT ($r = 0.133$, $p < 0.05$) as well as the "other"

recommendation, pacing of feeds ($r = 0.167$, $p < 0.05$). These results in relation to the literature have been discussed in *Chapter Four*.

With regards to RMMCH, it was concerning to note that of the 25 infants who received food modification as part of their intervention, only 13 infants were managed with a speech-language therapist's intervention. The remaining twelve infants who received food modification intervention only received intervention from a dietician and paediatrician. Furthermore, three infants from RMCCH were seen only by a paediatrician without any allied team intervention.

3.7 Normal swallowing in infants presenting with feeding difficulties

In contrast to the infants that presented with disordered swallowing upon VFSS, the presentation of infants with normal swallowing (n=57) in relation to the aetiological factors associated with the infants was analysed. What was noted was that the aetiologies experienced by the infants were similar to those of the infants with disordered swallowing. When the aetiologies of the infants with normal swallowing were analysed it was determined that 35.1% (n=20) and 29.8% (n=17) of infants had pneumonia and failure to thrive respectively as an aetiological factor. Furthermore, of the infants with normal swallowing, 80.7% (n=46) presented with a systemic illness as one aspect of their diagnosis and 50.9% (n=29) experienced aetiologies that were classified in the "other" category including FTT (n=19), prematurity (n=9) and GOR (n=4).

To determine whether any statistical relationships between the aetiological categories and normal swallowing exist, a logistic regression analysis was computed. The only significant result was with regards to normal swallowing and a neurological aetiology. The correlation revealed that infants with a neurological aetiology were 1.176 times less likely to present with normal swallowing ($r = 0.0431$, $p < 0.05$). This is in line with literature, as feeding and swallowing is dependent on the intact functioning of the neuromuscular system (Ertekin & Aydogdu, 2003; Prasse & Kikano, 2009). Therefore, disruptions to this system as seen in a neurological based aetiology may have negative feeding and swallowing consequences.

The fact that infants with aetiologies such as pneumonia and FTT, may have either dysphagic or normal swallowing outcomes indicates that at present no assumptions can be made with regards to the presence of absence of swallowing impairment that is based on a medical diagnosis alone. This can be seen in that 35.1% (n=19) of infants with a diagnosis of FTT presented with normal swallowing physiology. Therefore, the VFSS is still pertinent in the assessment process in order to accurately diagnose a feeding impairment and make subsequent, appropriate management decisions.

When the caregivers' complaints were analysed, it was determined that similar complaints were noted in infants with normal swallowing in comparison to the infants with dysphagia. It was noted that 52.6% (n=30) presented with respiratory complaints in the form of coughing and/or breathing difficulties. A further 43.9% (n=25) of infants experienced vomiting as one of the primary complaints.

What was interesting to note was that the management strategies provided for those infants with confirmed swallowing dysfunction and those with normal swallowing was similar in strategies and nature. *Table 6* delineates the management strategies used for those infants with normal swallowing and it can be seen that medical management and positioning strategies were the most frequently used. It was not evident as to the reason for the use of therapeutic strategies such as positioning for a child with normal swallowing physiology. In addition, from *Table 6* it can be seen that more aggressive intervention strategies such as the insertion of NG and PEG tubes as well as surgical intervention were also required for infants that presented with normal swallowing. This is not what was expected. The use of NG tubes may have been a result of respiratory difficulties resulting in the child refusing to feed, although this is merely a hypothesis. An argument that could be made is that the VFSS may have not been entirely accurate and the infant may have infant been experiencing dysphagia which was not evident during the VFSS.

Table 6

Management strategies provided to infants with normal swallowing on VFSS (n=57)

Management strategies	Number of infants	Percentage (%)
Medical	42	73.7
Positioning	10	17.5
Other management strategies	10	17.5
Food modification	8	14
Nasogastric feeding tube	8	14
Surgical intervention	7	12.3
Utensil modification	5	8.8
Oral motor therapy	4	7
Total parental nutrition	2	3.5

In comparison to that of disordered swallowing, the aetiology, caregiver's complaint and management strategies indentified and employed were similar to that for infants presenting with normal swallow physiology. This is concerning as it indicates that infants with dysphagia and those with normal swallowing are presenting in a similar manner. It perhaps could imply that the VFSS procedures conducted at the hospitals are in fact not sensitive to dysphagia. This could be attributed to staff experience, policies or manner in which the VFSS is conducted.

3.8 Conclusion of results

From the results it can be seen that infants experiencing paediatric dysphagia in a developing country such as South Africa, experience aetiological factors that differ to those experienced by infants in developed countries. The most evident difference was the sheer number of aetiological combinations experienced by the infants (n=214). Furthermore, the majority of infants (n=175) experiencing dysphagia secondary to a systemic illness which has not previously been highlighted in literature. Communicable diseases such as pneumonia and HIV/AIDS typically seen in developing countries have also been shown to have negative feeding consequences and in some instances, resultant dysphagia. In addition, the health professionals involved in the assessment and management of infants with dysphagia differ slightly to that recommended in literature in that in only 53.4% (n=117) were seen by a speech-language therapist, with the primary health professional involved in paediatric dysphagia in the three hospitals analysed was a paediatrician. In terms of management, it was also determined that the primary management strategy provided to infants with dysphagia was medical intervention. This was significantly correlated to dysphagia secondary to a systemic illness, thus indicating that in a

developing country, therapeutic intervention secondary to medical intervention for infants with dysphagia may be the required management procedure.

CHAPTER FOUR

DISCUSSION

Chapter Four provides a discussion of the results from this study in relation to literature from both local and international sources. This section will place these results in the context of paediatric dysphagia as a whole and provide reasons and explanations for the similarities and differences in findings between this research and literature.

Previous, studies (Barratt & Ogle, 2010; Calis et al., 2008; Hawdon et al., 2000) have typically considered the type of dysphagia experienced by specific paediatric populations, such as infants with neurodevelopmental delays, cerebral palsy and those born premature. There has been limited research into the general paediatric dysphagic population as whole, with the focus of most studies either on aspects of dysphagia such as aspiration (Newman et al., 2001) and management strategies employed (Miller & Willging, 2007). In contrast, this research aimed to consider the paediatric dysphagic population as a whole, regardless of the nature of dysphagia or underlying aetiology. This allowed for a description of both paediatric dysphagia in its entirety and included a description of the nature of dysphagia as well as the underlying aetiologies and the interplay between these. In addition this research provided information into the presenting symptoms of infants with dysphagia as well as the health professionals and management strategies employed in state hospitals in Gauteng, South Africa. From the results it can be seen that the profile of infants with dysphagia in South Africa differs somewhat to dysphagia experienced by infants in first world countries and contributes to new information regarding aetiological factors and type of dysphagia experienced by infants in other developing countries.

The value of this is that paediatric dysphagia in the context of a developing country has not previously been reported. These findings may assist in the creation of appropriate policies and protocols for the assessment and management of paediatric dysphagia in developing countries and in particular, South Africa.

The primary difference noted in this research in comparison to that from developed countries (Newman et al., 2001; Rommel et al., 2003; Schwartz et al., 2001) was with regards to the aetiological factors experienced by the infants with dysphagia. In comparison to infants in developed countries, it was determined that that the infants experienced a multitude of aetiological conditions and combinations of these conditions that either directly or indirectly affected their feeding ability. The results revealed that the infants experienced 214 different aetiological combinations that ranged from one condition to eight different conditions impacting their overall health and in particularly their feeding ability.

It became apparent from the research that the infants experienced dysphagia primarily as a result of a systemic illness, and specifically as a result of communicable diseases including pneumonia, HIV/AIDS, respiratory distress and tuberculosis. These illnesses have been reported in other developing countries besides South Africa (United Nations, 2010). The concerning factor with regards to communicable diseases is that these diseases can potentially be minimised or eradicated with proper sanitation, improved access to health care and better nutrition (United Nations, 2010). Thus, what emerged from this research is that the prevalence of paediatric dysphagia in the South African context has the potential to be significantly reduced through improved access to clean water and sanitation, improved nutrition schemes and better access to

health care services. This would minimise not only the infant mortality rates from communicable diseases alone, but may also reduce the negative growth, cognitive and developmental sequelae that may occur as a result of paediatric dysphagia.

In addition, the 2015 United Nations Millennium Development Goals established a number of aims to be achieved by 2015. Some of these goals included the need to eradicate extreme hunger and poverty; reduce childhood mortality, address HIV/AIDS, malaria and other diseases; as well as the halve the number of people that do not have access to safe drinking water and sanitation (United Nations, 2010). A report published on the progress of attaining these goals indicated that although these goals have been proposed, many may not be achievable due to the economic recession and current rate of goal achievement since 1990 (United Nations, 2010). However, as the United Nations has identified that hunger, poverty, illness and poor access to sanitation and drinking water are dilemmas particular to developing countries, it suggests that reform and change is occurring. In terms of this research, it was identified that the main cause of paediatric dysphagia in infants was due to systemic illness and in particular communicable diseases. It has been proposed that communicable diseases have the potential to be reduced with improved social circumstances including poverty, sanitation, nutrition and access to health care (United Nations, 2010). It therefore begs the question as to whether paediatric dysphagia in a developing country, to at least a certain extent, may be preventable.

4.1 Classification of Paediatric Dysphagia

One of the difficulties that arose during this research and a concern that has been raised in literature is with regards to the classification of feeding disorders. Throughout literature an argument has been made for multiple classification systems including a dichotomous system (Burklow et al., 1998; Rommel et al., 2003) a medical, oral and behavioural system (Rommel et al., 2003) structural, neurological, cardio-respiratory, metabolic and behavioural system (Burklow et al., 1998), classification according to phases of swallowing dysfunction (Calis et al., 2008; Schwartz, 2003) and more recently the ICF (Lefton-Grief & Arvedson, 2007; Miller, 2009). For the purposes of this research a classification system proposed by Arvedson and Brodsky (2002, p. 5) was employed. In addition to the Arvedson and Brodsky (2002, p. 5) classification system an "other" category had to be created in order to accommodate those aetiologies that did not fall into any of the other categories. However, this classification system was not comprehensive and sensitive to all of the possible aetiologies experienced by the infants with dysphagia. The system also did not provide a description of multiple aetiological factors that fell into one category for example, pneumonia, tuberculosis and HIV/AIDS. For these aetiologies, the classification category would be that of dysphagia secondary to systemic illness although the fact that the dysphagia is a result of multiple aetiologies is not evident. At present, the classification systems reported in literature and mentioned above are not applicable to the context of a developing country.

In addition to the concern with regards to the classification system, there is at present no internationally recognised operational definition for many of the terms used in the aforementioned classification systems.

Therefore, in order to address this dilemma, a comprehensive classification system has been proposed. The system comprises three elements related to the aetiology of the paediatric dysphagia. The benefit of the model is that combinations of elements can be selected for example; if an infant presents with cerebral palsy and pneumonia the dysphagia classification would be: *prenatal, neurological, permanent and acquired cardio-respiratory, transient*

This will provide a comprehensive description of paediatric dysphagia and assist not only in the intervention provided but also provide a basis from which research and populations of infants with dysphagia and be compared. In addition this model will allow for comparison of dysphagia over time. For example: if an infant presents with cerebral palsy and pneumonia, at the follow up appointment the speech-language therapist or paediatrician can refer back to the model to determine whether the dysphagia has remained the same or whether other aetiological factors are now interfering with the infant's feeding ability.

The concern with regards to operational definitions in paediatric dysphagia has also been addressed in this model whereby definitions for each of the elements have been provided (Appendix S).

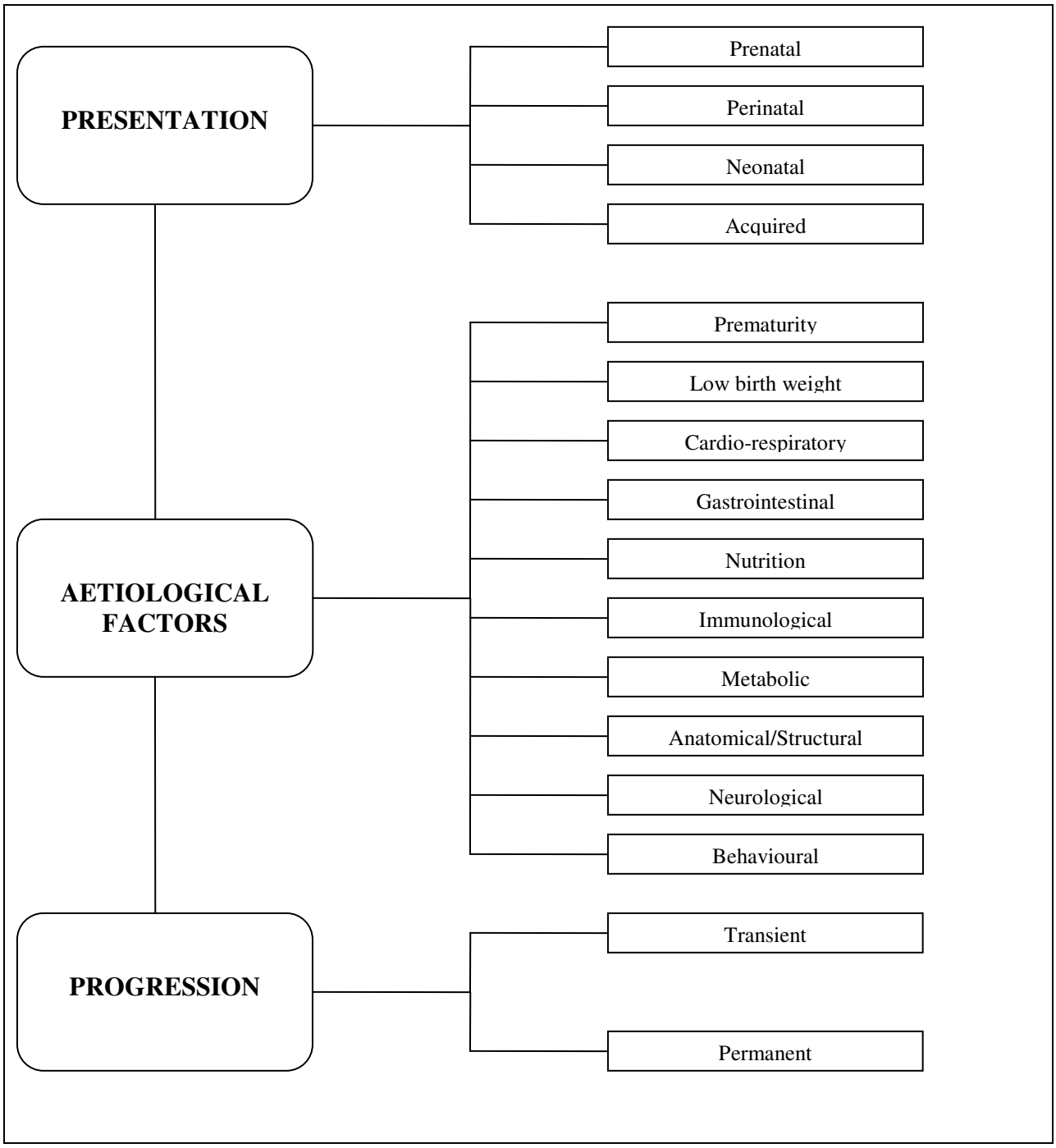


Figure 3. Schematic representation of the classification of paediatric dysphagia in relation to aetiology.

4.2 Differences Between the Hospitals

As mentioned in the results, the hospitals were initially analysed separately in that CHBH and CMJAH were combined to form a quota sample with RMMCH analysed separately. This was due to the initial assumption that as RMMCH is a regional level hospital; the results for RMMCH would differ to CHBH and CMJAH, the tertiary level hospitals. However, statistical analysis revealed no significant differences between the nature of dysphagia experienced by the infants at the three hospitals. However, what was evident was that oesophageal phase dysphagia was found to be the most common swallowing difficulty when the three hospitals were analysed together, whereas at CHBH it was the least prevalent phase of dysphagia affected. Furthermore, the aetiologies experienced by the infants at CMJAH and RMMCH were similar across the two hospitals. This was unexpected as CHBH and CMJAH are tertiary level hospitals that typically deal with more complex based feeding difficulties and have a higher number of staff with potentially more expertise than at the regional level hospital, RMMCH. This indicates that perhaps the less complex feeding cases are also being seen at the tertiary level hospitals and not being referred primarily to the regional level hospitals. This is relevant as it indicates that the South African health system is not functioning in the manner it which it is meant to, as stipulated by the Department of Health (2000). This may result in unnecessary over referral to the tertiary level hospitals and place a burden on these hospitals that may otherwise have been lessened by the regional level hospitals.

The differences between hospitals may be attributed to the different personal, procedural and equipment facilities at the hospitals. At CHBH, all VFSS that are undertaken are required to

include a radiologist and speech-language therapist. It is recommended that a speech-language therapist should be present during the VFSS to assist in analysing the oral and pharyngeal phase components of swallowing, to determine the presence or absence of aspiration and to implement management during the VFSS to determine efficacy (Arvedson & Brodsky, 2002, p. 366). From the limited number of infants with pharyngeal phase impairments and the high number of infants with oesophageal phase dysphagia at CMJAH and RMMCH it can be assumed that the absence of a speech-language therapist at the VFSS decreases the sensitivity of the assessment to oral and pharyngeal phase difficulties. In addition, as the terminology used at CMJAH and RMMCH to describe a VFSS was inconsistent, it can be said that the procedures conducted may not have always been a true VFSS. Therefore, the test conducted may have been more similar to that of a barium oesophagram which is more sensitive to gastro-oesophageal reflux that the VFSS (Baker et al., 2007; Hall, 2001, p. 79). Therefore, in comparison between CHBH in relation to CMJAH and RMMCH, the number of infants experiencing oesophageal phase difficulties at CHBH may have been missed or overlooked due to the fact that the VFSS is not the most sensitive tool for establishing GOR.

Therefore if a team approach had been employed at CMJAH and RMMCH it may have assisted in ensuring that the VFSS conducted at all hospitals is sensitive to all phases of the swallowing and therefore the profile of dysphagia in the infants may have presented with somewhat different results. A further contributing factor to the differences in the type of dysphagia found may be a result of the VFSS procedure itself. The terms VFSS, video swallow, hexabrix swallow, modified barium swallow, oesophagostomy and barium swallow were used interchangeably at CMJAH and RMMCH. These procedures, particularly that of a hexabrix

swallow, barium swallow and oesophagostomy in fact relate to other procedures where the focus is on gross anatomy, oesophageal structure and function and gastric components (Allen et al., 2009; Levine et al., 2009). As a result of the nature of a retrospective record review and as these terms were used interchangeably it could not be determined whether the correct VFSS procedure was used for every infant. Therefore the objective assessment measures employed at CMJAH and RMMCH may not be overly sensitive to oral and pharyngeal phase dysphagia. This is concerning in that infants presenting with oral or pharyngeal phase dysphagia may have been overlooked. These infants may then not have received the relevant intervention and may have experienced potentially avoidable negative long term consequences of the feeding impairment.

In addition to the procedure followed with regards to VFSS, some differences were noted between the hospitals and the levels of health care each hospital is concerned with. The history of the health system within South Africa is fraught inequalities both with regards to social aspects such as access to water and sanitation but also with regards to access to health care (Coovadia et al., 2009). Following 1994, the Department of Health proposed health reform with the focus on PHC (Department of Health, 2000). In terms of primary health care, level of care was assigned to all of the government hospitals and clinics with the focus on the primary level of intervention. For the purposes of this research the hospitals selected were regional (RMMCH) and tertiary (CHBH and CMJAH) level hospitals. These hospitals provide more advanced care for complex cases. From the dysphagia profile of infants in this study, it was determined that the majority of infants had dysphagia secondary to a communicable disease. Due to poor access to health care within South Africa (Coovadia et al., 2009) it can be assumed that many of these infants did not receive intervention at a primary level of intervention. This indicates that

potentially with intervention at a PHC level, the effects of the communicable diseases and therefore the subsequent dysphagia may have been minimised. If many of these infants were seen at a PHC level, and the underlying aetiology addressed, the number of infants requiring intervention at a regional or tertiary level may decrease. In addition, the prevalence of dysphagia as a result of communicable diseases may reduce and thereby require less VFSS procedures and potentially minimise not only the length of stay in hospital but reduce the risk of co-infections.

4.3 Phases of Swallowing in Relation to Aetiological Factors

A unique aspect to this research that has not been fully explored in other studies is the relationship between disorders in phases of swallowing and the aetiology of the dysphagia. Schwartz, et al. (2001) analysed diagnoses of children (n=79) in relation to specific dysphagia markers such as GOR and aspiration. Similarly Newman, et al. (2001) analysed the aetiology of dysphagia in relation to aspiration, penetration and nasopharyngeal reflux. This research however, provides new insight into the relationship between the nature and aetiology of dysphagia experienced by infants in a developing country.

Of the infants that experienced oesophageal phase dysphagia, either exclusively or with the involvement of other phases, only 18.2% experienced oesophageal based aetiology for example; gastro-oesophageal reflux or oesophageal atresia. Whereas, 53.4% of infants that experienced oesophageal phase dysphagia, experienced respiratory difficulties in the form of pneumonia or respiratory distress syndrome. With these correlates it may be hypothesised that the gastro-oesophageal reflux may be contributing to the respiratory difficulties in the form of

secondary aspiration (Arvedson & Brodsky, 2002, p. 163). The effects of gastric contents entering the larynx in the form of GOR may result in respiratory based difficulties such as coughing and a hoarse voice (Arvedson & Brodsky, 2002, p. 164). These symptoms may lead to a diagnosis of pneumonia. However, the concern arises when the underlying GOR is not addressed and the secondary aspiration continues to occur. This may result in chronic aspiration, long term laryngeal structural changes and frequent bouts of respiratory illnesses and difficulties reducing the infants' immunity and health (Arvedson & Brodsky, 2002, p. 473).

Pneumonia appeared to be the most prevalent disorder (n=89) affecting infants under the age of 18 months in the South African, state hospital context. What was particularly noted in this context is that as mentioned previously, the majority of the infants presented with multiple aetiological factors influencing their feeding ability. This was once again noted with regards to pneumonia whereby only eight infants presented with pneumonia sans another diagnosis. The presence of pneumonia in conjunction with other aetiologies is not a new phenomenon. Literature (Kirkwood et al., 1995) has reported that the not only is the prevalence of pneumonia high in children in developing countries, but that many factors associated with developing countries place children at greater risk for contracting pneumonia. Social factors such as malnutrition and dehydration, co-morbid infections such as HIV/AIDS and unsanitary living circumstance increase the risk of a child contracting pneumonia (Kirkwood et al., 1995). However, in lieu of the fact that these infants presented with simultaneous feeding difficulty, and in some cases dysphagia, as well as the pneumonia, it cannot be assumed that all of these infants contracted pneumonia through unsuitable social circumstances or viral infection. It may indicate that although these infants are exposed to a multitude of factors that may place them at risk for

contracting pneumonia the cause of the pneumonia may have been a result of the dysphagia itself.

As a result of this, an argument could also be made that the infants with pneumonia may have acquired this diagnosis as a consequence of the dysphagia due to aspiration of material into the airway. Weir, et al. (2007) report that although pneumonia may be bacterial or viral in nature, aspiration is the most common cause of recurrent pneumonia in children. However, this study was conducted in Australia, a developed country whereby the aetiology and factors influencing the children may differ considerably in comparison to those in developed countries. In this current study it was determined that seventeen infants experienced pneumonia in addition to aspiration on VFSS, although only two of these infants presented with pneumonia as the only aetiological factor. These results therefore suggest that the pneumonia experienced by many of the infants in this study may have been a viral or bacterial in nature and not necessarily related to the dysphagia itself. However this is merely speculation and from the data collected cannot be conclusively proved.

In comparison to people that reside in affluent areas, infants born into areas of lower social standings are susceptible to communicable diseases such as diarrhoea, tuberculosis and HIV/AIDS (Benatar, 2004). Furthermore, research has shown that infants born in lower socioeconomic areas have a higher chance of being born prematurely and experiencing extremely low birth weights (Emerson & Hatton, 2007). The sample from this research, largely residing in lower socio-economic areas, experienced similar aetiological factors as those described in international research. However, the aetiological factor that may have been

underestimated in this research was that of HIV/AIDS. As mentioned in the *Chapter Three*, only infants with a confirmed HIV/AIDS diagnosis had this disordered recorded as an aetiological component. The process to definitively confirm the presence of HIV/AIDS is a complicated one particularly in infants below the age of 18 months (Layton & Davis-McFarland, 2000; World Health Organisation, 2007). At birth, passive HIV/AIDS antibodies from the mother may be transmitted to the infants without the infant actually being infected by the disease (World Health Organisation, 2007). As not all infants in this research that were considered to have HIV/AIDS exposure underwent the definitive virology testing, the incidence of HIV/AIDS within this sample population may have in fact been higher than what was reported in the records. Research into the prevalence of HIV/AIDS within South Africa has estimated that 2.5% of the population of children between the ages of two and fourteen years is infected with the virus (Kosek et al., 2008). However as there is a dearth of literature into the prevalence of the disease in infants under the age of 24 months, one cannot definitively determine the prevalence of HIV/AIDS in the young infant population.

In terms of the prevalence of HIV/AIDS in the infants identified in this study, it appeared that 15.2% (n=40) were infected by the illness. Furthermore, it appears that the prevalence may even be higher in terms of those that had not formerly been diagnosed or perhaps are not yet manifesting clinical symptoms. As a result of this, the number of infants affected by HIV/AIDS who then experience feeding difficulties may be higher than originally detected or expected. In terms of assessment and management of these infants the exact presentation, management options and effects of the new antiretroviral medications have not yet been fully investigated or explored. Therefore, the speech-language therapist and health professionals dealing with the

infant and the feeding problem may not yet fully understand the implications and feeding correlates of infants with HIV/AIDS.

Furthermore, in terms of HIV encephalopathy and its correlates, nasal regurgitation has been identified as one of the initial symptoms of stage four HIV/AIDS and concomitant HIV encephalopathy (Rabie et al., 2007). What was noted in this research was that very few of the infants identified with HIV encephalopathy presented either with nasal regurgitation on VFSS or as a component to the caregiver complaint. What should be taken from these findings is that a diagnosis of HIV encephalopathy needs to be taken into consideration with other investigative measures and symptoms and not on one aspect alone. For those working with infants with feeding problems in developing countries, HIV/AIDS and subsequent HIV encephalopathy should be included as part of the differential diagnosis in an infant presenting with nasal regurgitation. This may result in early detection that the illness has moved into more advanced stages which may assist in the subsequent provision of medical intervention that may minimise the affects of both the HIV encephalopathy and the dysphagia.

Other aetiologies typically associated with lower socio-economic settings include gastroenteritis, failure to thrive and growth impairments such as kwashiorkor and marasmus (Cameron et al., 2005). What was determined in this research is that 8.7% of infants experienced gastroenteritis and a further 8.7% of infants presented with growth difficulties. All of these illnesses if left untreated or managed incorrectly have potentially long term health, nutrition and cognitive consequences (D'Anci et al., 2006; Kar et al., 2008; Laing & Wong, 2002; Watanabe et al., 2005). In particular, hypernatraemia can result in neurological conditions and deficits in

the form of confusion, cerebral oedema, hydrocephalus and potentially intracranial haemorrhage (Laing & Wong, 2002). What has not been fully researched in the literature is the dysphagia correlates of these illnesses. One can hypothesise that if neurological fall out occurs with hypernatraemia; neurologically based feeding difficulties may be a negative consequence. However, as the aetiological factors experienced by the infants in this research vary, vast and multifactorial specific correlates from these aetiological factors could not be determined. What this research shows is that not only is diarrhoeal disease one of the leading causes of infants mortality in South Africa (Bradshaw et al., 2003) but it also appears to result in negative feeding correlates. This is most likely attributable to the negative neurological effects of hypernatraemia (Laing & Wong, 2002). Therefore, further research into the long term feeding correlates of these illnesses needs to be conducted.

In addition to negative outcomes as a result of diarrhoeal disease, nutrition and growth conditions such as kwashiorkor and marasmus also present with long term negative cognitive development (Alberda et al., 2006). This occurs as a result of the lack of correct proteins and nutrients in the body that are required for brain development (Alberda et al., 2006). Evidence (D'Anci et al., 2006; Kar et al., 2008; Motion et al., 2001; Rudolf and Logan, 2005) has shown that infants that experience poor nutrition and hydration in early life have long term negative cognitive and academic correlates. Therefore, not only do infants with diarrhoeal disease and inadequate nutrition have documented negative health and development consequences, it appears that feeding impairments may be associated with these disorders too.

Furthermore, in relation to these disorders, the efficacy of a combination of medical and therapeutic intervention strategies should be investigated. As with many of the other secondary illness factors perhaps, early medical intervention may prevent or minimise the feeding difficulties experienced by the infants. As with many of the other communicable disease mentioned previously, improved nutrition, sanitation and access to primary health care (Horwood et al., 2011) many minimise the burden of these conditions on government resources and the health, social development and educational departments.

With such a high number of infants experiencing factors pertaining to illness, it could be argued that when the underlying medical condition, such as the pneumonia, is resolved, the infant's feeding difficulties should resolve. However, this has not been fully investigated and the long term effects on an infants' feeding has not been considered. Furthermore, many of the infants included in this research experienced multiple aetiological conditions and factors. As a result of this it may be difficult to determine which aetiological factor the one is affecting the infants' ability to feed the most.

As this multiple aetiological phenomenon affects the paediatric dysphagia population that health professionals are dealing with on a daily basis; research needs to be conducted into not only which aetiology may contribute the most to feeding difficulties but the affects that they have on each other. For example, an infant with an aetiology such as acute gastroenteritis, failure to thrive and pneumonia. All three illnesses may have their own feeding correlates but may not necessarily be the underlying root of the problem. Therefore, a multi-disciplinary, multi-

management approach is recommended whereby the medical, feeding and growth aspects can be addressed simultaneously.

Cameron, et al. (2005) conducted research in Tanzania and determined that many infants experienced health related complications as a result of infectious diseases, namely gastroenteritis and pneumonia. However, in that study the focus was on profiling the social factors influencing child health and not paediatric dysphagia. Research (Baudon et al., 2009; Calis et al., 2008; Cooper-Brown et al., 2008; Miller & Willging, 2003; Prasse & Kikano, 2009; Reid & Kilpatrick, 2007; Schwartz et al., 2001) has typically investigated the profile of dysphagia with regards to specific aetiological factors. Examples of these aetiologies included neurological, anatomical, genetic anomalies and systemic illness whereby the dysphagia was classified as cardiovascular, gastrointestinal or metabolic in nature. An aspect of this study that provided new information into paediatric dysphagia in South Africa was the fact that unlike infants in developed countries, the infants in this study presented with multiple aetiological complications influencing the dysphagia. Silverman (2010) reviewed aetiologies of dysphagia and reported that dysphagia can present with a combination of aetiological factors although conclusive evidence supporting this in literature is scarce. Rommel, et al. (2003) evaluated feeding in infants in the Netherlands and it was determined that 86.1% of the infants presented with medical aetiologies classified as gastrointestinal, neurological, nephrological, cardiological or oro-facial. Some combinations of aetiological factors were identified, for example gastrointestinal-neurological; gastrointestinal-genetic and gastrointestinal-ENT-oro-facial (Rommel et al., 2003). In the same study the dysphagia was classified as either oral motor, oral sensory, pharyngeal dysphagia, experience delay or a combination of these factors. Therefore this study is the only one that was determined

to analyse the nature and aetiological factors related to paediatric dysphagia although these were not analysed in relation to each other and the specific aetiological conditions were not described. Therefore, from this study it can be seen that there is a vast number of aetiological factors may coexist influencing the health and feeding ability of these infants. Furthermore, it was noted that in no other documented literature were infants reported to experience the vast number of aetiological combination as found in this research.

Failure to thrive (FTT) is used to describe infants who experience poor weight gain in early infancy or childhood (Drewett et al., 2002). Fifty-four infants in this research presented with FTT as one of the aetiological factors in their dysphagia. Traditionally the term FTT was used to diagnose poor weight gain without an apparent underlying medical condition (Drewett et al., 2002). However, what was noted in this research is that the term FTT was used to describe poor weight gain even in the presence of another aetiological factor. Similarly to the consequences of malnutrition, FTT can result in long term negative social, cognitive and health correlates (Drewett et al., 2002; Emond et al., 2007). Furthermore, what is interesting to note is that the majority of infants diagnosed with FTT did in fact have an underlying swallowing difficulty affecting their ability to feed and consume adequate nutrition, thus, indicating that the VFSS is a useful tool in determining the contributing reason to an infant's poor weight gain. However, 35.1% of the infants diagnosed with FTT had normal swallowing physiology indicating that in conjunction with VFSS further investigations are required in many of the cases to adequately determine the reason for poor weight gain in young infants.

Prematurity is a well-documented factor that may have resultant health and developmental consequences (Hawdon et al., 2000). In addition, many premature infants have been found to present with specific feeding disorders that are dependent on their gestational age, birth-weight, medical status and aspects of intervention (Manikam & Perman, 2000). Within developing countries infants are more susceptible to poor intrauterine growth, prematurity and low birth-weight due to poor access to health care, malnutrition and maternal stress levels (Chopra, Daviaud et al., 2009). In this study it was determined that prematurity and birth-weight below 2500g was found in 52 and 28 infants respectively. In this research, no significant relationship was found to occur between the nature of dysphagia and prematurity or low birth weight. A concern with regards to prematurity and low birth-weight was with regards to the classification system in that these aetiological factors could not be categorised under the system employed and therefore an "other" category was created. This is a concern as prematurity and low birth weight are well documented health conditions with dysphagia correlates. Therefore, a relevant and appropriate classification system that allows for the incorporation of these conditions is required.

In contrast to international research (Mercado-Deane et al., 2001) the infants at the state hospitals in Gauteng appeared to have a higher prevalence of disordered swallowing with respect to specific aetiologies. With regards to prematurity, the number of infants in this study that experienced swallowing difficulties was two to three fold more (76.5%) than that experienced by infants in the United States of America (Burklow et al., 1998; Mercado-Deane et al., 2001; Thoyre, 2007). A contributing factor that may have played a role that was not addressed in either research was the degree of prematurity experienced by each infant. Furthermore, it could be

argued that improved first world intensive care facilities for premature infants may lower the rate of feeding difficulties compared to that of state hospitals. However this can only be hypothesised and further research examining the differences in care facilities in relation to gestational age between developed and developing countries is recommended to shed light into this large discrepancy in dysphagia.

Literature (Schwartz et al., 2001), reports that infants with neurological impairments present with specific difficulties in the phase of swallowing and in particular oral-pharyngeal phase dysphagia. This was confirmed in this research whereby logistical regression analysis revealed that infants with neurological aetiology are 68.5% times more likely to present with an oral phase dysphagia. Schwartz, et al. (2001) further determined that 27% of infants with cerebral palsy presented with an oral phase dysphagia. A similar result was found in this research whereby 21.7% of infants in this study with cerebral palsy experienced similar oral phase swallowing difficulties. Furthermore, a study conducted in South Africa (Barratt and Ogle, 2010) indicated that parents of children presenting to a neurodevelopmental clinic reported feeding difficulties in 29% of infants. The files reviewed in the Barratt and Ogle (2010) study experienced predominantly neurological and genetic disorders. Given the similarities between this research and that of Barratt and Ogle (2010), comparisons may be drawn. It appears that with regards to neurological aetiology similar dysphagia prevalence is seen both locally and internationally and further highlights the need for multidisciplinary team interventions within hospitals and setting whereby children with dysphagia are seen. This is interesting to note due to the number of aetiological factors prevalent in South Africa that may result in neurological

impairment. Examples of these factors include gastroenteritis and hypernatraemia (Laing & Wong, 2002) and HIV encephalopathy (World Health Organisation, 2007).

4.4 Dysphagia in Relation to Caregivers' Primary Complaints

The caregiver's primary complaint upon presentation to either the hospital or VFSS was analysed to determine whether predictions could be made with regards to the type of dysphagia or underlying aetiology of the feeding difficulty. The only significant relationship determined was with regards to coughing and dysphagia secondary to a systemic illness. This is in line with the findings of the study related to the aetiological factors affecting the infants whereby the majority of infants experienced a respiratory based aetiology such as pneumonia. This is in line with the clinical presentation of pneumonia whereby coughing, tachypnoea, feeding difficulty and nasal flaring are all symptoms (Gessman & Rappaport, 2009). This further indicates that pneumonia in infants in this research were affected by community acquired respiratory difficulties as opposed to as a result of the dysphagia. In addition, as coughing was found to be an indicator of both dysphagia and respiratory disease, it could not be assumed that all infants presenting with coughing and poor feeding had either dysphagia or pneumonia. Thus, indicating the need for VFSS as part of the assessment and diagnosis process.

However, what was evident in the analysis of the caregiver's complaint was with regards to the number of records that had missing data. This may have been due to the note taking of the health professional initially involved in the assessment of the infant. This indicates that the overall information achieved with regards to the caregiver's primary complaint with respect to

the feeding impairment may not have been representative of the paediatric population. What was not evident was whether the primary complaints were specifically obtained from the caregiver or in some instances whether it was related to the symptoms that the infant displayed upon initial assessment. Therefore, apart from the relationship between infants presenting with coughing and dysphagia secondary to a systemic illness, no significant relationships could be established between the nature or aetiological factors of paediatric dysphagia and the caregiver's primary complaint. Very little research has considered the presenting symptoms of children with feeding difficulties in a developing country. Research (Gessman & Rappaport, 2009; World Health Organisation, 2007) does however provide guidelines as to the presenting symptoms of specific illnesses that may provide some insight into the underlying aetiology affecting the infant. This is particularly useful with regards to communicable diseases in that intervention with regards to these specific illnesses may reduce the severity of the paediatric dysphagia and allow for a more rapid recovery and ability to feed effectively. However, this does indicate that due to the overlap between symptoms of paediatric dysphagia and certain aetiologies that may influence the infants health and therefore feeding ability, the VFSS still remains the gold standard for evaluate swallowing ability and efficacy.

4.5 Assessment Procedures and Videofluoroscopic Swallow Studies

The crucial need for videofluoroscopy in diagnosing swallowing disorders was further emphasised with regards to those infants that presented with normal swallowing physiology. It was determined that infants with normal swallowing on VFSS experienced similar aetiological components to that of infants with disordered swallowing. In addition to the aetiological factors

present, the caregiver's complaint in relation to normal swallowing was analysed and once again the complaints related to infants with normal swallowing and those with disordered swallowing were similar in nature. Recent research (DiSantis, 2008; Levine et al., 2009) in the field of radiology has suggested that barium studies and fluoroscopy may no longer be relevant due to the advancement in radiological imaging. DiSantis (2008) commented that the use of upper gastrointestinal and barium studies in first world radiology has diminished dramatically. This was contributed to the more advanced imaging measures such as the computer topography (CT) scan and endoscopic procedures. It has to be noted however that both DiSantis (2008) and Levine, et al. (2009) reported on statistics from developed countries whereby advanced modern imaging is widely available. In addition to lack of advanced equipment in developing countries, it has further been noted that VFSS is a relatively non-invasive, quick procedure that delivers minimal radiation to the child (Levine et al., 2009; Zammit-Maempel et al., 2007). DiSantos (2008) further acknowledges that although radiological procedures may have changed with regards to abdominal imaging, the gold standard for swallowing studies still remain fluoroscopy. Thus, in agreement with literature, this research serves to indicate that when done correctly, videofluoroscopy is still the most sensitive and accurate method for detecting swallowing abnormalities in infants and adults.

In terms of correct procedure and practice with regards to VFSS, some irregularities were noted with regards to the VFSS conducted at CMJAH and RMMCH. Literature (Arvedson, 2008) recommends that a clinical evaluation of swallowing should be conducted prior to VFSS. The health professional typically involved in the clinical assessment is a speech-language therapist (Puntis, 2008). Furthermore, it is suggested that a radiologist and a speech-language

therapist should be present at the VFSS (Hiorns & Ryan, 2006) in order to accurately determine the infant's feeding ability, make recommendations and perhaps implement management strategies during the VFSS to determine their efficacy. What was noted with regards to CMJAH and RMMCH is that primarily the clinical evaluation of swallowing did not always occur in that only 35.4% (n=56) of infants across the two hospitals received a consultation by a speech-language therapist. It is therefore hypothesised that if all of the infants received a clinical evaluation as recommended, the number of infants having to undergo a VFSS may have been reduced. This would have not only saved resources and time but the infants may have not needed to be exposed to the radiation doses associated with VFSS. In addition to a lack of clinical assessment, Mathers-Schmidt and Kurlinski (2003) administered a questionnaire to 150 speech-language therapists in Washington, USA in order to determine whether consistency exists with regards to the clinical evaluation. What was determined is that there was very little consistency with regards to the assessment procedure conducted by the speech-language therapists. Although research in this area with respect to South Africa is lacking it could be theorised that similar findings may be erodent internationally. Therefore, not only were only a small proportion of infants seen by speech-language therapists but the assessment procedures conducted may not be routine and standardised thereby influencing the outcome, need for objective measures and potentially management strategies. A reason for the lack of clinical evaluation and immediate VFSS referral may have been due to limited staffing in the speech therapy department or the need to save time by immediately conducting a VFSS particularly if silent aspiration is indicated. Research (DeMatteo et al., 2005) has determined that the agreement between a clinical evaluation of swallowing and VFSS is dependent on the experience of the speech-language therapist and whether or not the infant is experiencing silent aspiration. Therefore, the health

professionals involved in the assessment of the infant may have opted for an objective measure initially in order to acquire an accurate picture of the infant's swallowing ability and the presence or absence of aspiration.

In addition to the apparent lack of clinical evaluation it was also evident that speech-language therapists were not always present at the VFSS at CMJAH and RMMCH. This again is not in line with recommendations made internationally (Hiorns & Ryan, 2006). The VFSS provides an opportunity for the detection of aspiration and other swallowing difficulties for which the speech-language therapist is typically a decision maker with regards to intervention. The VFSS also provides an opportunity for the implementation of management strategies that may assist the infants feeding abilities (Prasse & Kikano, 2009). Therefore, if a speech-language therapist is not present at VFSS, these management strategies, for example thickening feeds, cannot be assessed and have to be implemented and monitored clinically. The concern is that infants may then be required to undergo repeat VFSS to determine the efficacy of these approaches further exposing them to unnecessary radiation.

4.6 Health Professionals Involved in Paediatric Dysphagia

In terms of implementation of management strategies, it is particularly worrisome when a speech-language therapist is not involved. For many of the infants attending CMJAH and RMMCH, therapeutic feeding interventions such as food and utensil modification and positioning were advised without the input of a speech-language therapist. An example of this concern is with regards to thickening of feeds, a common strategy for infants with GORD

(Vandenplas et al., 2005). Research (Wenzl et al., 2003) has shown that thickening feeds does not always eliminate the GORD and may just lower the height to which the infant is refluxing. Therefore, the overt signs such as regurgitation and halitosis (Arvedson & Brodsky, 2002, p. 165) may no longer be present but the child may still be experiencing the structural changes from prolonged stomach content exposure (Carroll et al., 2002; Wenzl et al., 2003). Therefore, if thickening of feeds is implemented by a medical professional alone without the intervention and monitoring from a speech-language therapist, the infant's symptoms may resolve but the underlying feeding difficulty may not. Consequently, as a result of the ongoing GOR, infants may refuse food, exhibit poor weight gain and subsequently have long term negative health and feeding correlates that with careful monitoring may have been minimised.

Furthermore, the inclusion of a speech-language therapist in all VFSS and paediatric dysphagia cases may assist in alleviating the work load of the physicians and doctors as many of the feeding interventions can be implemented and monitored by the speech-language therapist. Therefore, in a resource strapped environment such as state hospitals, the doctors can focus on the management of the infants' medical conditions and the speech-language therapist and allied team can further focus on the feeding and nutritional aspects.

With regards to the health professionals involved in the assessment and management of paediatric dysphagia it was determined that the most common health professional involved in paediatric dysphagia was a paediatrician or general doctor. In light of the findings related to the aetiological factors affecting the infants with dysphagia, this is encouraging. This further linked

to the management provided in that the most predominant form of intervention provided was with regards to medical intervention.

In comparison to developed countries it was determined that HIV and paediatric palliative care (PPC) teams formed part of the health professionals involved in paediatric dysphagia. Palliative care is defined as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (World Health Organisation, n.d.). Research conducted in Malawi (Lavy, 2007) determined that HIV/AIDS is the most prevalent terminal illness in infants with multiple pain, nutrition and social correlates particularly towards the end stage of the disease (Lavy, 2007). This supports the findings for the need for palliative care in developing countries, where HIV/AIDS is rife, in order to not only alleviate the pain and suffering on the part of the child but also the family. Therefore, it is encouraging to note that these services are being provided in state hospitals.

Over time it may be apparent that through early intervention from HIV/AIDS teams and the early introduction of antiretroviral medication may minimise the progression from HIV to AIDS as well as improve the immunological status of infants that decreases their susceptibility to communicable diseases (Layton & Davis-McFarland, 2000). Therefore, the inclusion of HIV/AIDS specific teams in the hospitals to assist in the counselling and administration of antiretroviral treatment and specific medicines appears to indicate that some of the needs of both the infants and families are being met. The World Health Organisation (2007) stipulates that feeding difficulties related to HIV/AIDS present early on in the illness manifestation including

odynophagia, oral candida as well as in the late stages, HIV encephalopathy. Therefore it is hypothesised that the fact that many infants in state hospitals in South Africa are receiving intervention from HIV/AIDS teams, infants are perhaps receiving antiretroviral treatment at an early stage in their illness thereby reducing the progression of the illness (Layton & Davis-McFarland, 2000). However, at present there are not clearly stipulated guidelines delineating the role of the HIV/AIDS and PPC professionals and therefore this may result in role confusion and either under or over management of the infants. What is worth noting is that over time, with the inclusion of HIV/AIDS teams and PPC early on in the diagnosis of dysphagia and in light of the aetiology of dysphagia in infants in South Africa, it may be seen that effective role-out of antiretroviral treatment, family counselling and regular monitoring and developmental consultations, the profile of paediatric dysphagia in the birth to eighteen month population may change. Due to this regular monitoring, antiretroviral therapy and involvement of the HIV teams, infants may have improved immunology and therefore may no longer be as susceptible to opportunistic infections. This may therefore change the profile of paediatric dysphagia in infants in developing countries such as South Africa.

4.7 Management of Paediatric Dysphagia

As seen with regards to the intervention strategies employed, it appeared that a combination approach of treating not only the underlying aetiological factors but the symptoms of the swallowing difficulties provided the most favourable outcomes for minimising the feeding impairment and the long term negative health and development consequences. With particular reference to this research, it was noted that the majority of infants presented with multiple

aetiological factors that may or may not have contributed to the dysphagia. Therefore, the fact that the collaboration of multiple health professionals and diverse intervention approaches were employed with respect to paediatric dysphagia was not a surprise.

What was evident with regards to this research was that medical intervention was the most common management strategy employed for infants presenting with paediatric dysphagia. This is most likely linked to the fact that the majority of infants presented with dysphagia secondary to a systemic illness. Early intervention with regards to systemic illnesses such as diarrhoeal disease, pneumonia (Gessman & Rappaport, 2009; Kosek et al., 2003) and the introduction of antiretroviral treatment (World Health Organisation, 2007) for those infants presenting with HIV/AIDS may minimise the negative consequences and health correlates of these illnesses. Therefore, when the management strategies were considered with regards to the time of VFSS it was promising to note that infants in South Africa are receiving early medical intervention. It is hypothesised that with early medical intervention, the systemic illnesses underlying the paediatric dysphagia have the potential to be resolved or reduced in severity. However, this provides information towards the need for close collaboration between health professionals such as speech-language therapists and paediatricians. It is vital for those speech-language therapists involved in infants with dysphagia secondary to systemic illness to familiarise themselves with the effects of medication on the disease profile and progression of systemic illnesses. Clinical feeding ability can therefore be linked to the provision of medical intervention and it can be determined as to whether or not the paediatric dysphagia has the potential to be resolved if the systemic illness is addressed.

As many of the conditions experienced by these infants such as pneumonia, HIV/AIDS, gastroenteritis and tuberculosis can be treated or managed fairly effectively with medicine; this medical intervention would typically be the first line of treatment. What was further noted however is that many infants received multiple intervention strategies related both to medical, surgical and therapeutic intervention.

The strategies related to positioning (n=85) and food modification (n=80) across the three hospitals attempted to alter the feeding environment as opposed to the infant itself. These management strategies were not used in isolation and combinations of management strategies were implemented. Correct positioning during feeding is typically prescribed for infants either with GORD or motor impairments secondary to neurological complications such as cerebral palsy (Carroll et al., 2002; Hall, 2001, p. 51; Workinger, 2005, p. 91). Elevation of the infant's head or lying in prone has been widely advocated for infants with GOR (Carroll et al., 2002; Nel, 2007; Vandenplas et al., 2005). The rationale behind this is to allow gravity to assist in preventing the stomach contents from moving into the oesophagus as well as to improve gastric emptying (Hall, 2001, p. 131). However there has been little or no conclusive evidence to support this technique for reducing the episodes of reflux. In a systematic review of the literature surrounding GOR management strategies (Carroll et al., 2005) it was noted that there is no conclusive evidence to support the efficacy of positioning as a technique to reduce reflux. One concern that has recently arisen with regards to positioning is minimising the risk of sudden infant death syndrome (SIDS). Current literature (Nel, 2007; Vandenplas et al., 2005) indicates that prone positioning in young infants should be cautionary and reserved as a final management option. However, even with a lack of conclusive, evidence-based research into the efficacy of

these strategies, the fact that they are non-invasive and pose minimal negative side-effects, they were widely adopted with regards to management in this study.

In terms of positioning with regards to neurologically based feeding difficulties, the principles include maintaining alignment and optimising the structural abilities for safe and efficient swallowing (Workinger, 2005, p. 106). Furthermore, positioning can have multiple benefits promoting the social aspects of feeding such as communication and eye contact (Arvedson & Brodsky, 2002, p. 400). What was not recorded was the positioning information provided to the caregivers and whether the parents and/or nursing staff were provided with information pertaining to the possible side effects. However, with the number of allied professionals included in the management, in particular occupational and physiotherapists it appears that positioning has become a multidisciplinary approach in the management both of the infant's underlying condition as well as the dysphagia. Significant relationships were found to exist between oral phase, dysphagia food modification, positioning, oral-motor therapy, utensil modification and the insertion of a naso-gastric (NG) tube. In addition, when the management strategies were analysed with regards to aetiological factors a significant relationship was found to exist between positioning strategies and dysphagia with a neurological aetiology. This is in agreement with literature whereby positioning techniques are implemented for children with postural, tone and stability difficulties typically associated with neurological impairments (Workinger, 2005, p. 91). In terms of utensil modification, the most frequently implemented intervention strategy was with regards to implementing cup feeding as opposed to breast or bottle feeding. This may have been due to the Baby Friendly Status implemented in many of the state hospitals in South Africa, including those reviewed in this study. The relationship between oral

phase dysphagia and utensil modification may indicate that due to the Baby Friendly initiative in the hospitals, those infants that presented with sucking difficulties were provided with cup-feeding as an alternate method, regardless of the underlying reason for the inability to breast feed (Flint et al., 2008).

It appears that the management strategies employed at the hospitals in this research were appropriate to the infant's nature of dysphagia. A significant relationship was found to exist between oral motor stimulation and oral phase dysphagia. This supports literature (Siktberg & Bantz, 1999) that advocates the use of oral motor strategies for infants with oral phase dysphagia. In addition, it was established that a relationship between oral phase dysphagia and the insertion of a NG tube exists. The combination of management approaches of oral motor stimulation and insertion of a NG tube is a promising one in that literature (Gisel, 2008; Mason et al., 2006; Pinelli & Symington, 2005) has indicated that an oral motor program in conjunction with NG tube feeding decreases the period in which the infant requires non-oral feeds and a decreased hospital stay. Therefore, it can be said that with regards to infants with oral phase dysphagia, the management strategies implemented are in agreement with those recommended in literature.

A large proportion of the infants (n=80) attending the three hospitals reviewed in this research received tube feeding in the form of NG or PEG feeds as an intervention strategy. In addition to oral phase dysphagia, a significant relationship was found between pharyngeal phase dysphagia and the insertion of a NG and PEG tube. This may have been a result of concern regarding the infant's ability to feed safely with minimal risk of aspiration. The period in which

the infants received NG feeds in particular ranged from one to 72 days. Gisel (2008) recommends that NG feeds be implemented for no longer than 42 days before long term non-oral feeding options are considered. Only four infants in this study received NG feeds for longer that the allotted period with the remainder either transitioning back to oral feeds or receiving a PEG for long term feeding. This alludes to the fact that either the underlying cause of the dysphagia resolved with intervention or other strategies were implemented to ensure safe feeding. When the four infants that received NG feeds over the recommended 42 days are considered, the debate surrounding the length of NG emerges. It can be argued that the therapists or doctors prescribing the NG were not aware of the consequences of prolonged NG exposure including oral sensitivity and reluctance to feed orally (Gisel, 2008). Alternatively, the prognosis for these infants may have been good in that the underlying aetiology was resolving and needed more time to resolve and therefore the NG tubes may have been considered a necessary risk. What was interesting to note is that all four infants returned to oral feeds, and this seems to support this hypothesis.

In terms of management strategies implemented with regards to those infants with dysphagia secondary to a systemic illness, a significant relationship was found to exist with regards to medical intervention, the insertion of an NG tube and pacing of feeds originally included as "other" management strategies. The fact that many infants with dysphagia as a result of systemic illness received medical intervention is not surprising. As mentioned the majority of systemic illnesses affecting the infant's feeding ability were communicable in nature; thus requiring medical intervention. An interesting aspect was with regards to systemic illness and the insertion of NG tubes. It is hypothesised that this may be due to the fact that infants with communicable diseases may present with symptoms specifically affecting respiration and

therefore compromising the respiratory system and the infant's ability to feed safely. In addition, infants with respiratory based aetiologies have been found to present with minimal lingual movement and desire to eat and it is hypothesised that this a strategy employed by the child in the protection of the airway (Baudon et al., 2009) therefore, requiring the need for alternative forms of feeding to promote weight gain, hydration and nutrition.

Pacing of feeds was also significantly correlated with infants with dysphagia secondary to a systemic illness. Dusick (2003) reports that pacing of feeds may be recommended for those infants either born premature or those with respiratory based feeding difficulties. This therefore links to the fact that the predominant systemic illness affecting the infants in this study was respiratory in nature. Once again this confirms that the management strategies implemented at the hospitals reviewed in this research are aligned with literature and are specific to the infant's specific aetiological factors and dysphagia profile.

In addition to those infants with disordered swallowing, 57 infants presented with normal swallowing physiology. When the aetiological factors, caregiver's complaint and management strategies employed with regards to infants with normal swallowing were analysed, it was determined that the infants with normal swallowing presented similarly to those with dysphagia. Once again it was determined that the predominant aetiological factor underlying feeding difficulties but not with a resultant dysphagia was a systemic illness, typically respiratory based. This indicates that in these infants the feeding difficulties may have been due to the aetiology. Furthermore, the management strategies implemented for those with normal swallowing were similar to those with disordered swallowing. This indicates that many conditions and illnesses

may have resultant negative effects on feeding ability although swallowing physiology was intact. Furthermore, it indicates that those infants with feeding difficulty but no dysphagia may require similar management strategies to promote weight gain, hydration and appropriate feeding until the underlying condition causing the feeding difficulties are resolved.

From this research it can be seen that the profile of infants with dysphagia in South Africa differs somewhat to that seen internationally. The most striking factor revealed was with regards to the aetiological factors associated with dysphagia whereby the predominant aetiological factor was a result of systemic illness and particularly related to communicable diseases. It was concerning to note that appropriate assessment and VFSS procedures were not always followed and the fact that a speech-language therapist was not consulted for the most part. However, it was promising to note that the management strategies employed by the staff at the hospitals reviewed were aligned with those recommended internationally. In addition the management strategies appeared to be significantly linked to the nature of dysphagia as well as the aetiological factors underpinning the dysphagia.

CHAPTER FIVE

CONCLUSION

Chapter five highlights the recommendations suggested for both future research and the potential implementation of policies and protocols within the South African context. In addition Chapter five concludes this research.

From this research a number of recommendations have been proposed both in terms of future research and practice in paediatric dysphagia specifically within the South African context.

One of the main difficulties faced with regards to this research was with respect to the research design. A retrospective record review, although beneficial for observing a phenomenon that would be otherwise difficult to analyse (Terre Blanche et al., 2006), is fraught with concerns regarding the integrity of the medical records and missing data in some of the medical files (Gearing et al., 2006). However, due to the complex nature of paediatric dysphagia and the vulnerability of the population under investigation it is still felt that this was the best research design to examine the nature and aetiological factors of infants with paediatric dysphagia in South Africa. For the purpose of future research however it will be useful to conduct a prospective, longitudinal study of infants with paediatric dysphagia to analyse whether medical intervention addressing the underlying systemic illness may eliminate or minimise the degree of feeding impairments in infants.

In addition to research into systemic illness, medical intervention and dysphagia, a study comparing the differences in infants from urban areas with access to private health care and those using the state health system should be conducted. This may provide a more comprehensive profile into whether infants with access to private health care exhibit paediatric dysphagia similar to that in developed countries or whether the social factors and circumstances surrounding infants in South Africa are similar throughout all levels of health care.

A concern raised in the literature and further reinforced within this research was with regards to the classification of paediatric feeding disorders. Internationally there is no one proposed classification system for paediatric dysphagia. Therefore the model for classifying paediatric dysphagia, as outlined in *Chapter Four* is proposed. This system provides a basis from which paediatric dysphagia can be described and compared. This model also provides a tool that can be implemented repeatedly to monitor the changes and progression of dysphagia in infants.

In terms of the aetiological factors, a longitudinal study is proposed that analyses the long terms effects of dysphagia as a result of a systemic illness. It has been determined that in a developing country, dysphagia as a result of systemic illness is the most predominant aetiological factor affecting infants with dysphagia. The long term effects of these illnesses on the infant's feeding ability has not yet been explored. As many of the communicable diseases are treated with medical intervention and have the potential to be treated, it is proposed that a longitudinal study in developing countries be conducted to determine whether the infants experience long term negative feeding consequences or whether the resolution of the communicable disease perhaps resolves the feeding impairment and potentially dysphagia.

As communicable diseases and paediatric dysphagia have not previously been intricately linked, it can be hypothesised that speech-language therapists practicing in state hospitals may not have knowledge of the relationship between paediatric dysphagia and communicable diseases and the social and health challenges they present. It is therefore suggested that University training as well as in-service training should be conducted at all of the state hospitals within South Africa. This training will assist in the differential diagnosis of paediatric dysphagia and provide a more holistic view of the medical, social and health factors that may influence the infant's feeding ability.

Literature (Mathers-Schmidt & Kurlinski, 2003) has also indicated that at present there is no standard clinical assessment procedure for evaluating paediatric dysphagia and that a lack of consistency was found across speech-language therapists. This research did not specifically evaluate consistency among the speech-language therapists but as discussed previously, there was a lack of consistency across the hospitals. It is therefore recommended that a standardised procedure for clinical assessments should be created. This will provide consistency across assessment procedures and intervention provided by speech-language therapists, hospitals and to assist in comparing literature internationally. In addition it will provide a specific assessment process that can be provided to other health professionals as a guide for the role of the speech-language therapist in the clinical assessment of dysphagia. This standardised procedure may assist in alleviating the role of the medical professionals in paediatric dysphagia, in that a referral for a clinical evaluation of feeding and swallowing may decrease the number of VFSS referrals.

In addition, a standardised clinical assessment may help provide a concrete decision-making process for those infants requiring VFSS. This may also further advocate the need for a speech-language therapist to be present at all VFS studies. This is particularly necessary in the South African context whereby as seen in this research, not all of the VFS studies were conducted with a speech-language therapist present. In addition to the presence of a speech-language therapist at all VFS studies it is recommended that a standardised recording form for the VFSS should be created. At present CMJAH and RMMCH utilise the standard x-ray form (Appendix Q) that is not specific to VFSS, whereas the speech therapy department at CHBH have created a specific form to be used during VFS studies (Appendix R). It is therefore recommended that either a form similar to that utilised at CHBH should be implemented nationally at all hospitals perhaps in conjunction with the Departments of Health in each of the South African provinces.

In order to assist in the referral process for an infant with feeding difficulties, a schematic diagram has been created that could potentially be implemented in the hospital system. This flow diagram was created as from this research it was determined that many of the infants are being seen by medical professionals yet few infants were seen by a speech-language therapist. This is a concern as feeding difficulties have many negative health, growth and developmental correlates (Calis et al., 2008; Schwartz et al., 2001; Prasse & Kikano, 2009) that could potentially be reduced with a combination of medical and therapeutic intervention. This model therefore allows for the collaboration between medical professionals and speech-language therapists in both the assessment and management of infants with feeding impairments.

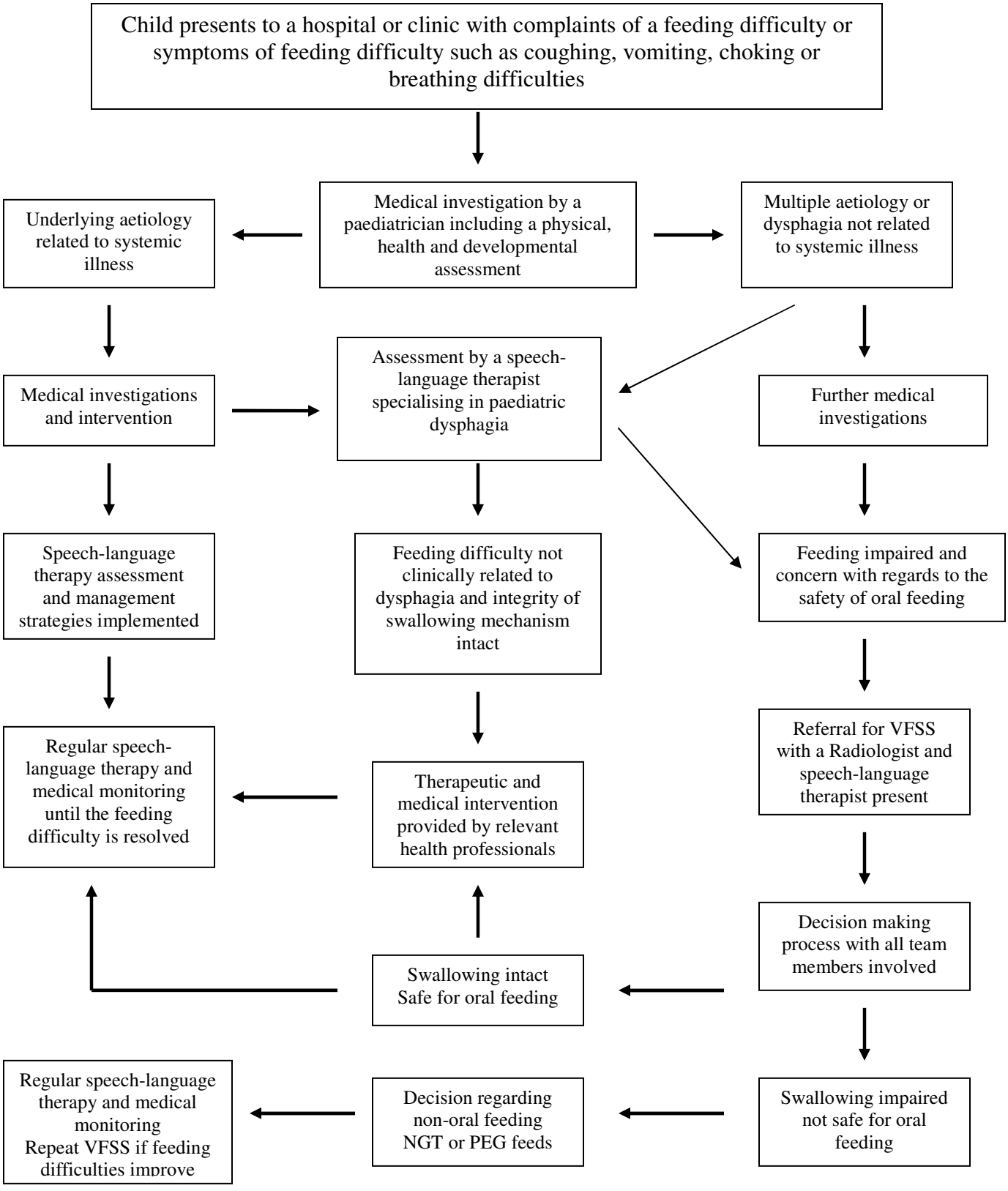


Figure 4. Schematic representation of the referral process for infants with feeding impairments

One of the goals proposed by the United Nations Millennium Development Goals (United Nations, 2010) to be achieved before 2015 is that the effects and prevalence of communicable diseases should be considerably reduced. As it has been discussed, many of the aetiological factors affecting the infants in this study are a result of communicable diseases which are potentially preventable. Therefore, it is suggested that the Department of Health should continue to be involved in promoting access and services at a district health level. Early intervention for communicable diseases may reduce the severity and long term negative consequences of communicable diseases. As it has been shown that a large proportion of paediatric dysphagia in South Africa is a result of communicable diseases, early intervention at a primary health level may reduce the prevalence of these diseases and subsequently reduce not only the number of infants with paediatric dysphagia but also the case load on regional and tertiary hospitals.

It has been established that paediatric dysphagia experienced by infants in South Africa is considerably different to dysphagia experienced by infants born into developed countries. This research showed that the most significant differences were with regard to the fact that infants presented with multiple aetiological factors influencing the dysphagia. Furthermore, it was determined that the majority of infants presented with dysphagia secondary to a systemic illness with many of the diseases communicable in nature. In terms of the systemic illnesses affecting the infants, it was determined that the infants presented predominantly with respiratory based systemic illnesses. In addition to respiratory based illnesses, many of the infants presented with HIV/AIDS. Failure to thrive, gastrointestinal diseases with resultant dehydration as well as nutritional based feeding problems such as kwashiorkor and malnutrition were found to affect

many of the infants in this research. Therefore, it appears that the majority of the infants in this study presented with dysphagia as a result of communicable illnesses and factors related to poverty and poor social circumstances.

The prevalence of these communicable diseases in infants account for a large proportion of infant deaths in South Africa (Bradshaw et al., 2003) and can be attributed to many of the negative social factors that plague infants in developing countries (Grantham-McGregor et al., 2007). In particular, these social factors were related to poor water and sanitation, poverty, under nutrition and minimal access to health care services. This links closely to the United Nations Millennium Development Goals whereby reforming social factors, reducing infant mortality, the prevalence of communicable diseases and access to clean water and sanitation are targeted for 2015. The United Nations has attributed these goals to predominantly social and health factors. As communicable diseases, malnutrition, dehydration and paediatric dysphagia have been found to have long term negative health and development consequences it appears that paediatric dysphagia has become a health, social, education and ultimately human rights issue.

This research was conducted through a retrospective record review, which as stipulated in literature has both advantages and disadvantages. This research design provided valuable information with regards to vulnerable population of infants. It further provides the basis for which future, prospective, longitudinal research can commence and provide greater research into the profile of infants with paediatric dysphagia in developing countries such as South Africa.

Thus, in conclusion, this research aimed to determine the nature and aetiology of paediatric dysphagia in infants (0-18 months) in state hospitals, Gauteng. The null hypothesis was disproved in favour of the alternate hypothesis stating that the profile of paediatric dysphagia in South Africa differs considerably in relation to paediatric dysphagia reported internationally. These differences were particularly noted with respect to the aetiological factors underpinning the paediatric dysphagia. It was found that the majority of paediatric dysphagia in state hospitals, Gauteng, South Africa could be attributed to communicable diseases. In addition, the profile of the aetiological factors influencing dysphagia was somewhat complex and included in some cases up to eight different aetiological factors. Therefore, in light of this, it was revealed that paediatric dysphagia in South Africa is not only a health concern but due to the number of communicable diseases contributing to the cause of dysphagia, a social factor too. These results are particularly important for the speech-language therapists working within the field of paediatric dysphagia. As discussed assessment and intervention practices for paediatric dysphagia are based on international literature that may not always be relevant to the South African context. Therefore, it is important that speech-language therapists practicing in the South African context should familiarise themselves with literature and information pertaining to the different aetiological and social factors that have been found to influence paediatric dysphagia. In addition, due to the complex nature of dysphagia it is important that all health professionals involved in feeding should keep up to date with current research and clinical practice and further promote team work and collaboration in order to manage the infants' with dysphagia holistically and effectively. This collaboration is particularly important in the South African context where it appears that the dysphagia experienced by infants, varies not only from infant to infant, but also

with regards to the complex, multiple and varied aetiological factors that underpin the feeding impairment.

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APPENDIX A

13 August 2009

Dear Sir/Madam

RE: Permission to conduct post-graduate research at your hospital

My name is Andrea Fourie and I am currently registered as a post-graduate student with the University of the Witwatersrand, Johannesburg. I am in the process of attaining a master's degree in Speech-Language Pathology within the domain of Paediatric Dysphagia (infants' with feeding difficulties). My research aims to investigate the aetiology and nature of dysphagia in infants, within the age range of birth-18 months, having undergone a videofluoroscopic evaluation. My research further aims to determine the health professionals involved in their care as well as the management provided for each infant. In order to achieve these aims I will need to conduct a medical record review of 300 infants' patient records at three Government Hospitals in the Gauteng Province.

I would like to obtain the details of the last 100 infants that have undergone a videofluoroscopic evaluation at your Radiology department. I then would access any other hospital records, for example speech therapy, physiotherapy, etc, related to the child's dysphagia and use these records as data for my research. During the research process I will not require the participation of any infants and their immediate families. I would however require some assistance from the staff in Radiology and filing in order to access the medical records. It should take approximately 30 hours (4-5 days) for me to collect all of the information required. If possible I will work in a quiet space in or near to the filing room to minimise disruptions and ensure quick return of the hospital files used.

The purpose of this study is to provide greater insight into paediatric dysphagia in the 0 -18 month infant population in a Gauteng, Government Hospital. It is the aim of this research to further clinical knowledge

in the domain of paediatric dysphagia as well as provide a means of evaluating and possibly improving the care of infants with dysphagia in the hospitals included.

Prior to submission to the ethics committee, I require consent from the hospitals for participation in the research. Once consent has been granted, the proposal will be submitted to the ethics committee. Following this, once the research has been approved by the ethics committee I will submit the ethics certificate and protocol number to the hospital. The information and consent letters have been sent to the following departments within your hospital for approval;

- the CEO of the hospital
- the head of Gastro-Radiology
- the head therapist within the Speech Therapy department

If you have any concerns or questions regarding the nature of my research or the involvement of your hospital please do not hesitate to contact me on my email address or work telephone number: andrea.l.fourie@gmail.com or 011 4890823

Alternatively you may contact my supervisor Joanne Barratt at joanne.barratt@wits.ac.za

I look forward to hearing from you in this regard.

Yours sincerely

Andrea Fourie

andrea.l.fourie@gmail.com

011 4890823 (w)

APPENDIX B

CONSENT FORM

I _____

(*Name, surname and job title*) hereby do/do not give permission to Andrea Fourie to obtain the medical records of patients, in the birth-18 months age group, having undergone a videofluoroscopic evaluation at _____ (*name of hospital*).

I have read the information letter attached and fully understand the implications of my hospital's involvement in this research process.

_____ _____

Signature Date

APPENDIX C

Private bag X39, Johannesburg 2000, South Africa
Tel: +27 (0) 11 488 4911, Fax: +27 (0) 11 643 1612
www.johannesburghospital.org

Gauteng Department of Health

Office of the CEO
Charlotte Maxeke Johannesburg
Academic Hospital
Enquiries: M. Motjelele
(011): 488-3792/3
(011) 488-3753
26th August 2009

Attention: Andrea Fourie
Post - Graduate Student
University of Witwatersrand

Dear Andrea Fourie

RE: Permission to do research on aetiology and nature of dysphagia in infants, within the age range of birth -18 months, having undergone a video fluoroscopic evaluation.

Permission is provisionally granted for you to conduct the study as stated in your request dated 3/06/2009 provided:

1. The Charlotte Maxeke Johannesburg Academic hospital will not in anyway incur or inherit costs as a result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.
5. Ethics approval will be obtained & submitted to the CEO's office before commencement of your study.

Please liaise with the Head of Department and Unit Manager or Sister in Charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

Yours sincerely

Dr. S. B. Mfenyana
Acting Chief Executive Officer

APPENDIX D

CONSENT FORM

I PROF. V. MAGOMEZULU HOD, RADIOLOGY

(*Name, surname and job title*) hereby do/~~do not~~ give permission to Andrea Fourie to obtain the medical records of patients, in the birth-18 months age group, having undergone a videofluoroscopic evaluation at

CMJA HOSPITAL (*name of hospital*).

I have read the information letter attached and fully understand the implications of my hospital's involvement in this research process.

Signature

26/08/2019.

Date

3

APPENDIX E

CONSENT FORM

I T. JOGIANNA (CAD: STEA)

(*Name, surname and job title*) hereby do/~~do not~~ give permission to Andrea Fourie to obtain the medical records of patients, in the birth-18 months age group, having undergone a videofluoroscopic evaluation at

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL (*name of hospital*).

I have read the information letter attached and fully understand the implications of my hospital's involvement in this research process.

Signature (CAD: STEA)

18/08/2009
Date

3

APPENDIX F

PERMISSION TO CONDUCT RESEARCH AT CHRIS HANI BARAGWANATH HOSPITAL

PRINCIPAL RESEARCHER:

FULL NAME: Andrea Lynn Fourie

DESIGNATION: Speech Language Pathologist

CONTACT NUMBER: 072 368 6501

EMAIL: andrea.l.fourie@gmail.com

DEPARTMENT/S: ~~The~~ Radiology and Speech Therapy.

HEAD/S OF DEPARTMENT/S: Acting HOD: Dr Najdee Sadna Bolton

TITLE OF RESEARCH: The nature and aetiology of paediatric dysphagia (0-18months) in State Hospitals Johannesburg, Gauteng.

OBJECTIVES OF RESEARCH: No patient contact : Record Review To To determine the aetiology and nature of paediatric dysphagia through videofluoroscopic evaluation record review. Describe medical factors contributing to dysphagia and professionals involved in paediatric dysphagia

STUDY SITE/S: Rahima moosa mother and child, CMJAH, CH Baragwanath hospital.

BRIEF OUTLINE OF METHODOLOGY: Record review of 100 patient (0-18months) files from each hospital. Retrospective in nature.

EXPECTED START DATE: Oct/Nov 09 EXPECTED DURATION: 6 months

ETHICS CLEARANCE ? Y / N / (PENDING)

CONFLICTS OF INTEREST ? Y / (N) DETAILS

COSTS TO HOSPITAL AND/OR PATIENTS ? Y / (N)

SOURCE OF FUNDING: self funded.

PERMISSION GRANTED (Y) / ~~N~~

SIGNATURE | NAME IN PRINT + DESIGNATION | OFFICIAL STAMP+DATE

CHRIS HANI BARAGWANATH HOSP
P.O. BERTSH/ SA
2009 -08- 27
CLINICAL

APPENDIX G

CONSENT FORM

I DR IA NAGIDEE (ACTING HOD RADIOLOGY)

(*Name, surname and job title*) hereby do/~~do not~~ give permission to Andrea Fourie to obtain the medical records of patients, in the birth-18 months age group, having undergone a videofluoroscopic evaluation at

CHRIS HANI BARAGWANATH (*name of hospital*).

I have read the information letter attached and fully understand the implications of my hospital's involvement in this research process.

Signature

21/08/2009.

Date

3

APPENDIX H

CONSENT FORM

I Dr Sadna Balton - Head of Department

(*Name, surname and job title*) hereby (do)/do not give permission to Andrea Fourie to obtain the medical records of patients, in the birth-18 months age group, having undergone a videofluoroscopic evaluation at

Chris Hani Baragwanath Hospital (*name of hospital*).

I have read the information letter attached and fully understand the implications of my hospital's involvement in this research process.

Signature

25/08/09.

Date

CHRIS HANI BARAGWANATH HOSPITAL

2009 -08- 25

SPEECH THERAPY AND AUDIOLOGY DEPARTMENT

3

APPENIDX I

CONSENT FORM

I LINDA F. Van der Ross A.D. PHYSIOTHERAPY.

(*Name, surname and job title*) hereby do/~~do not give~~ permission to Andrea Fourie to obtain the medical records of patients, in the birth-18 months age group, having undergone a videofluoroscopic evaluation at

RAHIMA MOOSA HOSPITAL (*name of hospital*).

I have read the information letter attached and fully understand the implications of my hospital's involvement in this research process.

Signature Romi micad. Date 5. 08 09

L.F. v.d. Ross
A.D Physiotherapy

GAUTENG ADMINISTRASIE
RAHIMA MOOSA HOSPITAL
RECEIVED BY
5 AUG 2009
Mrs. S. JORDAAN
CEO
GAUTENG ADMINISTRATION

3

APPENDIX J

CONSENT FORM

I Salma Patel.

(*Name, surname and job title*) hereby do/do not give permission to Andrea Fourie to obtain the medical records of patients, in the birth-18 months age group, having undergone a videofluoroscopic evaluation at

Rahima Moosa Mother & Child (*name of hospital*).

I have read the information letter attached and fully understand the implications of my hospital's involvement in this research process.

Signature [signature] Date 06-08-2009

3

APPENDIX K

CONSENT FORM

I Natalie Tog (Junior speech therapist & Audiologist)

(*Name, surname and job title*) hereby (do)/do not give permission to Andrea Fourie to obtain the medical records of patients, in the birth-18 months age group, having undergone a videofluoroscopic evaluation at

Rahima Moosa Hospital (*name of hospital*).

I have read the information letter attached and fully understand the implications of my hospital's involvement in this research process.

Signature

23/07/09

Date

3

APPENDIX L

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Miss Andrea Lynn Fourie

CLEARANCE CERTIFICATE	**M091041**
PROJECT	The Aetiology and Nature of Paediatric Dysphagia (0-18 months) in State Hospital Johannesburg, Gauteng
INVESTIGATORS	Miss Andrea Lynn Fourie.
DEPARTMENT	Speech Pathology & Audiology
DATE CONSIDERED	2009/10/30
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 2009/11/02 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : J Barrat

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

APPENDIX M

PARTICIPANT DEMOGRAPHICS

Participant number	Age in months at assessment	Area of residence

TYPE OF DYSPHAGIA

Oral Phase							
Participant number	**Poor suck**	**Delayed oral onset**	**Poor bolus formation**	**Poor bolus propulsion**	**Poor lateral tongue movement**	**Tongue thrust**	**Oral residue**

Pharyngeal Phase							
Premature spillage	**Delayed trigger**	**Penetration**	**Aspiration**	**Nasal regurgitation**	**Pharyngeal wall residue**	**Valleculae residue**	**Pyriform sinus residue**

Oesophageal Phase				
Gastro-Oesophageal reflux	**Oesophageal-oesophageal reflux**	**Impaired oesophageal motility**	**Tracheo-oespohageal fistula**	**Oesophageal residue**

AETIOLOGY OF DYSPHAGIA

Participant number	Neurological	Disorder	Anatomical	Disorder	Genetic	Disorder	Secondary to systemic illness	Disorder	Psych/ Behavioural	Disorder

CAREGIVERS PRIMARY COMPLAINT

Participant number	Poor weight gain	Coughing	Choking	Food refusal	Vomitting	Other

HEALTH PROFESSIONALS INVOLVED

Participant number	Speech-language therapist	Dietician	Paediatrician	Radiologist	GIT specialist	General surgeon	Physio	OT	Social work	Other

MANAGEMENT STRATEGIES

Participant number	Food modification	Utensil modification	Positioning	Oral-Motor therapy	Medical	Surgical	Alternative feeding	Other

APPENDIX N

Oral phase of dysphagia

Poor sucking, drinking, taking food off a spoon and/or chewing

Anterior spillage of liquid/food

Spillage/residue of liquid into the anterior and lateral sulci

Food pushed out of the mouth

Poor formation or propulsion of the bolus posteriorly

Multiple tongue swallows

Pharyngeal phase of swallowing

Pooling/residue in the valleculae

Pooling/residue in the pyriform sinuses

Delayed triggering of the swallow

Penetration

Aspiration

Pharyngeal wall residue

Nasal-pharyngeal backflow/regurgitation

Oesophageal phase of swallowing

Gastro-oesophageal reflux

Oesophageal dysmotility

Residue on the oesophageal wall

(Arvedson & Brodsky, 2002, p. 46, 320; Norman et al., 2007; Stroeckli et al., 2003)

APPENDIX O

PARTICIPANT DEMOGRAPHICS

Participant number	Age in months at VFSS	Area of residence

TYPE OF DYSPHAGIA

Participant number	Oral phase	Salient feature	Pharyngeal phase	Salient feature	Oesophageal phase	Salient feature	Aspiration

AETIOLOGY OF DYSPHAGIA

Participant number	Neurological	Disorder	Anatomical	Disorder	Genetic	Disorder	Secondary to systemic illness	Disorder	Psych/ Behavioural	Disorder

CAREGIVERS PRIMARY COMPLAINT

Participant Number	Poor weight gain	Coughing	Choking	Food refusal	Vomitting	Breathing difficulties	Other

HEALTH PROFESSIONALS INVOLVED

Participant Number	Speech Therapist	Dietician	Paediatrician	Radiologist	GIT specialist	General surgeon	Physio	OT	Social work	Other	Describe

MANAGEMENT STRATEGIES

Part no.	Food modification	Utensil modification	Positioning	Oral-Motor therapy	Medical	Surgical	NGT	Duration	PEG	Duration	TPN	Duration	Other

APPENDIX P

RESEARCH ASSISTANT CONFIDENTIALITY AGREEMENT

The aetiology and nature of paediatric dysphagia (0-18 months) in state hospitals Johannesburg, Gauteng.

Ethical Clearance certificate: M091041

I, Tracey Kennedy, agree to assist **Andrea Fourie**, with this study by collecting the required information as stipulated by Andrea Fourie from thirty files, in three hospitals in Johannesburg, Gauteng. I agree that I will:

- keep all research information shared with me confidential by not discussing or sharing the information in any form or format with anyone other than the primary investigator of this study;
- keep all research information in any form or format secure while it is in my possession.
- give all research information in any form or format to the primary investigator when I have completed the research tasks;
- erase or destroy all research information in any form or format that is not returnable to the primary investigator upon completion of the research tasks.

Kennedy
Signature of research assistant

30/06/2010
Date

Signature of primary investigator

30/06/2010
Date

№ 0130

Chris Hani Baragwanath Hospital
Department of Speech Therapy

PAEDIATRIC VIDEOFLUOROSCOPY RESULTS **Date:**

Name: **Age:** **GT Number:**

Currently Eating: oral / non-oral / both **Main Concern:** oral phase / aspiration / reflux / structural

Disorder: **Clinician:** **Radiologist:**

	Thin liquid		Thick liquid		Paste		Solid	
Trial	1	2	1	2	1	2	1	2
Utensil/Equipment used (e.g. cup, bottle, spoon)								
Oral Phase								
Delayed oral onset								
No bolus formation								
No bolus propulsion								
No lateral tongue movement								
Thrusting tongue movements to initiate swallow								
Material moving over base of tongue without initiation of swallow								
Multiple swallows								
Residue								
Comments:								
Pharyngeal Phase								
Residue on the pharyngeal wall								
Over the top spill								
Residue in the valleculae and/or pyriform sinus								
Nasal regurgitation								
Aspiration								
Comments:								
Oesophageal Phase								
Gastro-oesophageal reflux								
Oesophageal-oesophageal reflux								
Impaired motility of the oesophagus								
Residue on the oesophageal wall								
Tracheo-oesophageal fistula								
Comments:								

Comments and Suggestions:

Recommendations:

Short term non-oral feeding	Anti-reflux milk	Other:
Long term non-oral feeding	Positioning	
Liquid diet only	Further investigations	
Pureed diet only	Repeat videofluoroscopy	

Key ✓ indicates presence of that particular aspect of swallowing; a blank square means the absence of that particular aspect of swallowing; DNT indicates that this aspect was not tested.

Signature: (Radiologist)

Signature: (Speech Therapist)

10/03

APPENDIX R

81/508181
TPH.62D

DEPARTEMENT RADIOLOGIE/DEPARTMENT OF RADIOLOGY
MAG SLEGS DEUR GENEESHEER VOLTOOI WORD/MAY ONLY BE COMPLETED BY A DOCTOR

..... HOSPITAAL/HOSPITAL Rö No.: .....

PASIËNT/PATIENT: ..... LOPEND / WALKING ☐ BED VERVOER / BED TRANSPORT ☐ DRAAGBAAR / STRETCHER ☐

HOSP. No.: ..... STOEL / CHAIR ☐ **DOEN IN SAAL / DO IN WARD** ☐

GESLAG/ SEX	OUDERDOM/ AGE	INDELING/ CLASSIFICATION	AFDELING/ WARD	VOORHEEN GERADIOGRAFFEER/ PREVIOUSLY RADIOGRAPHED	JA/ YES	NEE/ NO

VORIGE Rö ONDERSOEK MET DATUMS/PREVIOUS Rö EXAMS WITH DATES

VOLLEDIGE KLINIESE BEVINDINGS EN INDIKASIE VIR AANVRAAG/COMPLETE CLINICAL FINDINGS INDICATIONS FOR REQUEST

ONDERSOEK AANGEVRA/EXAMINATION REQUESTED

IS PASIËNT MOONTLIK SWANGER? IS PATIENT POSSIBLY PREGNANT?	JA/ YES	NEE/ NO	DEPARTEMENTSHOOF HEAD OF DEPARTMENT

VERSLAG/REPORT	JA/ YES	NEE/ NO	PRIVAAT PASIËNT : RADIOLOOG PRIVATE PATIENT : RADIOLOGIST

VERWYSENDE GENEESHEER (Drukskrif) REFERRING DOCTOR (Please Print) **KONTAK NOMMER/CONTACT NUMBER**	HANDTEKENING EN DATUM SIGNATURE AND DATE

VIR DEPARTEMENT RADIOLOGIE/FOR DEPARTMENT OF RADIOLOGY

AANKOMS (A) VERTREK (D) VAN PASIËNT
ARRIVAL (A) DEPARTURE (D) OF PATIENT
RADIOGRAAF/RADIOGRAPHER

(A) (D)

DATUM VAN ONDERSOEK
DATE OF EXAMINATION
STUDENT: VOLLE NAAM/ FULL NAME

DEURLIGTINGSTYD/SCREEN TIME AANTAL BELIGTINGS/No. OF EXPOSURES	FILMS: GROOTTE EN GETAL/FILMS: SIZE AND NUMBER					
	18 X 24		24 X 30		35 X 35	
	18 X 43		30 X 40		35 X 43	
KONTRAS TOEGEDIEN EN STERKTE/ CONTRAST ADMINISTERED AND STRENGTH	HOEVEELHEID EN STERKTE/ AMOUNT AND STRENGTH					

Government Printing Works Tel: (012) 334-4500

APPENDIX S

Prenatal: Before birth, from conception until birth (Arvedson & Brodsky, 2002, p. 24)

Perinatal: Period between 20 weeks gestation until 27 days following birth (Rossetti, 2001, p. 16)

Neonatal: Pertaining to the first 28 days of life (Arvedson & Brodsky, 2002, p. 291)

Acquired: pertaining to a condition, or disease originating following not as a result of congenital or birth factors (Mosby, 2008)

Prematurity: Infant born at or prior to 36 weeks of gestational age (Rossetti, 2001, p. 15)

Low birth-weight: "Infant with a birth weight less than 2500g, regardless of gestational age" (Arvedson & Brodsky, 2002, p. 617)

Cardio-respiratory: cardiovascular anomalies such as congestive heart failure or congenital heart disease as well as disorders that result in brady- or tachycardia; as well as those conditions that affect respiration such as difficulties breathing, co-ordinating breathing and swallowing and those respiratory conditions related to structural damage or illness (Arvedson, 2008; Prasse & Kikano, 2009)

Gastrointestinal: Conditions that relate to anatomical abnormalities, dysmotility and inflammation of the oesophagus and stomach, including gastro-oesophageal reflux and constipation (Arvedson & Brodsky, 2002, p. 197)

Nutrition: conditions as a result of inadequate caloric and nutrient intake, abnormal absorption, increased caloric absorption, medical conditions impairing adequate nutrition intake, as well as poor oral and dental structures required for intake (Arvedson & Brodsky, 2002, p. 236)

Immunological: Allergy or immune disorders affecting feeding as well as overall health including specific food allergies, asthma and celiac diseases. Included in this category are conditions that directly compromise the immune status such as HIV/AIDS (Berlin et al., 2011)

Metabolic: "Metabolic diseases and syndromes which interfere with the development and/or maintenance of normal feeding patterns (e.g., hereditary fructose intolerance, glycogen, storage disease)" (Berlin et al., 2011, p. 43)

Anatomical/structural: Anatomical/structural conditions are abnormalities of the soft tissue and skeleton of the phase, oropharynx, larynx, pharyx, oesophagus or stomach. These conditions may be congenital or acquired (Arvedson & Brodsky, 2002, p. 37-38, 528)

Neurological: Conditions as a result of damage to the central nervous or neuromuscular systems including cerebral palsy, delayed development, muscular dystrophies, or any other disease or disorders that affects the integrity of the nervous system (Arvedson, 2008; Berlin et al., 2001)

Behavioural: conditions related to psychosocial aspects including poor environmental conditions; food aversion or selectivity and emotionally based conditions such as depression, anxiety and food phobias (Berlin et al., 2011).

Transient: pertaining to a condition that is temporary or of short duration, usually not recurring (Mosby, 2008)

Permanent: condition expected to remain unchanged indefinitely (Oxford Dictionaries, n.d.)