THE NEED FOR SPEECH AND LANGUAGE THERAPY INTERVENTION FOR INFANTS AND TODDLERS WITH TRACHEOSTOMIES: A RETROSPECTIVE STUDY

By

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LIST OF ABBREVIATIONS

Abbreviations that have been frequently used in the text are listed below.

BPD - Bronchopulmonary dysplasia

CNS - Central nervous system

ECI - Early Communication Intervention

GOR - Gastro-oesophageal reflux

GORD - Gastro-oesophageal reflux disease

HPCSA - Health Professions Council of South Africa

LBW - Low birth weight

NGT - Nasogastric tube

NJT - Nasojejunal tube

NICU - Neonatal Intensive Care Unit

PEG - Percutaneous endoscopic gastrostomy

RCCH - Red Cross Children's Hospital

RDS - Respiratory distress syndrome

UAO - Upper airway obstruction

TERMINOLOGY

The area of paediatric tracheostomies in ECI is regarded as a specialized field of practice and therefore requires an explanation of specific terminology to assist the reader.

DEFINITIONS:

Airway obstruction: A blockage, at any level, in the airway that interferes with the passage of air and significantly affects the ability to breathe.

Aspiration: Penetration of liquid/food below the level of the true vocal cords.

Barium Swallow: A radiologic examination of the anatomy and physiology of the oesophagus, stomach and duodenum.

Bronchopulmonary dysplasia: A chronic lung condition in premature infants that results from prolonged (>28 days) mechanical ventilation

Cannulation: Tracheostomy in place

Decannulation: Permanent removal of the tracheostomy tube

Endotracheal intubation: A tube is placed from the mouth or nose, through the vocal cords into the trachea so that air can reach the lungs.

Gastro-oesophageal reflux:	GOR is the backflow of the stomach contents into the oesophagus, and may extend as high as the hypopharynx with a risk of aspiration into the airway.
Gastro-oesophageal reflux disease:	Chronic GOR resulting in damage or ongoing symptoms affecting feeding, growth, nutrition and respiratory status.
Modified Barium Swallow:	Radiologic examination of the oral and pharyngeal phases of swallowing using barium contrast of various consistencies.
pH Probe:	A 24 hour pH monitoring of the acid level of the oesophagus to identify GOR.
Respiratory distress syndrome:	Respiratory impairment in premature babies due to the inability to produce surfactant.
Scintigraphy: (Milk scan)	Radionucleide scanning during and after a feed containing a radioactive tracer. Records transit times, GOR, gastric emptying and aspiration.
Subglottic stenosis:	Narrowing in the trachea below the level of the glottis.
Tracheostomy:	An opening between the skin and the trachea made at the level of the 2nd to 4th tracheal rings. The hole is maintained by a tracheostomy tube and is used for breathing.

(Compiled from: Arvedson & Lefton-Greif, 1998; Bleile, 1993; Hall, 2001; Kertoy, 2002; Rossetti, 2001).

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ABSTRACT

There has been a worldwide increase in the number of tracheostomies performed on the paediatric population, particularly during the first year of life, which has also been evident at Red Cross Children's Hospital in South Africa. Infants and toddlers with tracheostomies present with multiple risk factors for having or developing dysphagia and/or communication difficulties, due to the effects of the tracheostomy on the development of feeding, speech and communication, as well as the underlying medical conditions that necessitated the tracheostomy, and associated medical, social and environmental factors. There is, however, a dearth of literature in the area of paediatric tracheostomies in the South African context, particularly with regard to feeding and communication. The purpose of this study was to determine the incidence and describe the nature of dysphagia and communication difficulties in infants and toddlers with tracheostomies in the South African context, and detail the need for speech-language therapy intervention. It also attempted to determine whether there was an association between the underlying medical condition and the incidence of dysphagia and/or communication difficulties. A retrospective, descriptive survey of the folders of infants and toddlers with tracheostomies within the age range of 0 – 3 years from 2002 – 2004 at Red Cross Children's Hospital was conducted. A checklist for dysphagia and communication difficulties in infants and toddlers with tracheostomies was developed and used to collect data from participants' medical records. Results indicated that 80% of the study population presented with dysphagia. Oral phase difficulties were documented in 81.25%, pharyngeal phase difficulties in 60.9% and oesophageal phase difficulties in 79.7% of the dysphagic sample. Communication difficulties were recorded in 94% of the sample population. Speech production difficulties were documented in 78%, receptive language delays in 87% and expressive language delays in 96% of the sample population with communication difficulties. No statistically significant association was established between the underlying medical condition and the incidence of either dysphagia or communication difficulties. The results

in the present study support the limited available literature, and the need for early speech-language therapy intervention for infants and toddlers with tracheostomies.

Key words: paediatric tracheostomy, dysphagia, swallowing, speech, language, early intervention

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OPSOMMING

Wêreldwyd is daar 'n toename in die aantal trageostomies wat gedoen word in die pediatriese populasie, veral tydens die eerste lewensjaar. Dit was ook duidelik merkbaar by die Rooikruis Kinderhospitaal in Suid Afrika. Babas en peuters met trageostomies het veelvuldige risikofaktore wat hulle in gevaar stel om disfagie en kommunikasie probleme te hê of te ontwikkel, as gevolg van die effek wat trageostomies op hulle voeding, spraak en kommunikasie ontwikkeling het, sowel as die onderliggende mediese toestand wat die trageostomie noodsaak en geassosieerde mediese, sosiale en omgewingsfaktore. Daar is egter 'n gebrek aan literatuur in die area van pediatriese trageostomies in die Suid Afrikaanse konteks, veral wat voeding en kommunikasie betref. Die doel van die studie was om die voorkoms en die aard van disfagie en kommunikasie probleme in babas en peuters met trageostomies in 'n Suid-Afrikaanse konteks te beskryf en die behoefte aan spraak-taalterapie ingryping uiteen te sit. Daar is gepoog om te bepaal of daar 'n verband tussen die onderliggende mediese toestande en die voorkoms van disfagie en/of kommunikasie probleme bestaan. 'n Retrospektiewe, beskrywende studie is onderneem deur die lêers van babas en peuters (tussen die ouderdom van 0 – 3 jaar) met trageostomies, tussen 2002 – 2004 by die Rooikruis Kinderhospitaal, te bestudeer. Die "Checklist for dysphagia and communication difficulties in infants and toddlers with tracheostomies" is ontwikkel en gebruik om data van die deelnemers se mediese verslae te verkry. Resultate toon dat 80% van die teiken populasie disfagie het. Probleme in die orale fase is in 81.25% geïdentifiseer, terwyl probleme in die faringeale fase in 60.9% van die gevalle opgemerk is en 79.7% het probleme in die esofageale fase ervaar. Kommunikasie probleme is in 94% van die teiken populasie geïdentifiseer. Spraakproduksie probleme is in 78% geïdentifiseer, terwyl reseptiewe taal agterstand in 87% en ekspressiewe taal agterstand in 96% van die teiken populasie met kommunikasie probleme ervaar is. Die resultate van die studie ondersteun die beperkte

literatuur, sowel as die behoefte aan vroeë spraak-taalterapie vir babas en peuters met trageostomies.

Sleutelwoorde: pediatriese trageostomie, disfagie, sluk, spraak, taal, vroeë intervensie

1. INTRODUCTION

The present focus on early childhood intervention in healthcare began in the 1960's and has been accepted as best practice for infants and toddlers with special needs (Guralnick, 1997; Meisels & Shonkoff, 2000). As a result, early communication intervention (ECI) developed to meet the needs of infants and toddlers, who are at risk of developing or have an established communication or feeding disorder, and their families, at the earliest possible time, in order to prevent or minimize the effects of these risk factors on development (Louw, 1997; Rossetti, 2001).

Certain ECI populations may be at greater risk for having or developing feeding and/or communication difficulties. The need for ECI and research in these specific early intervention populations will continue to grow as medicine advances, because the number of infants surviving who are at risk for feeding difficulties and communication delays will continue to increase (Rossetti, 2001).

The specific population of paediatric tracheostomies may be of interest to the speech-language therapist working in ECI, as there has been a worldwide increase in the number of tracheostomies performed in the paediatric population, particularly during the first year of life (Midwinter, Carrie & Bull, 2002), which has also been evident at Red Cross Children's Hospital (RCCH) in Cape Town, South Africa. The average number of tracheostomies performed annually at

RCCH has increased from between 10 and 20 per year, to between 35 and 40 per year, over the last 5 years and this number continues to increase (Booth, 2005).

Advances in medical care have resulted in an increase in the survival of premature infants, and infants and children who are medically fragile, which may explain the increased number of paediatric tracheostomies being performed (Midwinter et al., 2002). Tracheostomies are required in these infants and children for various reasons, the most prevalent being for long term ventilation and airway obstructions, which may be due to craniofacial abnormalities or acquired subglottic stenosis secondary to endotracheal intubation (Hadfield, Lloyd-Faulconbridge, Almeyda, Albert & Bailey, 2003; Midwinter et al., 2002).

These infants and toddlers with tracheostomies and their families should be a priority for early intervention by a team of early interventionists because of the increased risk for developmental problems due to the biological (Rossetti, 2001; Meisels & Shonkoff, 2000; Shonkoff & Marshall, 2000), environmental and social risk factors (Garbarino & Ganzel, 2000; Rossetti, 2001) associated with the medical conditions underlying the need for a tracheostomy. The team members would generally include a neonatologist or paediatrician, tracheostomy nurse, social worker, caregivers, speech-language therapist, dietician, physiotherapist, occupational therapist, psychologist, ear nose and throat surgeon (ENT), educator, psychologist and a primary developmental specialist, depending on the

individual needs of the infant or toddler and his/her family (Kertoy, 2002). It can be argued that the speech-language therapist should be included in the core team of all paediatric patients with tracheostomies, as the need for speech-language therapy has been established in the literature (Abraham, 2000; Murray & Brzozowski, 1998) because of the effects of the underlying medical condition, as well as the effects of the tracheostomy itself on the development of feeding, speech production and communication (Kertoy, 2002).

The infant and toddler with a tracheostomy is at risk for swallowing problems and ongoing feeding difficulties (Abraham & Wolf, 2000; Arvedson & Brodsky, 2002), as well as delayed or disordered speech production (Hill & Singer, 1990; Kamen & Watson, 1991) and delayed communication development (Hill & Singer, 1990; Jiang & Morrison, 2003; Kaslon & Stein, 1985).

Swallowing and feeding difficulties may have a negative impact on health, as a result of aspiration or compromised nutrition (Arvedson & Brodsky, 2002), as well as the development of appropriate oral motor skills that are important in normal development and later speech development (Hall, 2001; Hawdon, Beauregard, Slattery & Kennedy, 2000; Hodges & Harris, 2000; Morris & Klein, 2000). Swallowing and feeding difficulties may also affect social and emotional development, because of the negative influence on caregiver-infant interaction and attachment (Parrish, 1997), and the additional stress experienced by

caregivers when their infant or toddler cannot feed adequately (Hodges & Harris, 2000; Kedesdy & Budd, 1998).

Apart from the effects of feeding difficulties on normal development, difficulties experienced by infants and toddlers with tracheostomies in speech production and communication development may affect the acquisition of skills required for communication (Kertoy, 2002). This will not only affect their ability to communicate optimally, but has implications for social and cognitive development (Rossetti, 2001).

The speech-language therapist working with infants and toddlers with tracheostomies therefore needs to have specialized knowledge regarding the specific feeding, speech production and communication difficulties experienced by infants and toddlers with tracheostomies. This will ensure that early, appropriate and optimal intervention is provided for this population.

The following sections will describe the specific swallowing and feeding, speech production and communication difficulties experienced by infants and toddlers with tracheostomies.

1.1 SWALLOWING AND FEEDING DIFFICULTIES IN INFANTS AND TODDLERS WITH TRACHEOSTOMIES

The following paragraphs will describe the impact of the tracheostomy tube, associated feeding difficulties, as well as co-occurring medical conditions on swallowing and feeding in infants and toddlers with tracheostomies.

1.1.1 Impact of the tracheostomy tube on swallowing and feeding

The tracheostomy tube may affect swallowing because it restricts the upward and forward movement of the larynx during swallowing, thus reducing laryngeal closure, which increases the risk of aspiration (Abraham & Wolf, 2000; Arvedson & Brodsky, 1992). A delayed triggering of the pharyngeal swallow response and slowed laryngeal movement have associated risks of aspiration, and are also characteristic of the patient with a tracheostomy (Abraham & Wolf, 2000). In addition, the airflow through the tracheostomy may result in reduced sensation to the larynx, which may affect the larynx's reflexive ability to provide airway protection (Arvedson & Brodsky, 1992). This desensitization may result in an unawareness of aspiration and therefore aspiration may be silent and remain undetected by caregivers until secondary symptoms due to aspiration pneumonia result (Nash, 1988). Apart from the obvious danger to the airway that may result from aspiration, such as airway obstruction and pneumonia, life-threatening physiologic changes are also associated with chronic aspiration (Arvedson &

Brodsky, 2002). Reduced sensation also affects the co-ordination of laryngeal closure, resulting in unco-ordinated and shortened laryngeal closure, both of which place the patient at risk for aspiration (Nash, 1988; Shaker, Milbrath, Ren, Campbell, Toohill & Hogan, 1995). It is therefore essential that speech-language therapists working with infants and toddlers with tracheostomies evaluate and monitor their swallowing skills closely to identify aspiration immediately and provide appropriate intervention (Arvedson & Brodsky, 2002).

Besides the direct mechanical and physiological effects of the tracheostomy tube on swallowing, the medical conditions often associated with tracheostomies place the infant and toddler at risk for swallowing and feeding problems, for example prematurity and low birth weight (LBW), respiratory disorders and gastro-oesophageal reflux (GOR) (Kertoy, 2002; Wolf & Glass, 1992).

1.1.2 Effects of frequently co-occurring conditions on swallowing and feeding

Prematurity and LBW are associated with infants requiring tracheostomies (Kertoy, 2002). Premature infants are at risk for swallowing and feeding problems for various reasons. Neurological immaturity should be considered as a risk factor in premature infants, as there is general consensus in the literature that safe and co-ordinated oral feeding is established by 34 weeks gestational age (Arvedson & Lefton-Greif, 1996). Uys (2000) suggested that an infant's

weight is an important consideration for oral feeding, as it is essential to balance weight gain with caloric expenditure. This means that small-for-gestational-age infants are at risk for using more calories to feed orally than they gain from the feed, thus preventing the positive outcome of weight gain from feeding. The South African population has a higher prevalence of low birth weight (12%) (WHO Report, 1990 in Kritzinger 2000) compared with 6-8% in developed countries (WHO Report, 1996 in Kritzinger 2000), illustrating that infants with tracheostomies in the South African context may have an additional risk for feeding difficulties associated with low birth weight. Infants and toddlers with tracheostomies that have a history of prematurity or LBW have multiple risk factors for having or developing swallowing or feeding difficulties and should therefore be carefully assessed and monitored by a speech-language therapist to provide the earliest possible intervention.

Infants and toddlers with tracheostomies may also suffer from conditions that affect their breathing, including airway obstructions, respiratory distress syndrome (RDS) and bronchopulmonary dysplasia (BPD), neuromuscular disorders and central nervous system (CNS) damage (Kertoy, 2002). A respiratory disorder, whether structural or physiological, may impact on effective oral feeding skills, because feeding needs to be co-ordinated with breathing (Brodsky, 1997).

Infants and toddlers with poor respiratory support may have increased respiratory requirements when feeding or may not be able to complete feeds due to fatigue or extended feeding periods, which then affect the benefit obtained from the oral feed (Arvedson & Brodsky, 2002). Therefore, infants and toddlers requiring ventilation may have an additional risk for feeding difficulties. Prolonged ventilation (more than 14 days) of premature infants is associated with a high risk of developing swallowing and feeding dysfunctions, and particularly oral aversion (Oliver, Forcht & Lawrence, 1998). This again illustrates the multiple risk factors experienced by infants and toddlers with tracheostomies for having or developing swallowing and feeding difficulties.

Swallowing and feeding difficulties are also associated with gastro-oesophageal reflux (GOR). GOR is the backflow of the stomach contents into the oesophagus and occurs normally in young infants (Hall, 2001). It resolves spontaneously in the majority of infants, with the greatest improvement occurring between 8–10 months, which is associated with an infant's ability to sit independently and an increase in solid food intake (Arvedson & Brodsky, 2002; Wolf & Glass, 1992). GOR occurs more frequently, and possibly more severely, in premature infants and neurologically impaired infants and toddlers (Field, Garland & Williams, 2003; Hall, 2001), and is therefore commonly diagnosed in infants and toddlers with tracheostomies. GOR is commonly associated with failure to thrive, oesophagitis, stricture formation, food refusal, oral hypersensitivity and oral aversion (Dellert, Hyams, Treem & Geertsma, 1993; Field et al., 2003). In a

study by Field et al. (2003) GOR was correlated with more severe feeding problems, particularly food refusal and dysphagia. The diagnosis and treatment of GOR in infants and toddlers with tracheostomies is therefore essential to optimize normal development, including oral feeding, mealtime interaction and social interaction within the family (Morris & Klein, 2000). Negative feeding experiences associated with GOR may not only impact on feeding, but also the learning, both social and cognitive, that occurs during mealtimes (Morris & Klein, 2000). Infants and toddlers with a history of gastro-oesophageal reflux disease (GORD) or ongoing GORD may develop oral hypersensitivity or oral aversion (Dellert et al., 1993; Field et al., 2003), which will be discussed in the next section.

1.1.3 Associated feeding difficulties

The infant and toddler with a tracheostomy is at risk for developing oral hypersensitivity or oral aversion due to a number of reasons. Oral hypersensitivity is defined as an exaggerated response to oral-tactile stimulation, for example, gagging when the anterior portion of the tongue is touched (Wolf & Glass, 1992), while oral aversion is a stronger negative reaction and usually prevents oral feeding (Wolf & Glass, 1992). This may be due to a generalized tactile aversion (Wolf & Glass, 1992), lack of positive oral experiences (Comrie & Helm, 1997), long-term non-oral feeding via a nasogastric tube, which is associated with negative effects on the swallowing mechanism (Huggins, Tuomi

& Young, 1999), or gastrostomy tube, both of which are associated with a lack of oral experience (Hall, 2001), delayed introduction of oral feeding, interrupted oral feeding, delayed introduction of solids and a variety of tastes and textures (Harris, Blisset & Johnson, 2000; Hawdon et al., 2000; Wolf & Glass, 1992) and GOR (Dellert et al., 1993; Field et al., 2003).

The infant and toddler with a tracheostomy may experience frequent hospitalisations, which may affect the development of, or transition to, oral feeding because of multiple feeders, limited time for feeding and a distracting environment (Arvedson & Brodsky, 2002). They may also be exposed to negative oral experiences such as suctioning and force-feeding, which reinforce food refusal (Hall, 2001). Caregivers are frequently anxious to ensure optimal caloric intake because of a complicated medical history and may therefore resort to force-feeding (Arvedson & Brodsky, 2002). Therefore, apart from initial swallowing difficulties, infants and toddlers with tracheostomies may also have or develop long-term feeding difficulties.

Swallowing and feeding difficulties experienced by infants and toddlers with tracheostomies not only affect the normal development of oral feeding, but also have implications for health (Arvedson & Brodsky, 2002), general development, social and emotional development (Morris & Klein, 2000), and may result in feelings of frustration, fear and failure for caregivers (Craig, Scambler & Spitz,

2003; Guerriere, McKeever, Llewellyn-Thomas & Berall, 2003; Hodges & Harris, 2000).

Infants and toddlers with tracheostomies are therefore at double risk for having swallowing or feeding difficulties as a result of the underlying medical diagnosis, the effects of the tracheostomy tube, associated medical conditions and feeding difficulties, along with the complications of long-term hospitalisation and caregiver-infant separation. Speech-language therapists working with this population therefore need specialized knowledge and skills in the particular area of swallowing and feeding in infants and toddlers with tracheostomies in order to provide appropriate assessment and optimal intervention to maximize their feeding skills, with the positive resultant impact on other areas of development as discussed above.

In addition to swallowing and feeding difficulties infants and toddlers with tracheostomies may also experience difficulties with speech production.

1.2 SPEECH PRODUCTION DIFFICULTIES IN INFANTS AND TODDLERS WITH TRACHEOSTOMIES

In infants and toddlers with tracheostomies, the tracheostomy tube is below the level of the vocal cords resulting in voicing difficulties because air is expired

through the stoma and not the vocal cords (Handler, 1993). Initially, when the tracheostomy tube is placed, it fits tightly in the trachea to allow for maximum air exchange, however this means that no air is able to pass up beside the tube and through the vocal cords resulting in the inability to vocalize (Handler, 1993). As the infant and toddler grows so does the space around the tracheostomy tube, allowing air to pass up beside it and through the vocal cords, thereby facilitating voice production. Alternatively, the tracheostomy tube may be downsized as the infant or toddler's secretions decrease or the respiratory disease settles, allowing space around the tube for expired air to pass up through the vocal cords and produce voice (Handler, 1993). Periods of aphonia may negatively influence the normal development of babbling and speech production (Bleile, Stark & McGowan, 1993; Simon, Fowler & Handler, 1983).

The normally developing infant starts vocalizing immediately after birth by crying, and later vocalizations include crying, cooing and eventually babbling (Owens, 2001). Initial babbling consists of random sound play, but develops to reflect adult speech, particularly with regard to syllable structure and intonation (Owens, 2001). Babbling is thought to facilitate later speech development, and therefore an inability to vocalize would negatively affect speech development (Bleile et al., 1993; Fus & Wacker, 1993; Sell & McCurtain, 1988). The infant with a tracheostomy's vocal play tends to be limited to vegetative sound production (e.g. blowing raspberries) and oral motor imitation is limited to highly visual oral postures, such as in labial sounds (Bleile et al, 1993). According to Bleile et al.

(1993) the infant with a tracheostomy only develops pre-speech skills beyond the initial stages of babbling and imitating oral postures when able to benefit from auditory feedback of vocalizations. It has also been noted that infants who were previously able to babble stopped once the tracheostomy was in place and they were aphonic (Simon et al., 1983), indicating a disruption in the development of speech production skills in infants and toddlers with tracheostomies. Limited vocalizations and difficulties in producing speech sounds have been shown to correlate with later phonological difficulties and language delays (Ross, 1982; Simon et al., 1983; Stoel-Gammon & Herrington, 1990). Voice production and voice therapy may therefore be considered an early goal in speech-language therapy with infants and toddlers with tracheostomies (Woodnorth, 2004).

Infants and toddlers with tracheostomies may therefore benefit from a speaking valve, which assists in directing the air up through the vocal cords (Handler, 1993). A speaking valve is a one-way valve (diaphragm) that fits onto the outside of the tracheostomy tube. It allows air to be inhaled through the tracheostomy, but closes on exhalation, thereby redirecting the air upwards, beside the tracheostomy tube and through the vocal cords and can only be utilized if there is enough air escape around the tracheostomy tube to allow for adequate air exchange (Cho Lieu, Muntz, Prater & Stahl, 1999; Gereau, Navarro, Cluterio, Mullan, Basilla & Ruben, 1996; Handler, 1993). Wearing a speaking valve facilitates more consistent vocalizations, which is important for speech development (Cho Lieu et al., 1999; Gereau et al., 1996). It may also result in

decreased secretions, improved swallowing and sense of smell, as well as preparing the infant or toddler with a tracheostomy for decannulation by occluding the tracheostomy tube intermittently (Gereau et al., 1996).

The inability, or limited ability, to produce voice may affect the development of speech in those patients cannulated during the prelinguistic stage or during the onset of speech. Although there is very little available research to support this hypothesis, three separate studies have investigated speech outcomes of children who had been tracheostomized during the prelinguistic period and decannulated during the linguistic period. Periods of cannulation ranged from six to twenty-seven months and all subjects experienced periods of aphonia while cannulated (Bleile et al, 1993; Locke & Pearson, 1990; Simon et al, 1983). In all three studies subjects demonstrated a delay in speech development at the time of decannulation, with improvement in speech function noted over time (Bleile et al, 1993; Locke & Pearson, 1990; Simon et al, 1983). Improvement in voicing seems to be noted first, with subsequent improvement in the variety of consonants and syllables used and phonological development later (Bleile et al, 1993). These findings support the theory that vocalizing is a prerequisite for speech development, which illustrates the increased risk for a speech delay in infants and toddlers with tracheostomies.

The tracheostomy not only affects speech development through the inability to vocalize, but may also result in anatomic and physiologic changes in the speech

production mechanism (Kamen & Watson, 1991). Upper and lower airway function is altered because the tracheostomy bypasses the upper airway and the vocal tract does not follow normal developmental changes, resulting in a more primitive vocal tract shape, which limits tongue range of movement (retracted position) and resonance (Kamen & Watson, 1991). This affects speech production in the control of pitch, loudness and voice quality. It may also affect the development of the respiratory muscles, which in turn may affect the child's ability to control airflow during respiration and phonation, resulting in inadequate breath support for increased utterance length and intensity (Kamen & Watson, 1991). Intervention should therefore focus on developing oral movements, stimulating vocal practice, increasing the repertoire of sounds produced, as well as the complexity of syllables and the mean length of utterances (Kertoy, 2002).

The effects of the tracheostomy tube on speech seem to persist even after decannulation, and include reduced acoustic vowel space, backing, stopping, voiced-voiceless confusion, stridency deletion, liquid deviation and cluster reduction (Kamen & Watson, 1991; Kertoy, Guest, Quart & Lieh-Lai, 1999). The available research on the speech development of infants and toddlers with tracheostomies clearly emphasizes the impaired articulation of previously tracheostomized patients, which indicates that periods of aphonia and the effects of the tracheostomy tube on the vocal tract have long-term effects on speech production, including articulation, phonation and resonance, indicating the need for ongoing speech-language therapy involvement, even after decannulation

(Bleile et al, 1993; Kamen & Watson, 1991; Kertoy et al, 1999; Singer, Kercsmar, Legris, Orlowski, Hill & Doershuk, 1989).

Infants and toddlers with tracheostomies therefore require early communication intervention to establish and improve oral movements and control, breath support for speech and voicing required for speech production.

1.3 COMMUNICATION DIFFICULTIES IN INFANTS AND TODDLERS WITH TRACHEOSTOMIES

The inability to vocalize may affect the caregiver-infant interaction and language development, because it has been noted that caregivers of infants and toddlers with tracheostomies who cannot vocalize tend to talk less frequently to their children and that there is less evidence of reciprocity in their interactions (Aradine, 1983). This will have an impact on the development of communication.

The speech-language therapist working with infants and toddlers with tracheostomies and their families needs to assess their verbal and non-verbal communication abilities to determine whether an augmentative and alternative communication system is needed to facilitate communication development (Kertoy, 2002). It is important to make a communication system, such as gestures or signs, available immediately to allow the infant or toddler and

caregiver the opportunity to communicate in a nonverbal manner. The selected system will support the development of symbolic communication, prevent frustration, as well as develop and improve language skills while in the aphonic period (Adamson & Dunbar, 1991; Kertoy, 2002; Simon et al, 1983). This system may need to be changed and adapted over time as the individual's needs change (Kertoy, 2002).

Many infants and toddlers with tracheostomies develop their own nonverbal communication system with their caregivers, but this may often be limited to attention getting and behaviour regulation, rather than social interaction, and is seldom understood by outsiders (Kertoy & Waters, 1995). It has been the author's clinical practice to initiate the use of a gestural system with aphonic infants, while encouraging oral motor activities in preparation for speech production, while with an older toddler who had previously acquired speech, a gestural system would be encouraged to supplement 'silent' speech. If necessary the gestural system would be advanced to a more formalized sign language system such as South African Sign Language or Makaton, or an augmentative system such as a communication board using Picture Communication Symbols or Bliss Symbols (Kertoy, 2002; Beukelman & Mirenda, 1998).

There is evidence in research (Adamson & Dunbar, 1991; Romski & Sevcik, 2005), that when language has developed, the transition from non-verbal to

verbal communication can occur with relative ease once the toddler is able to vocalize with the tracheostomy tube in place or has been decannulated. It is therefore important for the speech-language therapist working with infants and toddlers with tracheostomies to select a communication system that suits their current developmental level and physical skills, and will facilitate immediate and ongoing development of expressive communication, reduce frustration and foster social interaction (Adamson & Dunbar, 1991; Beukelman & Mirenda, 1998; Kertoy, 2002).

Research on the communication development of children with long-term tracheostomies is sparse, contradictory and affected by small sample sizes, overall intellectual functioning of patients and underlying medical factors (Arvedson & Brodsky, 1992; Bleile et al, 1993; Hill & Singer, 1990; Kamen & Watson, 1991). These limited research findings have affected clinical practice, as there are limited evidence-based guidelines for clinicians in the treatment of communication in infants and toddlers with tracheostomies.

Delays in the communication development of children with tracheostomies are reported in both receptive and expressive skills by some researchers (Kaslon & Stein, 1985) and increase as the length of time that a tracheostomy is in place increases (Jiang & Morrison, 2003; Simon et al., 1983). Other researchers only report delays in expressive communication skills (Hill & Singer, 1990; Ross, 1982), while Singer, Wood and Lambert (1985) reported age-appropriate speech

and language skills in a group of children with long-term tracheostomies. Apart from a study by Hill and Singer (1990) demonstrating an expressive communication delay in older (school-aged) subjects, there is no available literature on the long-term effects of a tracheostomy on later academic progress. This again illustrates the lack of research in the particular area of paediatric tracheostomies, which may compromise optimal assessment and intervention provided by speech-language therapists, because they may be unaware of the possible long-term effects of a tracheostomy on communication development and later schooling.

Available literature indicates that those infants who are decannulated before language function of 9 months seem to have better communication developmental outcomes than those who were decannulated after some manual/spoken communication had developed (Jiang & Morrision, 2003; Simon et al, 1983). Children decannulated during the linguistic period were found to have delays in receptive and expressive communication, although receptive skills were better (Kaslon & Stein, 1985; Sell & MacCurtain, 1988; Simon et al, 1983). In children with normal intelligence these delays in communication were remediated with speech-language therapy within a short period (six months) according to a number of authors (Bleile et al, 1993; Kaslon & Stein, 1985; Simon et al., 1983), however, Hill and Singer (1990) noted difficulties in the expressive communication abilities of normal intelligence school-going children with a history of tracheostomy.

Considering that communication skills are reported to be most predictive of later intelligence and academic progress (Rossetti, 2001), it is felt that infants and toddlers who previously had tracheostomies may be at risk for later difficulties at school. Their communication skills should therefore be monitored by a speech-language therapist on an on-going basis to identify areas of difficulty as early as possible and provide early intervention when necessary.

Although the literature on the communication skills of infants and toddlers with tracheostomies may seem inconclusive, it is clear that the infant or toddler with a tracheostomy is at risk of developing communication difficulties. This may be due to periods of aphonia which disrupt the normal development of babbling and speech production, the impact of hospitalisation and caregiver-infant separation on the caregiver-infant relationship and interactions, as well as the impact of cognitive development on communication development, which may be affected by limited exploration and play due to chronic illness, as well as underlying medical diagnoses.

The available research therefore indicates that infants and toddlers with tracheostomies are at risk for having feeding, speech production and communication difficulties and would therefore require ECI from a speech-language therapist

1.4 ADDITIONAL RISK FACTORS ASSOCIATED WITH A DEVELOPING COUNTRY

In the context of a developing country, such as South Africa, specific additional risk factors may affect infants and toddlers with tracheostomies and need to be considered. These include, but are not limited to, poverty and HIV and AIDS.

Fifty percent of South Africa's population live in poverty (Editors Inc, 2003; USAID, 2005), which is associated with an increased incidence of malnutrition, poor access to healthcare (Shonkoff & Marshall, 2000), prematurity, low birth weight (Farran, 2000; Rossetti, 2001), exposure to toxic substances and violence (Halpern, 2000) and increased infant mortality rates (Editors Inc, 2003). These factors place infants and toddlers at increased risk for medical conditions that may necessitate a tracheostomy, as well as having or developing dysphagia and communication difficulties (Kertoy, 2002; Rommel, De Meyer, Feenstra & Veereman-Wauters, 2003; Rossetti, 2001).

Secondly, the South African ECI population is at a greater risk of the medical, environmental and social impact of HIV and AIDS. According to the National HIV and Syphilis Antenatal Sero-Prevalence Survey in South Africa in 2004, 29.5% of pregnant women in South Africa were infected with HIV and AIDS (www.journ-aids.org, 2005). An estimated 5.3 million South Africans were HIV-positive in 2003, with the current prevalence rate estimated to be 20% of the South African population (www.journ-aids.org, 2005). Until February 2003 mother-to-child-

transmission (MTCT) programmes were limited to a few sites in South Africa (www.journ-aids.org, 2003), therefore the vertical infection of infants was potentially high, and remains high because of inaccessibility, lack of resources and a lack of knowledge of HIV status (www.journ-aids.org, 2003). The progression from HIV to AIDS is much quicker in children than in adults (Department of Health, 2001) and problems of the upper airway, resulting in airway obstruction and respiratory compromise is documented in the literature (Wilson, Naidoo, Bekker, Cotton & Maartens, 2002).

It can therefore be expected that an increasing number of infants and toddlers with tracheostomies in SA will also be infected with HIV and AIDS. This may result in additional feeding and communication difficulties associated with HIV and AIDS (Davis-McFarland, 2000; Pressman, 1992).

1.5 SPEECH-LANGUAGE THERAPY INTERVENTION WITH INFANTS AND TODDLERS WITH TRACHEOSTOMIES

Infants and toddlers with tracheostomies are at risk for swallowing problems and ongoing feeding difficulties (Abraham & Wolf, 2000; Arvedson & Brodsky, 2002), as well as delayed or disordered speech production (Hill & Singer, 1990; Kamen & Watson, 1991) and delayed communication development (Hill & Singer, 1990;

Kaslon & Stein, 1985). It is therefore clear that infants and toddlers with tracheostomies are at increased risk for difficulties that require ECI.

Infants and toddlers with tracheostomies require specialized ECI services, as inappropriate assessment and intervention may result in long-term difficulties in feeding and communication, affecting normal development, health and resulting in an increased risk of morbidity and mortality (Abraham, 2000). Speech-language therapists working with infants and toddlers with tracheostomies and their families therefore require specialized knowledge and skills in order to provide accurate assessment, effective treatment and appropriate management (Manley, Frank & Melvin, 1999). In addition to clinical competence related to assessment and treatment of premature infants, medically fragile and 'at risk' infants and children, and understanding of the impact of biological, social, emotional and environmental factors on infants and toddlers and their families (Dunn, Van Kleeck & Rossetti, 1993; Kertoy, 2002; Louw, 1997; Rossetti, 2001), additional knowledge and skills in the specialized clinical area of tracheostomies is essential (Kertoy, 2002; Manley et al., 1999). This includes general information related to paediatric tracheostomies, such as incidence, indications, age at time of receiving tracheostomy, period of cannulation, tracheostomy tubes, complications of tracheostomies, underlying medical conditions and more specifically, the effects of a tracheostomy on the development of swallowing and feeding, speech production and communication (Kertoy, 2002).

In order for speech-language therapists working with infants and toddlers with tracheostomies to develop specialized knowledge and skills to provide the best possible service, they will need to consult the literature, research and experts in the field in order to provide an evidence-based service. Evidence-based practice in medicine, and more specifically, speech-language therapy, requires speech-language therapists to make clinical decisions that are based on science and research (Reilly, 2004a). This implies that speech-language therapists have to move away from making decisions based solely on experience and opinion, and rather make clinical decisions and provide assessment and treatment that combines their specialized knowledge and skills with the best available research (Reilly, 2004a).

1.6 PRESENT STUDY

To the author's knowledge, there is a dearth of research in the particular area of paediatric tracheostomies in the South African context, as well as minimal theoretical and clinical training of students and clinicians. According to a number of communication pathology tertiary training institutions in South Africa, the topic of paediatric tracheostomies is covered briefly at an undergraduate level and students have limited clinical exposure and hands-on treatment, particularly in the paediatric population with tracheostomies (Louw, 2003; Singh 2003; Van der Merwe 2003). The author's clinical experience has also indicated that qualified,

practicing clinicians require more training and experience in treating this population. However, the Health Professions Council of South Africa (HPCSA) does not require special licensing of speech-language therapists working with paediatric dysphagia or tracheostomies, compared to the requirements of developed countries' professional boards such as the American Speech-Language Hearing Association (ASHA) and the Royal College of Speech-Language Therapists in the United Kingdom. According to ASHA, certification standards required competence in dysphagia from 2005 (ASHA, 2002). Speech-language therapists working with infants and toddlers with dysphagia in the United States are required to receive specific academic and practical experience and demonstrate competence with specific populations in various treatment settings (ASHA, 2002). They have also provided recommendations for dysphagia coursework at a graduate level (ASHA, 2002).

After reviewing available literature in the area of ECI with infants and toddlers with tracheostomies, particularly in the South African context, the need for further research in this particular area was identified and the question formulated:
Do the medical records of infants and toddlers with tracheostomies indicate a need for speech-language therapy intervention, and what are the specific ECI needs of this particular population in the South African context?

While there is literature to support the *presence* of dysphagia in paediatric patients with tracheostomies (Abraham & Wolf, 2000; Arvedson & Brodsky,

1992), there is very little available literature on the incidence and specific nature of dysphagia in infants and toddlers with tracheostomies, as well as correlations to specific underlying medical diagnoses associated with tracheostomies, and no literature was found specific to the South African context. The reviewed literature reports speech production and communication difficulties in infants and toddlers with tracheostomies, however information regarding incidence was not available, and no information specific to the South African context or other developing countries was found.

The purpose of this study is therefore to determine the incidence and describe the specific feeding, swallowing, speech production and communication characteristics of infants and toddlers with tracheostomies in a large paediatric referral hospital in the South African context. It will detail the need for speech-language therapy intervention with this population, and possible correlations between underlying medical conditions and the presence of dysphagia and communication difficulties.

This study will yield information specific to the early intervention population and more specifically, unique information to the context of South Africa. It is hoped that this research will provide information that will assist in the training of students and therapists to better serve this population and provide a foundation for future research into the particular area of paediatric tracheostomies.

2. METHODOLOGY

2.1 AIMS

AIM - The main aim of this study was to describe whether the hospital records of infants and toddlers (0-3 years) with tracheostomies indicated a need for speech-language therapy intervention.

To achieve the main aim the following sub-aims were formulated:

1. To determine the incidence and nature of dysphagia recorded in the records of infants and toddlers (0-3 years) with tracheostomies.
2. To determine whether a relationship exists between the underlying medical condition and the presence of dysphagia in the sample population.
3. To describe the incidence and nature of communication difficulties in the records of infants and toddlers (0-3 years) with tracheostomies.
4. To determine whether a relationship exists between the underlying medical condition and the presence of communication difficulties in the sample population.

According to Katzenellenbogen, Joubert and Abdool Karim (1997, p.15) incidence is defined as “the number of new cases reported during a specified time in a defined population”.

2.2 RESEARCH DESIGN

The research design selected for the study was a retrospective, descriptive review (Leedy & Ormrod, 2004) of the folders of infants and toddlers with tracheostomies at Red Cross Children's Hospital within the age range of 0-3 years from 2002-2004 within both the qualitative and quantitative paradigms.

The present study was *retrospective*, and was selected because it was unobtrusive in nature and cost-effective in terms of time and money (Babbie & Mouton, 2001), and in this particular study was selected in preference to a direct participant evaluation process in order to maximize the sample size. A retrospective study allowed the researcher to collect data on all potential participants that were between the ages of 0-3 years during the period from 2002-2004. Retrospective studies may be affected by a lack of recorded data, however a protocol was established in 2001 whereby all patients receiving tracheostomies at Red Cross Children's Hospital are referred to the speech-language therapist for assessment and therefore information was available for a large majority of participants.

The study was *descriptive* in nature in that it described the effects of tracheostomies on the development of swallowing, feeding, speech production and communication in the sample population, by determining the incidence and nature of difficulties (Katzenellenbogen et al., 1997). Descriptive studies allow

the researcher to describe characteristics in detail, through narrative or statistical methods (Babbie & Mouton, 2001) and are used to assist service providers in planning and providing better service delivery and resources, which was part of the purpose of this study (Katzenellenbogen et al., 1997). Descriptive research cannot identify relationships, and the researcher needs to show an awareness of the effects of the participants and instrument used to collect data (McMillan & Schumacher, 2001), which will be discussed in a later section that addresses reliability and validity. Due to the descriptive nature of the research there is a possibility that different assessments and terms may have been used to classify difficulties in the medical records. However, the data that was collected from records was recorded by one clinician specifically working with infants and toddlers with tracheostomies, thereby reducing the variability in recorded results.

In this study a *survey* of participants' folders provided information that describes the characteristics of a specified population (Leedy & Ormrod, 2004). A survey of records has many advantages, namely: there is little expense related to data collection and it may be quicker than other methods (Katzenellenbogen, et al., 1997). The disadvantages of this method of data collection include incomplete data and inconsistency resulting from data recorded by different people (Katzenellenbogen et al., 1997). The latter should, however, not be a disadvantage as all information, regarding participants' swallowing, feeding, speech production and communication skills, was recorded by the clinician

working with infants and toddlers with tracheostomies in the patient records between 2002 and 2004.

A *qualitative* approach to research seeks to provide a rich description and interpretation of observations and collected data (Leedy & Ormrod, 2004). The advantages include accessible results as descriptions, which may provide a foundation for further research, flexibility in the process and strategies used, and a skilled person, who is familiar with the subject and participants being researched, collecting the data (Katzenellenbogen et al., 1997; McMillan & Schumacher, 2001). In the present study the researcher was familiar with the participants as a clinician and with the topic under investigation. Trustworthiness was established through credibility, applicability/transferability, consistency and neutrality (De Vos, 1998) and will be discussed further in section 2.5.2.

The nature of dysphagia and communication difficulties reported in the study population was described in a qualitative manner, while the incidence of both was analysed quantitatively.

In contrast to a qualitative approach, a *quantitative* approach is controlled and exactly defined, focusing on specific questions; results are reported as quantities rather than descriptions (De Vos, 1998). The advantages of a quantitative approach focus on the method of data collection and the ability to control variables, and relate to reliability and validity of results (De Vos, 1998; Leedy &

Ormrod, 2004). In the present study correlation statistics were used to quantitatively analyze whether a relationship existed between the underlying medical condition and the presence of dysphagia and/or communication difficulties.

Disadvantages of a qualitative approach to research are related to researcher subjectivity and bias, and possible poor generalizability of results due to small sample sizes and non-random sampling techniques (Katzenellenbogen et al., 1997). The disadvantages of a quantitative approach include the lack of flexibility, resulting in an unnatural context for data collection and limitation of descriptive interpretation of results (De Vos, 1998). In the present study a *combined* approach was selected in an attempt to address the above-mentioned disadvantages. This combined approach enabled the researcher to provide a detailed description of the topic under investigation, as well as results that provided both statistical and qualitative information, in order to improve understanding of the sample population and to develop more appropriate and efficient services provided to infants and toddlers with tracheostomies, as well as provide information for future research into the topic.

2.3 ETHICAL ISSUES

Ethical issues need to be considered when planning and conducting research in order to protect participants from potential risks associated with research and to make certain that possible benefits of the research are distributed fairly (Katzenellenbogen et al., 1997).

In the present study, medical records were the only source of information and, as this was a retrospective study, many of the participants were no longer contactable, due to decannulation, demographics and possible participant mortality. Approval was therefore obtained from the University of Cape Town, Faculty of Health Sciences' Research Ethics Committee (Appendix A) and the medical superintendent of Red Cross Children's Hospital (Appendix C) to obtain this information from hospital records and present it in an anonymous format. In this way confidentiality and anonymity of the participants was maintained (Medical Research Council of South Africa, 2001).

Approval to conduct the research was obtained from the Research Ethics Committee of the University of Cape Town Health Sciences, as this body oversees research activities at Red Cross Children's Hospital (Appendix A). Approval was also sought from the University of Pretoria, Faculty of Humanities Research Proposal and Ethics Committee, as the researcher is registered at this university (Appendix B).

There was no identifiable risk to the participants or their families associated with this research (Medical Research Council of South Africa, 2001). The potential benefit of this research applied to the greater population of infants and toddlers with tracheostomies and treatment planning, rather than to those patients who were included in the study, because of the retrospective nature of the study (Medical Research Council of South Africa, 2001). It was also suggested that findings of such research would be beneficial to speech-language therapists working with infants and toddlers with tracheostomies (Kertoy, 2002) in providing information regarding the need for speech-language therapy intervention with particular reference to the South African context.

2.4 SAMPLE

According to Leedy and Ormrod (2004) one should attempt to survey the entire population when working with small populations (e.g.<100), rather than only collecting data on a sample of the population.

2.4.1 Population

Potential participants included all paediatric patients with tracheostomies that were treated at Red Cross Children's Hospital in South Africa from 2002-2004. These participants included both inpatients and outpatients. The time period of

2002-2004 was selected because the researcher started working with this population in 2001 and had therefore developed skills required to treat this population and had established a referral protocol for the assessment and treatment of swallowing and communication difficulties. Specific information regarding swallowing, feeding, speech and communication functions may not have been recorded prior to this date.

2.4.2 Participant Selection Criteria

The following selection criteria were formulated to identify participants.

2.4.2.1 Tracheostomy

The participants who were selected in this study had to have a tracheostomy in situ, because the study was specifically aimed at documenting dysphagia and communication difficulties within the paediatric population with tracheostomies.

2.4.2.2 Age

The participants in this study had to be between the ages of 0-3 years as ECI targets infants and toddlers within this age range and their families as recipients of services (Rossetti, 2001). The aim of this study was to describe whether the hospital records of infants and toddlers (0-3 years) with tracheostomies indicated a need for speech-language therapy intervention.

2.4.2.3 Hospital

The participants had to be patients at Red Cross Children's Hospital to limit the variables; the researcher works with the paediatric population with tracheostomies at this institution and had therefore recorded assessment and treatment results. This is also the institution where the majority of paediatric tracheostomies are performed in the Western Cape and in South Africa, and therefore provided a substantial and convenient sample population (Booth, 2005).

2.4.2.4 Length of cannulation time

Participants had to be cannulated for more than one month, as this is considered to be a long-term tracheostomy and may affect swallowing, feeding, speech and communication (Bleile, 1993).

2.4.3 Participant Selection Procedures

Purposive sampling was used to select participants. The aim of this study was to determine the incidence and nature of dysphagia and communication difficulties requiring speech-language therapy intervention within the specific population of infants and toddlers with tracheostomies and it was therefore acceptable to use a non-random sampling method to include participants that met predetermined selection criteria (Katzenellenbogen et al., 1997; Leedy & Ormrod, 2004).

- Permission was obtained from the Research and Ethics Committee of the hospital (Appendix A) and the medical superintendent (Appendix C) to review patients' medical records in the absence of the participants' caregivers.
- Potential participants, i.e. infants and toddlers 0-3 years, were identified from the Tracheostomy Care List.
- The records of all identified potential participants i.e. those infants and toddlers 0-3 years that had tracheostomies in situ for more than one month during the specified period 2002-2004 at Red Cross Children's Hospital were reviewed.

2.4.4 Sample size

Initially 91 potential participants were identified from the Tracheostomy Care List as falling within the age range of 0-3 years during the study period. However, data was collected on only 80 participants, who fulfilled all the selection criteria and whose records were available.

2.4.4.1 Description of participants

Participants are described in terms of their gender, age at cannulation, underlying medical condition, reason for tracheostomy and the primary caregiver trained to care for their tracheostomy. Appendix D provides a summary description of the participants (Appendix D).

It was noted that 67.5% (54/80) of the participants were male and 32.5% were female. This greater proportion of males is similar to other studies (Arvedson & Brodsky, 1992; Midwinter et al., 2002). The age at the time of cannulation was also recorded and is presented graphically below in Figure 1:

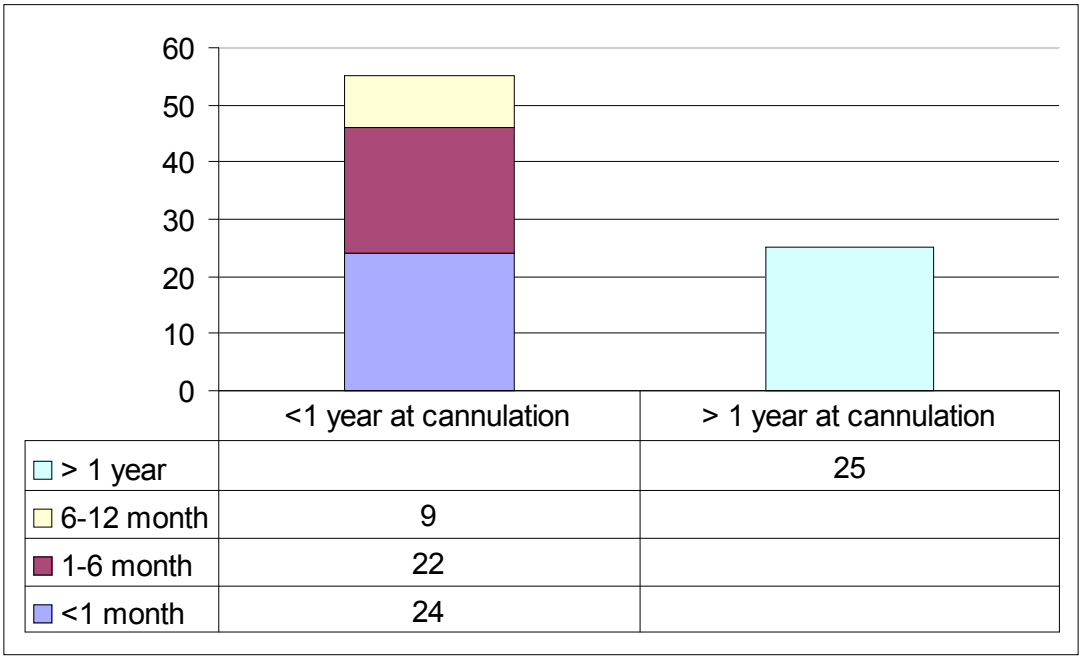

Figure 1. Age at cannulation (N=80)

In this sample 68.75% of the tracheostomies were performed on infants less than one year old, which is similar to other studies reporting more than half of their samples being cannulated before their first birthday (Carron, Derkay, Strope, Nosonchuk & Darrow, 2000; Midwinter et al., 2002; Ward, Jones & Carew, 1995). This shift to cannulating younger patients may be accounted for by the changed indications for tracheostomies.

Previously the majority of tracheostomies were performed because of infection (croup and epiglottitis) before endotracheal intubation became available as a method of treatment (Carron et al., 2000). Presently the majority of tracheostomies are performed due to airway obstruction (Midwinter et al., 2002), long-term mechanical ventilation and pulmonary toilet (Bleile, 1993; Carron et al., 2000; Midwinter et al., 2002), which is similar in the RCCH tracheostomy population. Figure 2 illustrates the distribution of indications for tracheostomies in the study population.

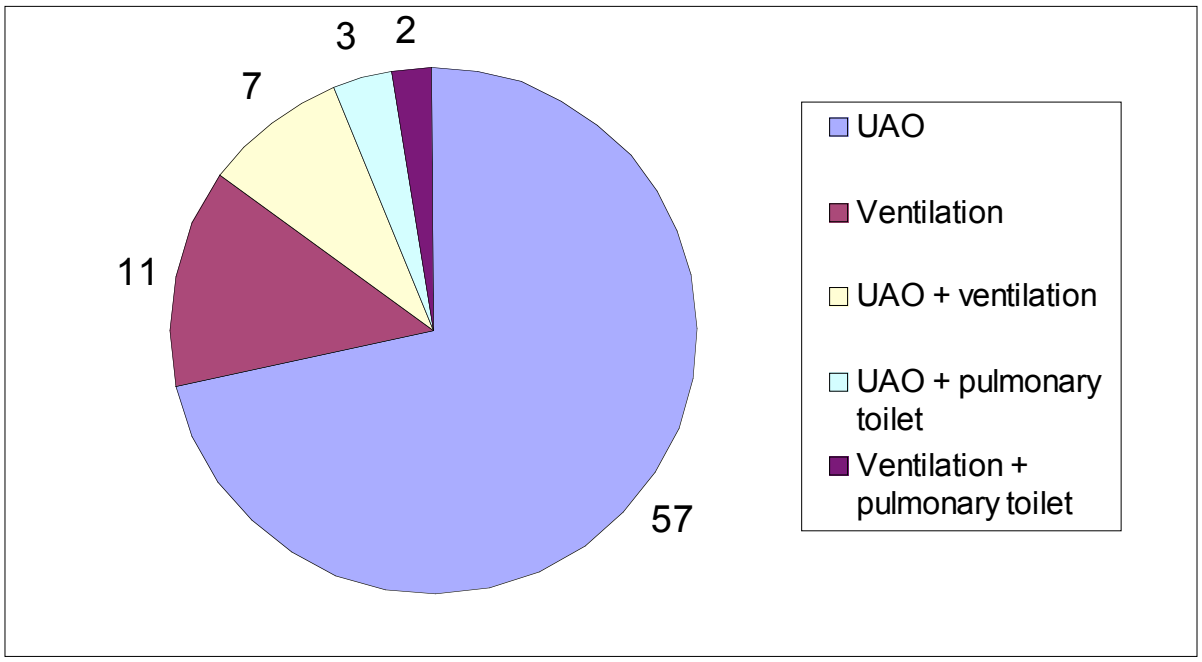

Figure 2. Reason for tracheostomy (N=80)

The most common reason for tracheostomy in infants and toddlers in this study was for upper airway obstruction (UAO) (71.25%), while long-term ventilation

requirements accounted for 13.75% of the sample. This is similar to some studies (Midwinter et al., 2002; Shinkwin & Gibbin, 1996), but differs from others who reported prolonged ventilation as the indication in the majority of their samples (Carron et al., 2000; Hadfield et al., 2003). The increased incidence of UAO in the study sample may be related to the prevalence of prematurity and low birth weight in the South African context (Kritzinger, 2000; SAHIMS, 2005), which in turn is related to a higher incidence of subglottic stenosis due to endotracheal intubation (Hadfield et al., 2003; Midwinter et al., 2002).

Participants were assigned to a general category that best described their underlying medical condition, as opposed to only describing the indications for the tracheostomy. Most studies in the literature have grouped participants according to the indication for the tracheostomy, and this has been limited to UAO, long-term ventilation and pulmonary toilet, with varying combinations and sub-categories (Carron et al., 2000; Hadfield et al., 2003; Midwinter et al., 2002; Shinkwin & Gibbin, 1996). However, this was considered limiting, because, for example, in the present study, a participant with an isolated UAO as a result of a laryngeal web, a toddler with severe cerebral palsy, an ex-premature infant with subglottic stenosis, an infant with foetal alcohol syndrome and a funnel larynx, an infant with Down Syndrome, gastro-intestinal problems and laryngomalacia, and an infant with an UAO secondary to HIV infection would all have been represented in the UAO category. It is clear that in addition to the UAO and tracheostomy, these participants all had significantly different risk factors

associated with their underlying medical conditions for difficulties in the development of feeding, speech production and communication. One of the sub-aims of the study is to determine whether there is an association between the underlying medical condition and the incidence of dysphagia and/or communication difficulties, and it was therefore important to classify participants according to a primary underlying medical condition.

The six categories used to describe participants' underlying medical conditions were: respiratory/ear, nose & throat (ENT), neurology, HIV and AIDS, respiratory and cardiac, respiratory and gastro-intestinal tract (GIT) and other. The distribution of medical conditions is presented in Figure 3.

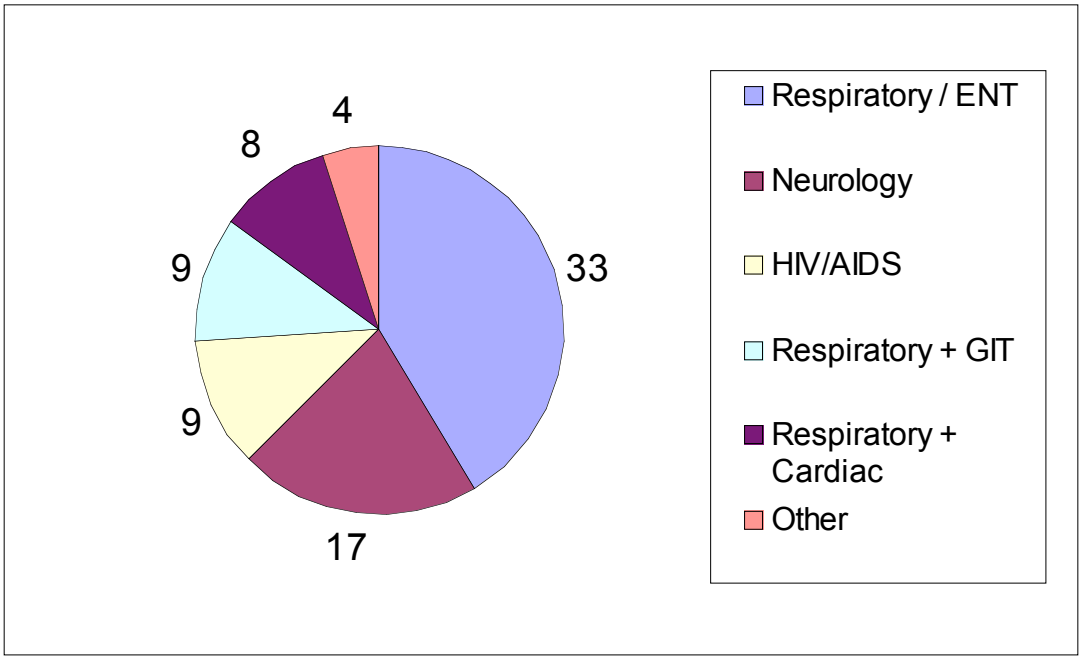

Figure 3. Underlying medical condition (N=80)

The underlying medical conditions listed above were chosen based on the participants' presenting problems and conditions referred to in tracheostomy, feeding and ECI literature (Hall, 2001; Kertoy, 2002; Rossetti, 2001).

The *Respiratory/ENT* category accounted for 41.25% of the participants, and included conditions resulting in airway obstructions, such as choanal atresia, laryngeal webs, laryngomalacia, micrognathia, retrognathia, as well as chronic lung disease (Hall, 2001; Kertoy, 2002). *Neurological* conditions, such as Guillan Barre Syndrome, various spinal muscular atrophies, cerebral palsy, Arnold Chiari malformation and head injuries (Hall, 2001; Kertoy, 2002), accounted for the second largest category at 21.25%. The remaining categories of *HIV and AIDS*, *Respiratory and Gastrointestinal Tract problems (GIT)* and *Respiratory and Cardiac* were fairly equally represented (Hall, 2001; Kertoy, 2002; Rossetti, 2001). Four participants were allocated to the O*ther* category, as they presented with individual conditions, namely: a cardiac defect, burns, potassium permanganate ingestion and a tumour. It is also noteworthy that 22 (27.5%) of the participants had a history of prematurity, because the effects of prematurity on feeding and communication development are well documented. These effects may include difficulty establishing oral feeding due to neurological immaturity, oral motor and/or oral sensory difficulties, GOR and respiratory complications (Arvedson & Brodsky, 2002; Hall, 2001; Kertoy, 2002; Rommel et al., 2003), as well as multiple risk factors for delayed communication development (Rossetti, 2001).

In the present study 71 (88.75%) of the infants and toddlers' mothers were trained to care for them at home, 3 of the participants' grandmothers were trained and one father received training (Appendix D). Three of the participants died before a caregiver was trained and two were abandoned and the facilities that they were referred to, had been trained to care for infants and toddlers with tracheostomies. The RCCH Tracheostomy Home Care Programme successfully trains caregivers from all socio-economic groups, including many disadvantaged families and those who live in informal dwellings, to care for their infants and toddlers with tracheostomies at home. This is important to note because it is considered a protective factor that encourages resilience (Rutter, 2000) in the population of tracheostomies that is at risk for developing difficulties requiring ECI.

The participants in the present study were considered to be representative of the paediatric tracheostomy population in South Africa, as they included infants and toddlers from various cultures, socio-economic and geographic groups. The Tracheostomy Home Care Programme at RCCH caters for all infants, toddlers and children with tracheostomies, from both the private and public sectors, as well as those from rural areas and other provinces when necessary.

2.5 MATERIALS AND APPARATUS

2.5.1 Materials

The researcher developed a checklist, *Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies* (Appendix E), to identify swallowing, feeding and communication difficulties from the medical records that were reviewed. The Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies (Appendix E) was based on tools, checklists and information used to assess swallowing, feeding, speech and communication skills in the ECI and tracheostomy populations available in the literature (Adamson & Dunbar, 1991; Arvedson & Brodsky, 2002; Arvedson & Lefton-Greif, 1998; Billeaud, 1998; Bleile, 1993; Bleile et al., 1993; Carron et al., 2000; Hall, 2001; Hill & Singer, 1990; Kamen & Watson, 1991; Kaslon & Stein, 1985; Katzenellenbogen et al., 1997; Kertoy, 2002; Kertoy et al., 1999; Locke & Pearson, 1990; Midwinter et al., 2002; Morris & Klein, 2000; Rossetti, 2001; Simon et al., 1983; Wolf & Glass, 1992).

The Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies (Appendix E) was used to record the information in Table 1.

Table 1. Information recorded in The Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies (See Appendix E)

INFORMATION	JUSTIFICATION	SOURCE
1. Reference number	1. Each participant was allocated a reference number to ensure confidentiality and anonymity, and prevent duplication of recorded information.	1.Katzenellenbogen et al., 1997.
2. Age at cannulation	2. The age at which participants were cannulated is important when considering feeding and communication development.	2. Kertoy, 2002.
3. Primary underlying medical condition	3. It was important to consider the primary underlying medical condition when assessing feeding and communication skills in infants and toddlers with tracheostomies, as the underlying medical condition may have affected these skills in addition to the presence of the tracheostomy.	3. Carron et al., 2000; Midwinter et al., 2002.
4. Indication for trache-ostomy	4. The indication for a tracheostomy was relevant because it is related to the underlying medical condition, and may also impact on feeding and communication development.	4. Bleile, 1993; Carron et al., 2000; Kertoy, 2002; Midwinter et al., 2002.
5. Dysphagia-related symptoms/difficulties assessed clinically and/or instrumentally		
5.1 Structural defects e.g. cleft:palate.	5.1 Structural abnormalities may result in swallowing and feeding difficulties.	5.1 Arvedson & Brodsky, 2002; Hall, 2001; Morris & Klein, 2000.

5.2 Oral phase		
5.2.1 Oral motor difficulties e.g. poor sucking, poor lip closure, reduced tongue movement.	5.2.1 Oral motor skills are essential for optimal swallowing and feeding	5.2.1 Arvedson & Brodsky, 2002; Hall, 2001; Wolf & Glass, 1992.
5.2.2. Oral sensory difficulties e.g. oral hypo/hypersensitivity , oral aversion.	5.2.2. Oral sensory disorders may result in impaired oral motor function and suboptimal feeding skills.	5.2.2. Arvedson & Brodsky, 2002; Morris & Klein, 2000; Wolf & Glass, 1992.
5.3 Pharyngeal phase:		
5.3.1. Delayed / absent swallow response	5.3.1. Delayed or absent swallow response is an increased risk for aspiration.	5.3.1. Arvedson & Lefton -Greif, 1998; Wolf & Glass, 1992.
5.3.2.Nasopharyngeal backflow	5.3.2. Nasopharyngeal backflow indicates a lack of co-ordination of swallowing and may compromise breathing.	5.3.2. Arvedson & Lefton-Greif, 1998.
5.3.3. Laryngeal penetration	5.3.3. Laryngeal penetration occurs when material enters the laryngeal vestibule above the vocal cords and increases the risk of aspiration.	5.3.3. Arvedson & Brodsky, 2002; Arvedson & Lefton-Greif, 1998.
5.3.4. Aspiration	5.3.4 Aspiration occurs when the swallow response is inco-ordinated and there is inadequate airway protection, resulting in material entering the trachea and possibly the lungs.	5.3.4. Arvedson & Brodsky, 2002; Hall, 2001.
5.3.5. Pooling in valleculae & pyriform sinuses; residue in pharynx.	5.3.5. Pooling of material in the pharynx before or after a swallow increases the risk of aspiration.	5.3.5. Arvedson & Brodsky, 2002; Arvedson & Lefton-Greif, 1998.

5.4. Oesophageal phase:		
5.4.1. Delayed / insufficient upper oesophageal sphincter opening.	5.4.1. Upper oesophageal sphincter dysfunction may result in aspiration, nasopharyngeal backflow, pooling in the pharynx, and may be indicative of a neurological cause or structural abnormality.	5.4.1. Arvedson & Lefton-Greif, 1998.
5.4.2. Structural abnormalities e.g. stricture, obstruction, tracheoesophageal fistula.	5.4.2 Structural abnormalities of the oesophagus may result in swallowing and feeding difficulties.	5.4.2. Arvedson & Brodsky, 2002.
5.4.3. Gastro-oesophageal reflux (GOR)	5.4.3. GOR may cause dysphagia, respiratory complications and failure to thrive.	5.4.3. Arvedson & Brodsky, 2002.
5.4.4.Oesophageal dysmotility	5.4.4. Oesophageal dysmotility may result in retrograde movement of material and subsequent aspiration, as well as associated pain, which may negatively affect feeding.	5.4.4. Arvedson & Lefton-Greif, 1998.
6. Feeding method: Oral, Nasogastric tube, Nasojejunal tube, Gastrostomy tube, Combination oral + tube.	6. Infants and toddlers with swallowing and feeding problems may require alternative feeding. While non-oral feeding may provide a safe method of feeding, or provide adequate nutrition that cannot be attained orally, the use of alternative feeding methods may affect the development of sensorimotor skills necessary for feeding and speech.	6. Arvedson & Brodsky, 2002; Hall, 2001; Morris & Klein, 2000; Wolf & Glass, 1992.
7. Communication skills.	7. Communication skills may be affected because of the underlying medical condition, or as a result of the tracheostomy and the associated effects on communication.	7. Kertoy, 2002; Rossetti, 2001.

7.1 Speech:		
7.1.1 Aphonia	7.1.1 The inability to produce voice may affect the normal development of speech.	7.1.1 Bleile et al., 1993; Locke & Pearson, 1990; Simon et al., 1983.
7.1.2 Indistinct/unintelligible speech production	7.1.2 The clarity of speech may be affected by a long-term tracheostomy tube.	7.1.2. Kamen & Watson, 1991; Kertoy et al., 1999.
7.2. Communication		
7.2.1. Means of communication: verbal / non-verbal.	7.2.1. During periods of aphonia it may be necessary to introduce a non-verbal means of communication to facilitate the development of communication.	7.2.1. Adamson & Dunbar, 1991.
7.2.2. Receptive language skills.	7.2.2. Delays in the receptive language skills of infants and toddlers with tracheostomies have been reported in the literature.	7.2.2. Kaslon & Stein, 1985; Simon et al., 1983.
7.2.3. Expressive language skills.	7.2.3. Delays in the expressive language skills of infants and toddlers with tracheostomies have been reported in literature.	7.2.3. Hill & Singer, 1990; Kaslon & Stein, 1985; Simon et al., 1983.
8. Hearing status	8.Hearing loss will affect speech and language development.	8. Billeaud, 1998.
9. Developmental delay	9.The infant and toddler with a tracheostomy is at risk for developmental delay because of the underlying medical conditions, health status and possible long-term / repeated hospitalisations.	9. Kertoy, 2002.

The Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies (Appendix E) was developed for the current study, and was the only material used to collect data from the participants' medical records.

2.5.2 Trustworthiness

Both quantitative and qualitative research trustworthiness was determined for the present study. The Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies (Appendix E) was developed because no readily available instrument/assessment tool for the sample population was available. Assessments of dysphagia and communication in the ECI population abound in the literature, and no one specific tool is considered the gold standard of assessment (Reilly, 2004b; Rossetti, 2001). The checklist was based on a number of assessment tools, checklists and information available in the paediatric dysphagia, ECI and tracheostomy literature and is therefore considered to have content, criterion and construct validity (De Vos, 1998; Leedy & Ormrod, 2004). The above-mentioned checklist was considered to be reliable, as the researcher had been trained in the clinical areas of paediatric dysphagia, ECI and tracheostomies, and had been clinically responsible for the participants, thereby reducing observer variation (Katzenellenbogen et al., 1997; Leedy & Ormrod, 2004). In addition, the information obtained should be repeatable, as the checklist identified information already recorded in medical folders during assessment and observation in clinical practice (De Vos, 1998).

It has been argued that one cannot apply the same measures of validity and reliability to qualitative research and it was therefore necessary to consider the concept of trustworthiness in the present study (De Vos, 1998). The present

study met the criteria related to trustworthiness, namely: credibility, applicability/transferability, consistency and neutrality (De Vos, 1998). The researcher established *credibility* through prolonged engagement in the field of study, persistent observation and peer debriefing, and demonstrated that the data was accurately identified and described (Babbie & Mouton, 2001; De Vos, 1998). *Transferability* of results has been ensured through providing sufficient descriptions of data to allow for comparison with other research (De Vos, 1998). *Consistency* relates to reliability and has been accounted for in the development of the checklist based on the best available literature (De Vos, 1998; Leedy & Ormrod, 2004). *Neutrality* relates to freedom from bias. Qualitative researchers try to increase their contact and involvement with participants and the focus of neutrality is therefore on the data, which is achieved through credibility and applicability, both of which were established for the present study (De Vos, 1998).

The researcher was also the speech-language therapist originally responsible for the assessment and treatment of participants' feeding and communication skills in the clinical setting. Researcher bias was therefore controlled for through the development of the checklist based on the best available literature (De Vos, 1998). Only information recorded in the participants' medical records was used to complete the checklist, to ensure validity and reliability of results and control for researcher bias (De Vos, 1998; McMillan & Schumacher, 2001). The retrospective nature of the study therefore also controlled for researcher bias, as

the information that was collected by the researcher had been recorded before the start of the study (Leedy & Ormrod, 2004).

2.6 PROCEDURES

The data collection was carried out as follows:

2.6.1 Data Collection and Recording Procedures

- After permission was granted from the University of Cape Town's Research Ethics Committee (Appendix A) and the University of Pretoria's Faculty of Humanities Research Proposal and Ethics Committee (Appendix B), medical records were requested in order to extract the relevant information for data collection.
- Each participant was allocated a reference number to ensure confidentiality and anonymity.
- The information was recorded on the Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies (Appendix E).

  Information regarding the participants' feeding had been recorded in the medical notes. Full oral feeds recorded in the nursing or clinical notes was considered evidence of normal swallowing and feeding in the

absence of a specific swallowing and feeding assessment by a speech-language therapist.

For the majority of participants the speech-language therapist had conducted a clinical, bedside evaluation of swallowing and feeding skills and recorded assessment results in the medical notes. In addition, instrumental evaluations such as barium swallows, modified barium swallows or scintigraphy (Hall, 2001; Wolf & Glass, 1992) may have been conducted to further assess swallowing skills and these results were also available in the medical notes.

Details regarding communication skills were recorded in the medical notes by the speech-language therapist in the majority of participants. However, in a few cases (10/80) this information was unavailable due to early mortality, transfer to other facilities or lack of assessment, possibly due to age at the time of data collection, and this has been noted in the Results and Discussion chapter.

Speech production skills were assessed informally and recorded in the medical notes by the speech-language therapist. Receptive and expressive language skills were assessed using the Rossetti Infant Toddler Language Scale (Rossetti, 1990) in the majority of the

participants, as well as informal assessments, and the results were recorded in the participants' medical notes.

- All the collected data was then recorded on an Excel spreadsheet.

2.6.2 Data Analysis Procedures

The data obtained from the Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies (Appendix E) was coded and then analysed using SPSS 12.01.1 for Windows. Descriptive statistics were used to describe the data in terms of proportions of the sample that presented with feeding difficulties and communication difficulties, as well as the nature of these difficulties (Leedy & Ormrod, 2004). A range of values, expected to include the true value in other samples, computed with a 95% confidence interval, has been reported with each proportion (Altman, 1991). These proportions were represented using histograms and tables, which organized the data visually and was useful in identifying distributions for the reader (De Vos, 1998; Leedy & Ormrod, 2004; McMillan & Schumacher, 2001).

The data was further analysed using inferential statistics, namely Fisher's Exact Test (Altman, 1991; Bland, 2000) to determine whether there was a relationship, and the strength of that relationship, between the underlying medical condition and the incidence of dysphagia and/or communication difficulties in the sample population (De Vos, 1998; Leedy & Ormrod, 2004). A major limitation in

determining a relationship between the underlying medical condition and the incidence of feeding and/or communication difficulties was the small number of participants in each of the categories, and this needs to be considered when interpreting the results (Leedy & Ormrod, 2004).

3. RESULTS AND DISCUSSION

The primary goal of evidence-based research is to provide information to improve clinical practice (Reilly, 2004a) through increasing knowledge in a specific topic, developing assessment and treatment protocols, motivating for resources and evaluating current practice (Katzenellenbogen et al., 1997). The results in this specific study are important in improving knowledge regarding feeding and communication difficulties in the specific population of infants and toddlers with tracheostomies within the South African context because there is a lack of available literature. The results of this study may be used to improve clinical practice and assist in training students, speech-language therapists and other professionals working with this population and thereby improve services provided for this population.

The results of the study are presented and discussed according to the aims and objectives stated in the methodology, using qualitative data and descriptive statistics, as well as quantitative data obtained from statistical analysis of the results. Descriptive statistics in the form of proportions were used to describe the incidence and nature of dysphagia and communication difficulties in the sample population (Leedy & Ormrod, 2004). A 95% confidence interval is reported for each proportion and was calculated using the sample estimate and its standard error (Katzenellenbogen et al., 1997).

3.1 THE INCIDENCE AND NATURE OF DYSPHAGIA DOCUMENTED IN THE SAMPLE POPULATION OF INFANTS AND TODDLERS (0-3 YEARS) WITH TRACHEOSTOMIES

The following sections will report the incidence of dysphagia in the study population, and describe the nature of dysphagia with regard to the types of difficulties experienced and compare these results to the literature.

3.1.1 Incidence of Dysphagia in Infants and Toddlers with Tracheostomies

The Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies (Appendix E) was used to identify swallowing and feeding difficulties in the participants. If any of the dysphagia-related symptoms were checked for a participant (excluding structural defects) he / she was considered to have a feeding or swallowing difficulty. The incidence of dysphagia in infants and toddlers with tracheostomies was therefore calculated as a proportion of the sample population and is illustrated in Figure 4.

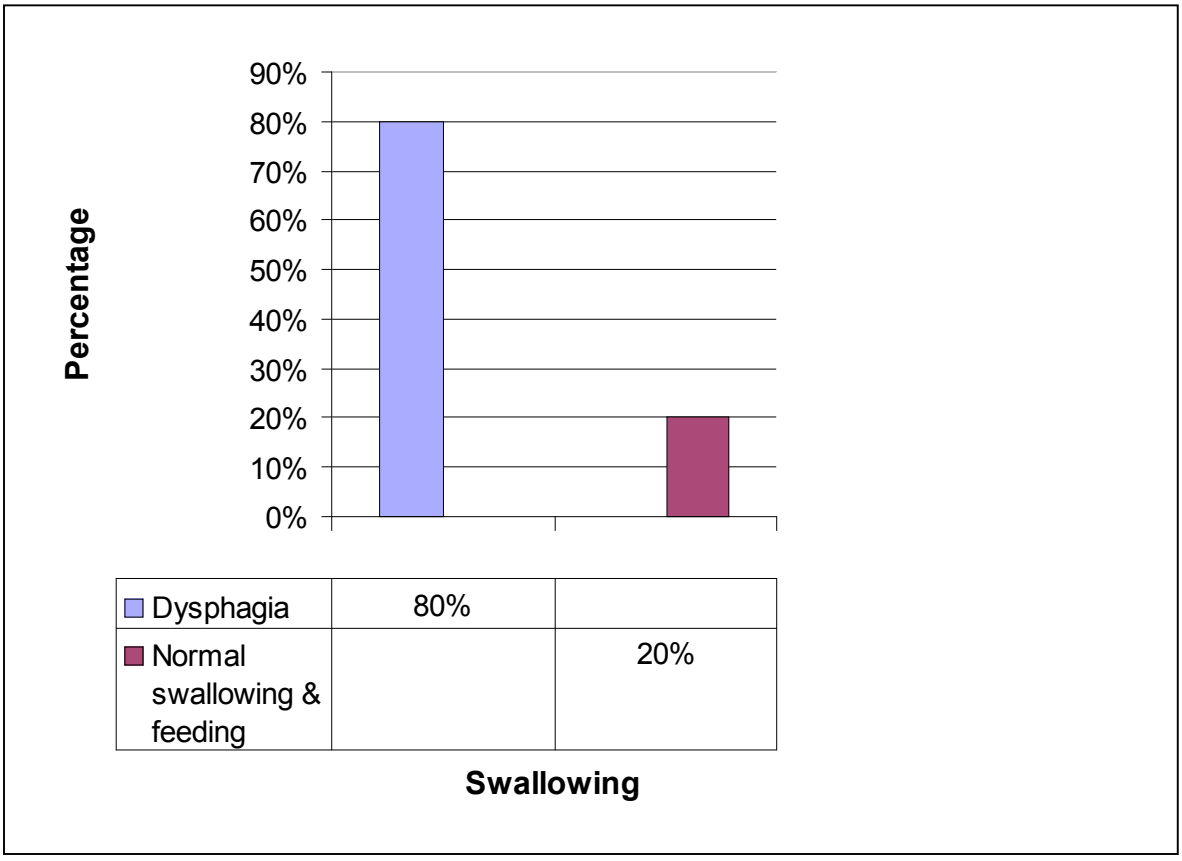

Figure 4. Incidence of dysphagia in the sample population of infants and toddlers with tracheostomies (N=80)

In the present study the incidence of symptoms related to swallowing and feeding difficulties was 80% (64/80 of participants) (range: 71-89%). This finding was compared to that of Rosingh and Peek (1999), who reported that 91% of the 36 infants with tracheostomies in their study had a swallowing difficulty, and only half could be attributed to an underlying neurological or anatomic deficit. The higher incidence of dysphagia in Rosingh and Peek's study may be related to the age of their participants (only infants) or their smaller sample size (Rosingh & Peek, 1999).

The incidence reported in this study, supported by the limited available literature (Rosingh & Peek, 1999), suggests that infants and toddlers with tracheostomies are more likely to present with swallowing and feeding difficulties than other paediatric populations, which range from 25-35% in the normal paediatric population, 40-70% in premature infants and up to 80% in developmentally delayed children (Manikam & Perman, 2000; Rudolph & Link, 2002). The reason for the increased incidence of swallowing and feeding difficulties in infants and toddlers with tracheostomies may be related to the multiple risk factors discussed earlier, namely: the presence of the tracheostomy tube (Abraham & Wolf, 2000; Arvedson & Brodsky, 2002), underlying medical conditions (Hall, 2001; Kertoy, 2002), long-term hospitalizations, long-term non-oral feeding and caregiver-infant separation (Arvedson & Brodsky, 2002; Morris & Klein, 2000).

It is important to consider factors that may affect the normal development of swallowing and feeding in infants and toddlers with tracheostomies because these difficulties have implications for nutrition, growth, health status, cognitive development, psychological well being, social interaction and development, as well as speech development (Arvedson & Brodsky, 2002; Kertoy, 2002; Morris & Klein, 2000).

No other studies related to the incidence of dysphagia in infants and toddlers with tracheostomies could be found in the literature, indicating again the need for research in this area and the relevance of the present results.

It is not only the incidence of dysphagia that is of importance to clinicians working with infants and toddlers with tracheostomies, but also the nature of swallowing and feeding difficulties, as this will assist clinicians in the prevention, early identification and management of swallowing and feeding difficulties in this population (Arvedson & Brodsky, 2002; Hall, 2001; Kertoy, 2002). The nature of swallowing and feeding difficulties will therefore be discussed in the following section.

3.1.2 Nature of Dysphagia in infants and toddlers with tracheostomies

It is important to describe the nature of dysphagia presenting in infants and toddlers with tracheostomies in order to identify trends within the population and plan optimal treatment and management (Arvedson & Brodsky, 2002).

Information regarding the nature of participants' swallowing and feeding difficulties was recorded using the Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies (Appendix E). Swallowing and feeding difficulties were categorized into three phases of swallowing, namely: oral, pharyngeal and oesophageal phase difficulties, based on paediatric dysphagia literature (Arvedson & Brodsky, 2002; Hall, 2001; Wolf & Glass, 1992). These categories as well as subcategories within each of them were not mutually exclusive i.e. a participant may have demonstrated difficulties in both the oral and oesophageal phases, and within these may have presented

with difficulties in oral motor and oral sensory skills. These results are represented graphically in Figure 5.

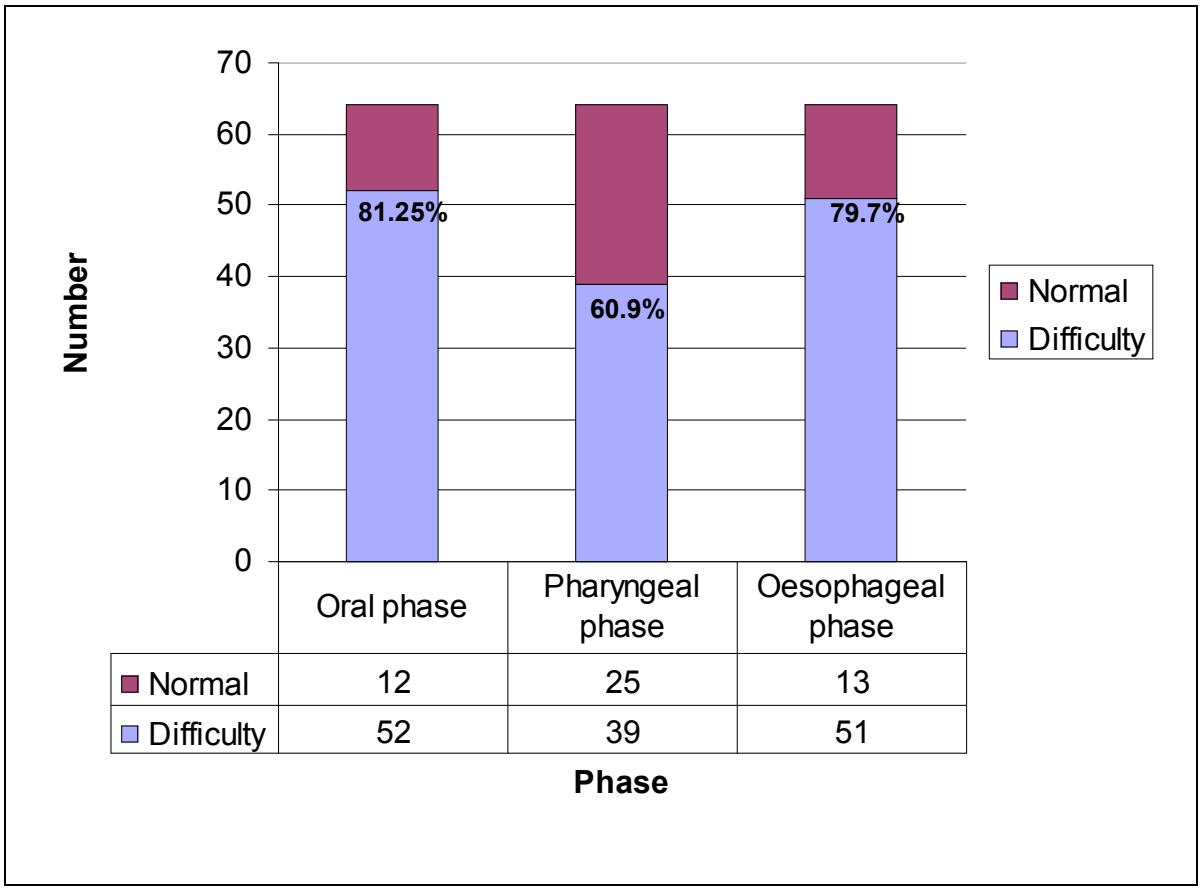

Figure 5. Nature of dysphagia in the sample population of infants and toddlers with tracheostomies (N=64)

Oral phase difficulties were recorded in 81.25% (range: 71-91%), and oesophageal difficulties in 79.7% (range: 69-89%) of the dysphagic participants (N = 64). Pharyngeal phase difficulties were less prevalent, recorded in 60.9% (range: 48.7-73.2%) of the dysphagic participants. Considering that the effects of the tracheostomy tube are expected to have the greatest impact on the

pharyngeal phase of swallowing (Abraham & Wolf, 2000; Arvedson & Brodsky, 2002) these results may indicate that other factors, such as the underlying medical conditions, prematurity and LBW, and long-term non-oral feeding, play an additional role in the swallowing and feeding difficulties experienced by infants and toddlers with tracheostomies. These multiple risk factors therefore need to be considered by speech-language therapists when assessing infants and toddlers with tracheostomies.

Oral phase:

Oral motor and oral sensory difficulties were described within the *oral phase* and included, among others, problems with latching, sucking, tongue movement, lip closure, bolus formation and manipulation, oral hypersensitivity, hypersensitive gag and food selectivity based on texture or taste.

Oral phase difficulties are commonly reported in premature infants (22/80 participants) due to neurological immaturity, abnormal muscle tone, immature and inadequate oral motor skills and oral hypersensitivity (Arvedson & Brodsky, 2002; Hall, 2001; Morris & Klein, 2000). Infants and toddlers with reduced oral tone, general muscle weakness and those with neurological involvement (17/80) have difficulty establishing sucking, developing and maintaining adequate oral motor skills to support oral feeding and may also experience oral hyposensitivity or oral hypersensitivity which may affect their ability to support oral feeding (Arvedson & Brodsky, 2002; Wolf & Glass, 1992).

Infants with oro-facial structural abnormalities (12/80), such as cleft palate, have difficulty creating negative pressure during sucking and may need compressible bottles (Kummer, 2001), while those with HIV and AIDS (9/80) may have oral motor difficulties related to HIV-encephalopathy or oral sensory difficulties as a result of hypersensitivity, odynophagia and oral candidiasis (Davis-McFarland, 2000; Pressman, 1992).

Infants and toddlers who have received long-term non-oral feeding (48/80) lack the normal developmental experience of oral feeding and exposure to positive oral experiences and may therefore experience oral motor and/or oral sensory difficulties with feeding (Arvedson & Brodsky, 2002; Hall, 2001; Morris & Klein, 2000).

Therefore, the high incidence (81.25%) of oral phase difficulties within the study population may be attributed to the underlying medical conditions of the participants. However, the long-term effects of a tracheostomy tube on the development of the vocal tract and position of the tongue (Kamen & Watson, 1991) may also be considered as possible contributing factors to difficulties in the oral phase, particularly with tongue control of the bolus, in infants and toddlers with tracheostomies. No literature describing oral phase difficulties in infants and toddlers with tracheostomies could be sourced at the time of writing this study. Difficulties in the oral phase are graphically presented in Figure 6 below.

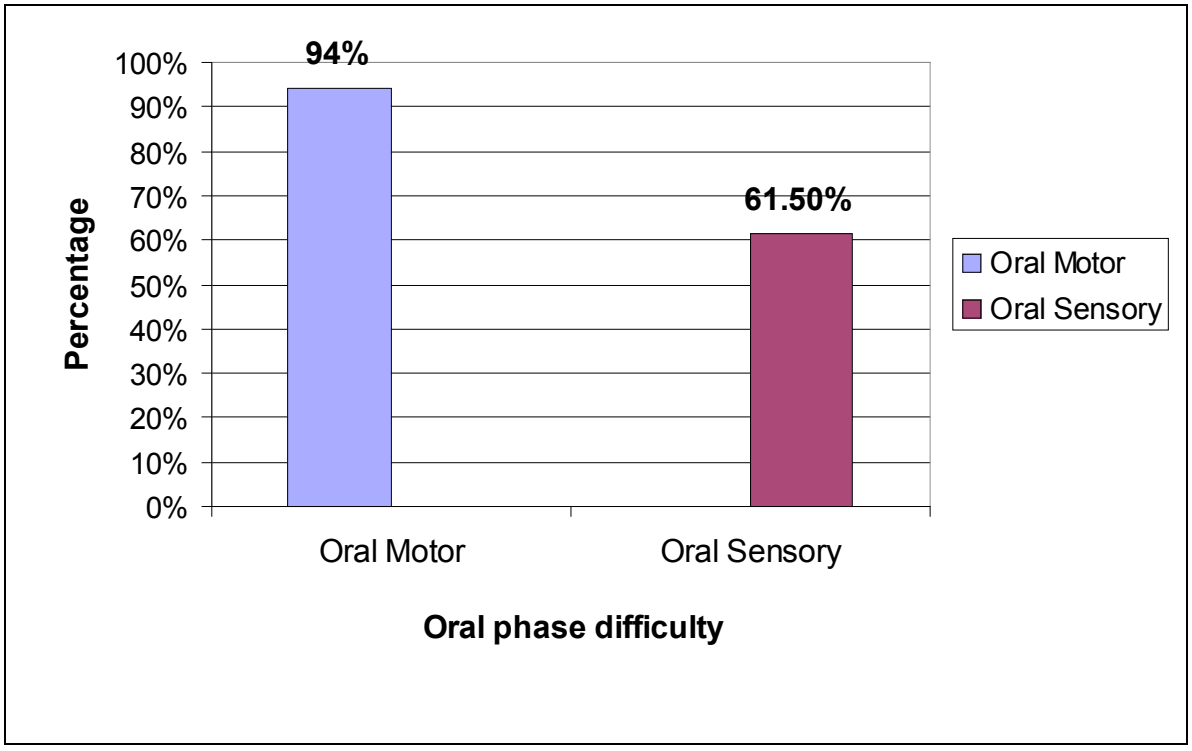

Figure 6. Oral phase difficulties recorded in the sample population of infants and toddlers with tracheostomies (N=52)

Oral motor difficulties were reported in 94% (49/52) of the participants with oral phase difficulties, compared to 61.5% (32/52) with oral sensory problems. While there is no literature specific to the paediatric tracheostomy population and oral phase difficulties, Rommel et al. (2003) described oral motor and oral sensory feeding problems in their study population of 700 infants with feeding problems. They reported that both oral motor and oral sensory problems correlated with a history of nasogastric and gastrostomy feeding, and that oral sensory problems were significantly associated with a history of aspiration and/or ventilation. Forty-

eight of the participants in the present study had a history of non-oral feeding, 20 a history of ventilation and 20 had documented aspiration, suggesting that the participants had risk factors mentioned by Rommel et al. (2003) for oral motor and oral sensory difficulties. Oral motor difficulties are reported in the literature in premature infants (Hall, 2001; Morris & Klein, 2000), infants and toddlers with neurological involvement (Arvedson & Brodsky, 2002; Hall, 2001; Morris & Klein, 2000), HIV and AIDS (Pressman, 1992) and those who have had long-term non-oral feeding (Morris & Klein, 2000). The participants in the present study therefore had multiple risk factors related to their medical history, underlying medical condition and tracheostomy, for having or developing oral phase difficulties in feeding, which may account for the high incidence reported in this study.

It is therefore important to consider the underlying medical condition of infants and toddlers with tracheostomies, as well as their medical history when assessing their swallowing and feeding abilities. An early oral sensorimotor programme should be implemented for infants and toddlers with tracheostomies, to prepare them for oral feeding and prevent possible delays in introducing oral feeds, poor oral motor skills and the development of sensory-based feeding difficulties (Arvedson & Brodsky, 2002; Morris & Klein, 2000; Rommel et al., 2003). Parents and medical staff, particularly nurses, should be educated regarding the normal development of the oral phase of feeding and possible difficulties experienced by infants and toddlers with tracheostomies. They should

be included in therapy programmes to prevent oral phase difficulties from developing and to develop oral sensorimotor skills in infants and toddlers with tracheostomies.

Pharyngeal phase:

Problems noted in the *pharyngeal phase* related to absent or delayed swallow response, nasopharyngeal backflow, laryngeal penetration, aspiration, pooling of material and residue in the pharynx, and are illustrated in Figure 7.

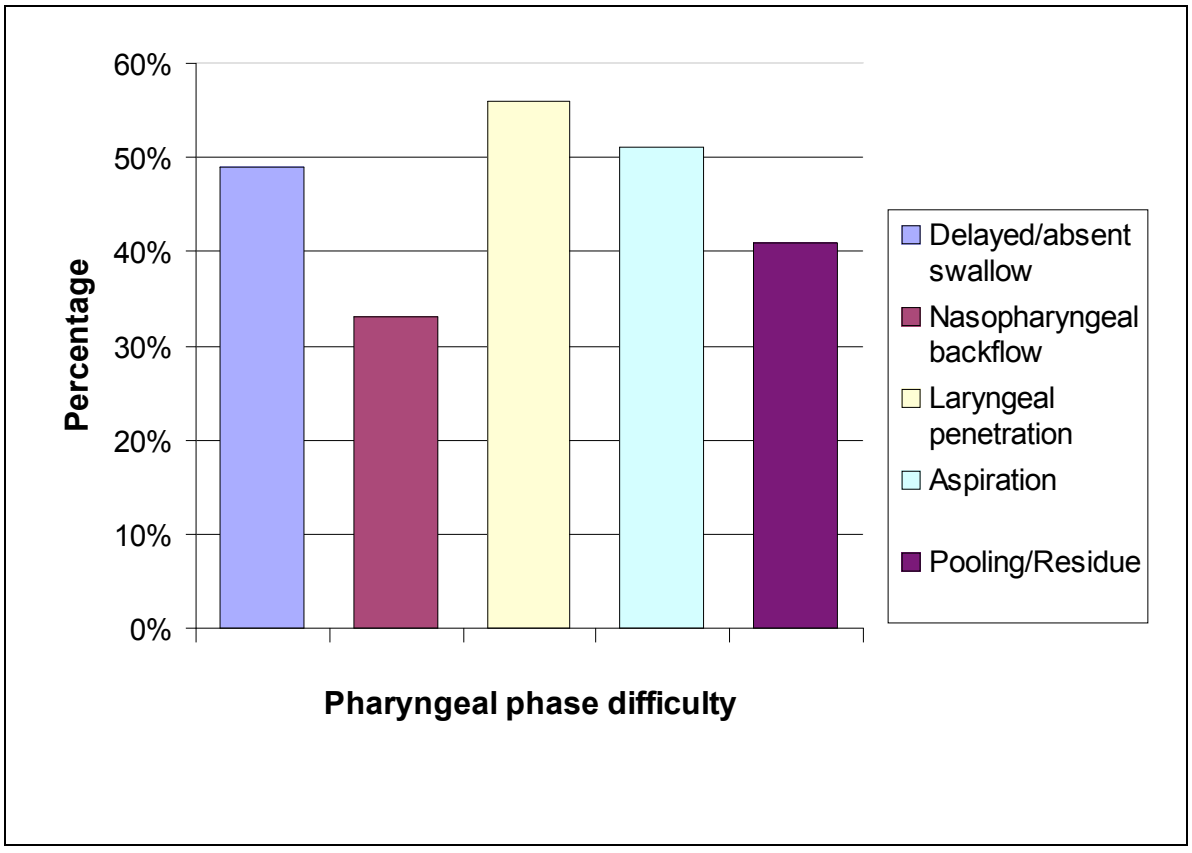

Figure 7. Pharyngeal phase difficulties in the sample population of infants and toddlers with tracheostomies (N=39)

A delayed or absent swallow response was reported in 48% (19/39) of participants with pharyngeal phase difficulties. Abraham and Wolf (2000) reported delayed initiation of the swallow response in all 4 of their toddlers with tracheostomies. This is important clinically because of the associated risk of laryngeal penetration of the material in the hypopharynx before the swallow response. Abraham and Wolf (2000) may have had a higher incidence of delayed swallow response because of their small sample size, while identification in the present study may not have been as sensitive, as this was part of a general swallowing assessment, while the aforementioned study was specifically assessing swallowing timing. Clinicians should therefore be aware of the possibility of a delayed swallow response when assessing infants and toddlers with tracheostomies and assess treatment options to ensure safe swallowing.

Nasopharyngeal backflow was reported in 33% (13/39) of the participants with pharyngeal phase difficulties, and may be the result of a structural abnormality such as a cleft palate, or due to velopharyngeal insufficiency during the swallow (Arvedson & Brodsky, 2002). Although 12 participants had structural abnormalities, only 5/12 experienced pharyngeal phase difficulties, therefore the nasopharyngeal backflow reported in this study cannot be attributed only to structural abnormalities. Nasopharyngeal backflow is only considered a problem if it occurs repetitively and with large amounts that may compromise breathing (Arvedson & Lefton-Greif, 1998). It should therefore be monitored by clinicians

and controlled through positioning during feed and thickening feeds if necessary (Arvedson & Brodsky, 2002; Hall, 2001).

Laryngeal penetration is defined in dysphagia literature as material entering the laryngeal vestibule above the level of the vocal cords, and while it is a considerable risk for aspiration, the material may be cleared from the larynx without aspiration (Arvedson & Lefton-Greif, 1998). The risk for aspiration should be estimated based on the frequency, amount and depth of the penetration (Arvedson & Brodsky, 2002; Arvedson & Lefton-Greif, 1998; Friedman & Frazier, 2000). Laryngeal penetration was reported in 56% (22/39) of the participants with pharyngeal phase difficulties, but aspiration was reported in 51% (20/39) of the participants. Therefore, there seems to be a relationship between laryngeal penetration and aspiration, compared with Abraham and Wolf's (2000) study, which demonstrated laryngeal penetration in all four subjects, but aspiration was only documented in one subject. This may be related to the larger sample size of the present study, as well as the age of participants, as there is limited available research on laryngeal penetration and associated aspiration in infants, however deep laryngeal penetration is considered a predictor of aspiration (Friedman & Frazier, 2000). Both acute and chronic aspiration may result in potentially life-threatening risks to the infant and toddler with a tracheostomy and should therefore be prevented (Arvedson & Brodsky, 2002).

Pooling and residue of material in the pharynx was reported in 41% (16/39) of the participants with pharyngeal phase difficulties. This is usually an indication of poor pharyngeal constriction, and may be as a result of generalized hypotonia or poor pharyngeal pressure generation, and is expected in infants and toddlers with muscular weakness and neurological involvement (Arvedson & Lefton-Greif, 1998). It may also be considered an additional risk factor for aspiration before or after the swallow, as pooling before the swallow may result in spillage into the airway before the airway is protected and residue after the swallow may spill over into the airway when respiration resumes after the swallow (Arvedson & Lefton-Greif, 1998). None of the participants in Abraham and Wolf's (2000) study demonstrated residue in the pharynx after the swallow, which may be due to their smaller sample size or their selection criteria. Pooling in the pyriform sinuses can usually be attributed to reduced laryngeal elevation during the swallow, which is reported in individuals with tracheostomies due to the anchoring of the larynx by the tracheostomy tube (Abraham & Wolf, 2000; Arvedson & Brodsky, 2002). The presence of pooling before the swallow and residue after the swallow in the present study may explain the higher incidence of aspiration reported, when compared with that of Abraham and Wolf (2000).

Pharyngeal phase difficulties are associated with the greatest risk for aspiration, and the multidisciplinary team working with infants and toddlers with tracheostomies should be vigilant in monitoring their swallowing and feeding skills so as to recognize early signs of aspiration. Infants and toddlers with

tracheostomies that are suspected of swallowing difficulties should be assessed both clinically and instrumentally, and management should ensure safe swallowing to prevent further respiratory difficulties as a result of aspiration (Arvedson & Brodsky, 2002).

Oesophageal phase:

Oesophageal phase difficulties recorded in the participants were related to structural abnormalities, gastro-oesophageal reflux and oesophageal dysmotility and are illustrated in Figure 8.

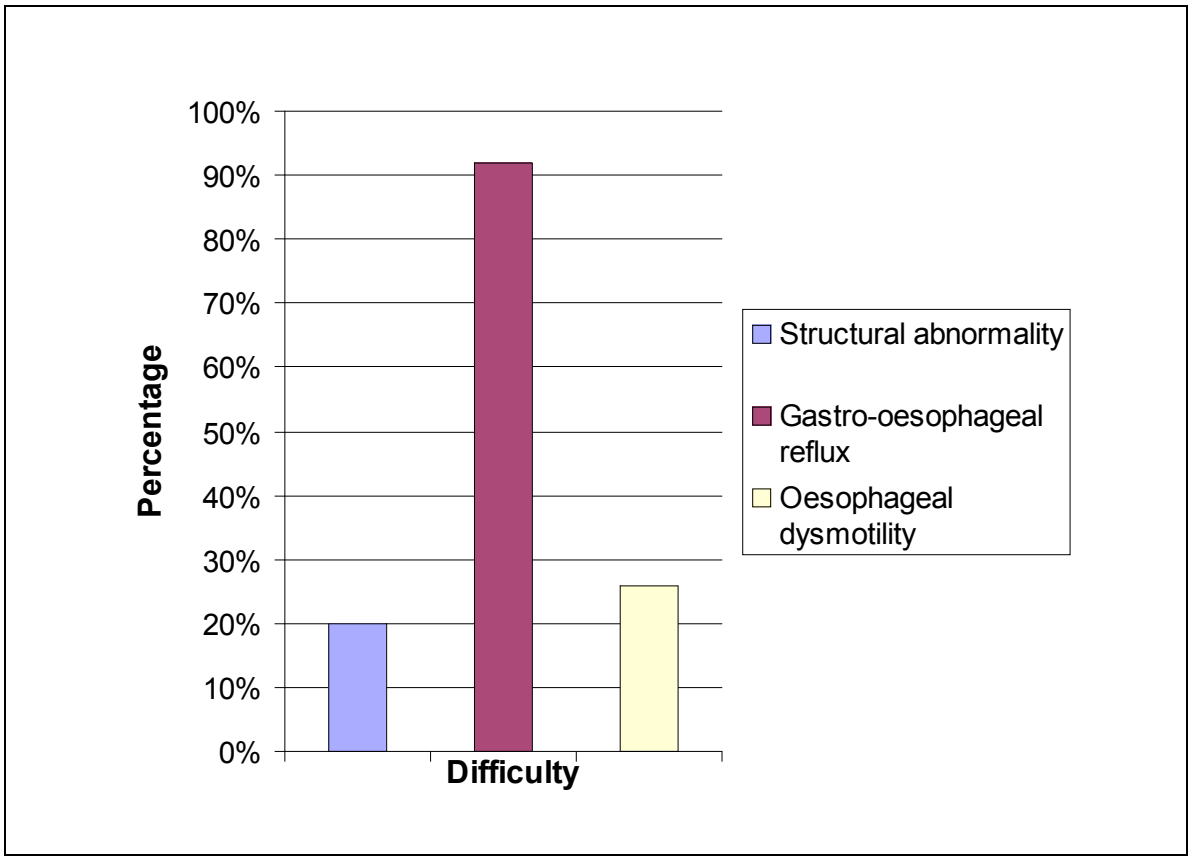

Figure 8. Oesophageal phase difficulties in the sample population of infants and toddlers with tracheostomies (N=51)

Gastro-oesophageal reflux (GOR) was the most common oesophageal symptom, reported in 92% (47/51) of the participants with oesophageal phase difficulties. Although there is no literature regarding GOR specific to the paediatric tracheostomy population, GOR has been reported as the most common gastrointestinal condition reported in infants with feeding difficulties (Field et al., 2003; Rommel et al., 2003). Feeding difficulties associated with GOR include oral motor dysfunction, feeding resistance, food refusal, selectivity and aspiration (Field et al., 2003; Matthiesen, Worrall, Masel, Wall & Shepherd, 1999), which may explain the high incidence of oral phase difficulties reported earlier, as some of the oral phase difficulties may be attributed to GOR (Field et al., 2003; Matthiesen et al., 1999). GOR should therefore be identified and managed effectively as soon as possible in infants and toddlers with tracheostomies, as it is an additional risk for developing feeding difficulties. Infants and toddlers with GOR may experience discomfort or pain when feeding, develop oral hypersensitivity, food aversion or refusal and emotional stressors related to feeding (Morris & Klein, 2000; Rommel et al., 2003), which will negatively impact on the normal development of oral feeding.

Structural abnormalities of the oesophagus (10/51) and oesophageal dysmotility (11/51) in the study population were noted in the participants that had a history of congenital oesophageal abnormalities, such as oesophageal atresia and tracheoeosophageal fistula, as well as premature infants, infants and toddlers with HIV and AIDS, neurological impairment and muscle weakness. Structural

abnormalities of the oesophagus and oesophageal dysmotility are also associated with feeding difficulties, such as feeding resistance, refusal and selectivity (Field et al., 2003; Karnak, Şenocak, Tanyel & Büyükpamukçu, 2001; Rommel et al., 2003).

The clinician should therefore be alerted to additional risk factors for feeding difficulties in infants and toddlers with tracheostomies that present with oesophageal difficulties.

Infants and toddlers with tracheostomies, who acted as participants in this study, presented with a range of swallowing and feeding difficulties, particularly in the oral and oesophageal phases. The results of this study report a high incidence (80%) of dysphagia in infants and toddlers with tracheostomies, which is higher than the incidence of dysphagia reported in paediatric dysphagia literature (Manikam & Perman, 2000; Rudolph & Link, 2002). The nature of dysphagia described in the participants was predominantly found in the oral (81.25%) and oesophageal (79.7%) phases of swallowing and appeared to be related not only to the presence of the tracheostomy tube, but also related to the underlying medical condition of the individual. While pharyngeal phase difficulties have been described in the literature (Abraham & Wolf, 2000; Rosingh & Peek, 1999), these were less prevalent than oral and oesophageal phase difficulties in the study population (60.9%). However, aspiration was documented in 20 (25%) of the participants, indicating the need for comprehensive assessment and

management of infants and toddlers with tracheostomies, considering the potentially life-threatening risks associated with aspiration, particularly in infants and toddlers with a history of respiratory compromise (Arvedson & Brodsky, 2002). Accurate and early assessment of dysphagia is therefore essential in providing optimal intervention to minimize feeding difficulties and maximize the individual's potential to feed safely orally.

3.2 THE RELATIONSHIP BETWEEN THE UNDERLYING MEDICAL CONDITION AND THE PRESENCE OF DYSPHAGIA IN THE SAMPLE POPULATION

Information regarding the participants' underlying medical conditions and presence of dysphagia was recorded on the Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies (Appendix E). This data was analysed using Fisher's Exact Test (Altman, 1991; Bland, 2000) to determine whether there was an association between the underlying medical condition and the incidence of dysphagia. Using Fisher's Exact Test (Altman, 1991; Bland, 2000) the exact significance was computed as $p=0.355$, however $p<0.05$ indicates a significant result. The Fisher's Exact Test therefore showed little association between the underlying medical condition and the presence of dysphagia.

Table 2. Fisher's Exact Test of association between the incidence of dysphagia and underlying medical conditions in the sample population of infants and toddlers with tracheostomies ($p<0.05$ is significant)**.**

Test	Test Value	Test p-value (exact significance)
Fisher's Exact Test	5.221	0.355

Figure 9 graphically illustrates the incidence of dysphagia in each underlying medical condition.

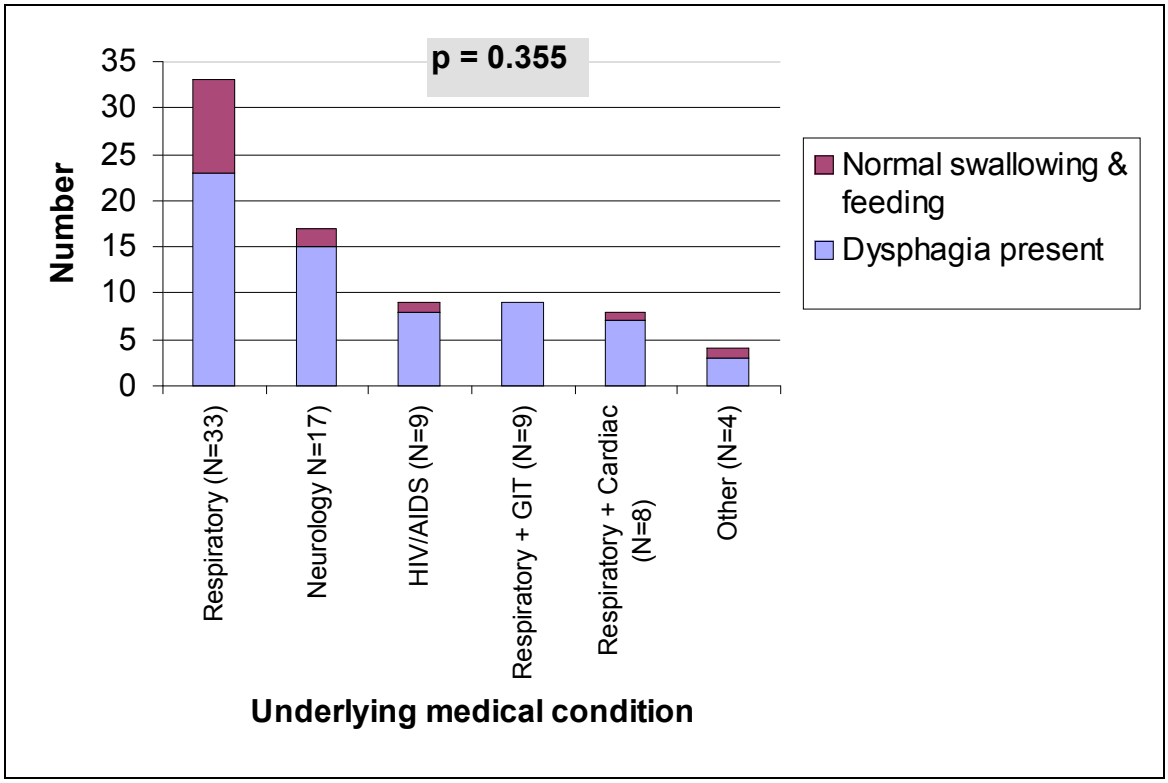

Figure 9. Incidence of dysphagia in each underlying medical condition in the sample population of infants and toddlers with tracheostomies (N=80)

A high incidence of dysphagia was reported in each underlying medical condition, related to the overall incidence of dysphagia (80%) reported in the study population.

All the participants in the *Respiratory and GIT* category had symptoms of dysphagia, which were likely due to the gastrointestinal medical condition, such as oesophageal structural abnormalities, oesophageal dysmotility and GOR. Feeding difficulties ranging from oral sensorimotor difficulties and aspiration, to severe gastro-oesophageal reflux disease (GORD) have been associated with GIT conditions (Field et al., 2003; Rommel et al., 2003).

A total of 80% of the participants in the *Neurology* and *HIV and AIDS* categories had dysphagia symptoms (See Figure 9). Feeding difficulties have been described in infants and toddlers with neurological impairment related to impaired oral sensorimotor skills (Morris & Klein, 2000), inco-ordination of swallowing (Wolf & Glass, 1992) and a higher incidence of GORD (Field et al., 2003).

The incidence of dysphagia symptoms in the *HIV and AIDS* category was higher than the 20% reported by Pressman (1992) and may be related to the smaller sample size and presence of the tracheostomy in the present study. Feeding difficulties in infants and toddlers with HIV and AIDS are associated with encephalopathy, which affects oral motor skills and swallowing co-ordination, odynophagia, oral and oesophageal candidiasis and oesophageal abnormalities

(Davis-McFarland, 2000; Halvorsen, Moelleken & Kearney, 2003; Wilson et al., 2002; Zalar, Olmos, Piskorz & Magnanini, 2003).

In the *Respiratory/ENT* category 75% of the participants presented with dysphagic symptoms (See Figure 9). Difficulty co-ordinating respiration and swallowing have been reported in infants and toddlers with respiratory and ENT difficulties (Arvedson & Brodsky, 2002). Structural abnormalities in the oral tract may also contribute to feeding difficulties (Hall, 2001), while chronic lung disease and ventilation requirements may affect endurance and therefore affect the infant or toddler's ability to feed orally (Hall, 2001).

These results were, however, not statistically significant, as no association was found between the underlying medical condition and the prediction of dysphagia using Fisher's Exact Test (Altman, 1991; Bland, 2000). These results reinforce the need to assess the swallowing and feeding skills of infants and toddlers with tracheostomies regardless of their underlying medical condition.

3.3 THE INCIDENCE AND NATURE OF COMMUNICATION DIFFICULTIES IN THE SAMPLE POPULATION OF INFANTS AND TODDLERS (0-3 YEARS) WITH TRACHEOSTOMIES

The following sections will describe the incidence and nature of communication difficulties in infants and toddlers with tracheostomies that participated in the study. In the present study information regarding speech production and communication skills was only available for 70 (87.5%) of the 80 participants, because of the ages of the participants, medical status or mortality.

3.3.1 Incidence of communication difficulties in infants and toddlers with tracheostomies

Information regarding participants' communication skills was recorded on the Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies (Appendix E). The incidence of communication difficulties was calculated as a proportion of the sample (N=70), for which communication information was available and is illustrated in Figure 10.

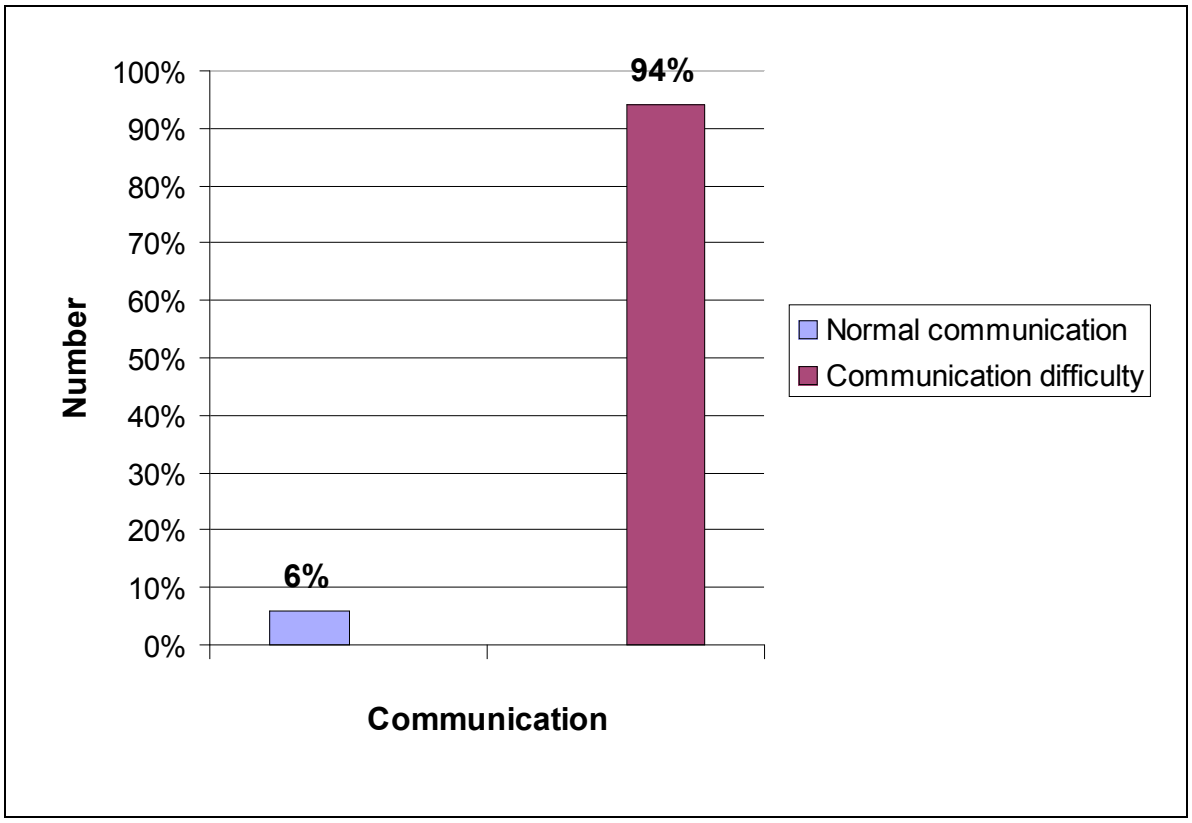

Figure 10. Incidence of communication difficulties in the sample population of infants and toddlers with tracheostomies (N=70)

According to Figure 10, the majority, 94%, of the 70 participants (range: 88 - 99%), with available information were identified with a communication difficulty. This finding is similar to that of Jiang and Morrison's (2003) group of neurologically disordered children with tracheostomies, but a higher incidence than their normally developing children. Arvedson and Brodsky (1992) reported that 70% of the children with tracheostomies that were referred for speech-language therapy assessment had moderate to profound communication difficulties. All symptoms related to communication skills of the participants,

including aphonia and speech production difficulties, were recorded as communication difficulties and could therefore account for the higher incidence recorded in the present study. However, according to the literature all the recorded difficulties, namely: aphonia, intelligibility, speech production, receptive and expressive language difficulties, have a significant impact on the development of communication (Kertoy, 2002; Woodnorth, 2004) and should therefore be considered risk factors in developing further communication difficulties.

There is therefore sufficient evidence to suggest that infants and toddlers with tracheostomies are at significant risk for having communication difficulties. Considering that communication skills are the best predictor of later cognitive skills and scholastic function in the ECI population, early identification and appropriate management of these difficulties within the tracheostomy population should be considered a priority once infants and toddlers are medically stable (Rossetti, 2001).

3.3.2 Nature of communication difficulties in infants and toddlers with tracheostomies

Information regarding the nature of participants' communication difficulties was recorded using the Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies (Appendix E). Difficulties were divided

into speech production (aphonia, indistinct / unintelligible speech), receptive language and expressive language difficulties.

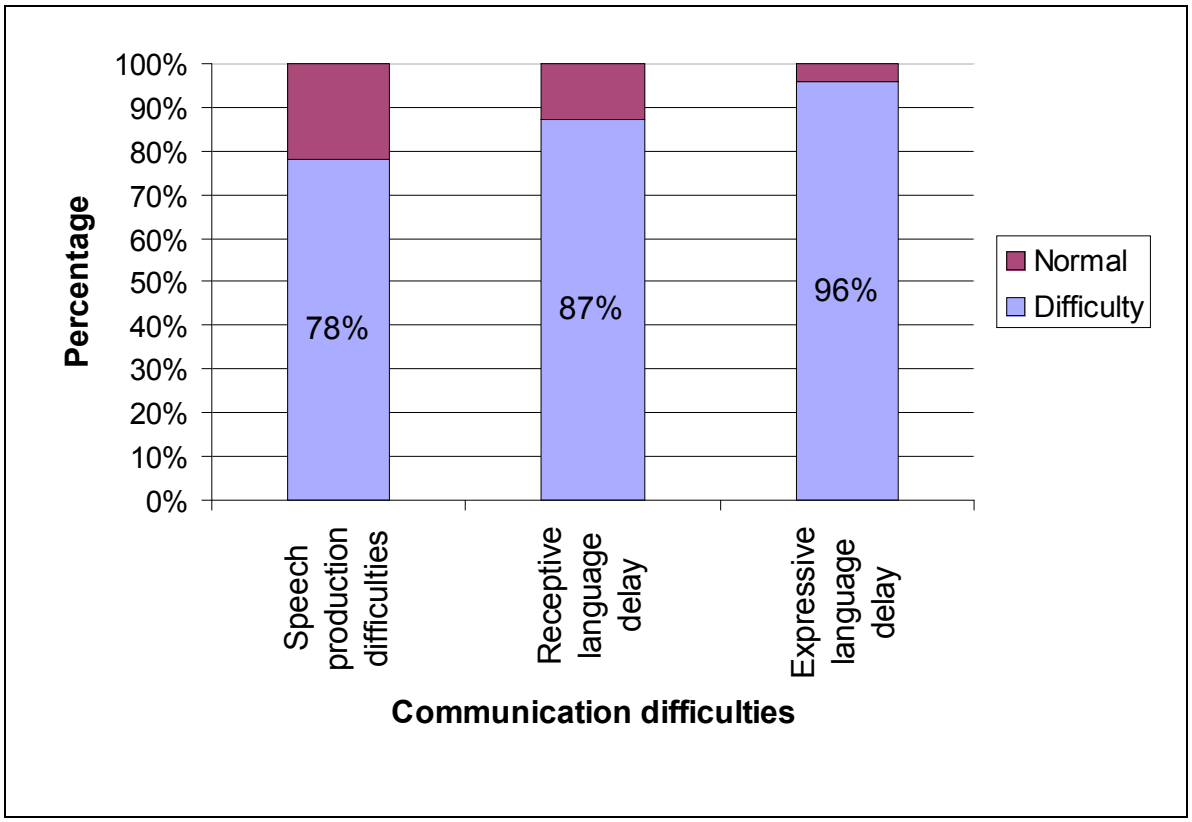

Figure 11. Nature of communication difficulties in the sample population of infants and toddlers with tracheostomies (N=70)

Speech production:

Speech production difficulties, including both aphonia and intelligibility, were reported in 78% (range: 68-88%) of the participants with available information (N=70; Figure 11). Previous studies (Bleile et al., 1993; Locke & Pearson, 1990; Simon et al., 1983) reported speech production difficulties, but no reference to

incidence could be found in the literature. Most studies related to communication have reported periods of aphonia or voicing difficulties in their subjects, which has a significant impact on the development of speech and language skills in infants and toddlers with tracheostomies (Bleile et al., 1993; Locke & Pearson, 1990; Simon et al., 1983; Woodnorth, 2004). Hill and Singer (1991) reported articulation difficulties in 15 of their 31 participants, which is low (<50%) when compared to the present study and reports in the literature that speech production difficulties are common in infants and toddlers with tracheostomies (Bleile et al., 1993; Kamen & Watson, 1991; Locke & Pearson, 1990; Simon et al., 1983).

Speech production difficulties have been reported to persist even after decannulation (Bleile et al, 1993; Kamen & Watson, 1991; Kertoy et al., 1999; Singer et al., 1989) and therefore the increased incidence in this study is of clinical concern, because the participants may have ongoing difficulties that affect their communication success.

It should be noted that of the 30 participants whose hearing was tested, 18 had a hearing loss (15/18 due to conductive hearing loss and were treated for otitis media with effusion), which could also contribute to delayed speech production skills (Billeaud, 1998; Northern & Downs, 1991). Developmental delay is also considered an additional risk factor for delayed speech development (Kertoy,

2002; Rossetti, 2001). Thirty-four of the participants were assessed by developmental paediatricians and found to have a developmental delay.

The participants in this study therefore had multiple risk factors for speech delay or speech difficulties, including prematurity (Rossetti, 2001) and structural abnormalities, such as cleft palate (Kummer, 2001), developmental delay (Rossetti, 2001), hearing loss (Billeaud, 1998; Northern & Downs, 1991), muscle weakness, neurological impairment (Paul, 2001), long-term hospitalization (Rossetti, 2001) and tracheostomy (Kertoy, 2002). These risk factors should be considered along with the tracheostomy when planning management.

A number of studies have shown that infants and toddlers with tracheostomies who are decannulated early have better speech production outcomes (Bleile et al., 1993; Jiang & Morrison, 2003; Locke & Pearson, 1990; Simon et al., 1983) and speech-language therapists should therefore be actively involved in stimulating vocal practice during cannulation to maximise speech production potential and advise ENT surgeons about the long-term impact of tracheostomies on speech development and encourage decannulation as soon as it is medically possible.

Communication skills:

Receptive language delays were reported in 87% (range: 78-95%) of the participants with available information (N=70; Figure 11). This is supported by some studies in the literature (Kaslon & Stein, 1985; Sell & MacCurtain, 1988;

Simon et al., 1983), while other studies have reported normal receptive language skills in children with tracheostomies (Hill & Singer, 1990), but have excluded children with neurological and developmental delays, as well as having small sample sizes. Receptive language is closely associated with cognitive development and expressive language development (Rossetti, 2001), and should therefore be assessed in infants and toddlers with tracheostomies, so that early intervention can be provided to optimise communication outcomes.

Expressive language delays were reported in 96% (range: 92-100%) of the sample (N=70; Figure 11). Previous studies have also reported delays in the expressive language skills of children with tracheostomies (Hill & Singer, 1990; Jiang & Morrison, 2003; Ross, 1982; Simon et al., 1983). Expressive language delays are reportedly influenced by the age at cannulation and duration of cannulation (Jiang & Morrison, 2003; Simon et al., 1983), with earlier decannulation resulting in better language outcomes in the long-term (Jiang & Morrison, 2003; Simon et al., 1983). Early decannulation is considered to be during the prelinguistic (<15 months) period (Jiang & Morrison, 2003; Simon et al., 1983).

A greater number of expressive language delays have been reported in the literature on infants and toddlers with tracheostomies, compared with receptive language delays, as well as in the present study (Hill & Singer, 1990; Jiang & Morrison, 2003; Ross, 1982; Simon et al., 1983). This may be due to the impact

of repeated and long hospitalization, caregiver-infant separation, illness, a history of prematurity and underlying medical conditions on the development of expressive language (Rossetti, 2001).

Attachment between an infant and mother (caregiver) is an essential bond which influences mother-infant interaction, later relationships and developmental outcomes (Klein & Briggs, 1987; Rossetti, 2001) and optimal mother-infant interaction is a precursor to communication development (Haney & Klein, 1993). The mother-infant attachment and interaction process may be disrupted in the infant with a tracheostomy because the underlying medical condition may limit early contact between the mother and infant, as well as limit caregiving responsibilities of the mother, which may result in feelings of detachment and poor self-esteem (Rossetti, 2001). The Tracheostomy Homecare Programme at RCCH actively involves mothers in the daily responsibilities of caring for infants with tracheostomies, and mothers are regarded as the primary caregivers, even in the hospital environment, which fosters better mother-infant attachment and interaction.

The infant with a tracheostomy may negatively affect the interaction process because of the inability to provide consistent cues, poor states of arousal and reduced eye-contact associated with medically fragile infants (Klein & Briggs, 1987; Rossetti, 2001).

The inability of an infant with a tracheostomy to vocalize may affect the caregiver-infant interaction and language development, because it has been noted that caregivers of infants and toddlers with tracheostomies who cannot vocalize tend to talk less frequently to their children and there is less evidence of reciprocity in their interactions (Aradine, 1983). Infants and toddlers that cannot vocalize demonstrate fewer attempts to initiate communication than those who vocalize normally and this may also negatively impact on communication development because of the limited intentional communication (Adamson & Dunbar, 1991). Infants and toddlers with tracheostomies have also demonstrated limited reasons for communication, generally using communication to request, which will also limit the normal development of communication (Kertoy & Waters, 1995).

Apart from the effects of the tracheostomy and long-term hospitalization on the normal development of language, the underlying medical conditions and associated problems may also have impacted on the language development of the sample population. Prematurity is a risk factor for language delay (Rossetti, 2001), hearing impairment has a significant impact on language learning, particularly in the first 3 years of life (Northern & Downs, 1991), cleft palate is also a risk factor for language delay, associated with the pre-requisite skills for learning language, as well as possible speech production difficulties and hearing impairment due to chronic otitis media (Kummer, 2001). Language delays, both receptive and expressive, with a greater effect on expressive language, and

language deterioration have been reported in toddlers with HIV and AIDS (Davis-McFarland, 2000; McNeilly, 2005; Pressman, 1992).

The participants in this study therefore had multiple risk factors for communication difficulties, related not only to the tracheostomy, but also the underlying medical condition, associated medical conditions, such as hearing loss, frequent and prolonged hospitalizations and separation from their caregiver.

There is concern that expressive language delays may persist long after decannulation in school-aged children (Hill & Singer, 1990) and may impact on children's academic progress. Apart from receiving speech-language therapy intervention while they are cannulated, it is therefore important that a speech-language therapist monitors their language development after decannulation, and optimises communication abilities and scholastic development.

3.4 THE RELATIONSHIP BETWEEN THE UNDERLYING MEDICAL CONDITION AND THE PRESENCE OF COMMUNICATION DIFFICULTIES IN THE SAMPLE POPULATION

Information regarding the participants' underlying medical conditions and presence of communication difficulties was recorded on the Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with

Tracheostomies (Appendix E). This data was analysed using Fisher's Exact Test (Altman, 1991; Bland, 2001) to determine whether there was an association between the underlying medical condition and the incidence of communication difficulties. Using Fisher's Exact Test (Altman, 1991; Bland, 2000), the exact significance was computed as $p=0.866$, however this is not statistically significant, as $p<0.05$ indicates a significant result. The Fisher's Exact Test therefore showed little association between the underlying medical condition and the presence of communication difficulties.

Table 3. Fisher's Exact Test of association between the incidence of communication difficulties and underlying medical conditions in the sample population of infants and toddlers with tracheostomies ($p<0.05$ is significant)**.**

Test	**Test Value**	**Test p-value** (exact significance)
Fisher's Exact Test	2.367	0.866

Figure 12 illustrates the incidence of communication difficulties in each underlying medical condition.

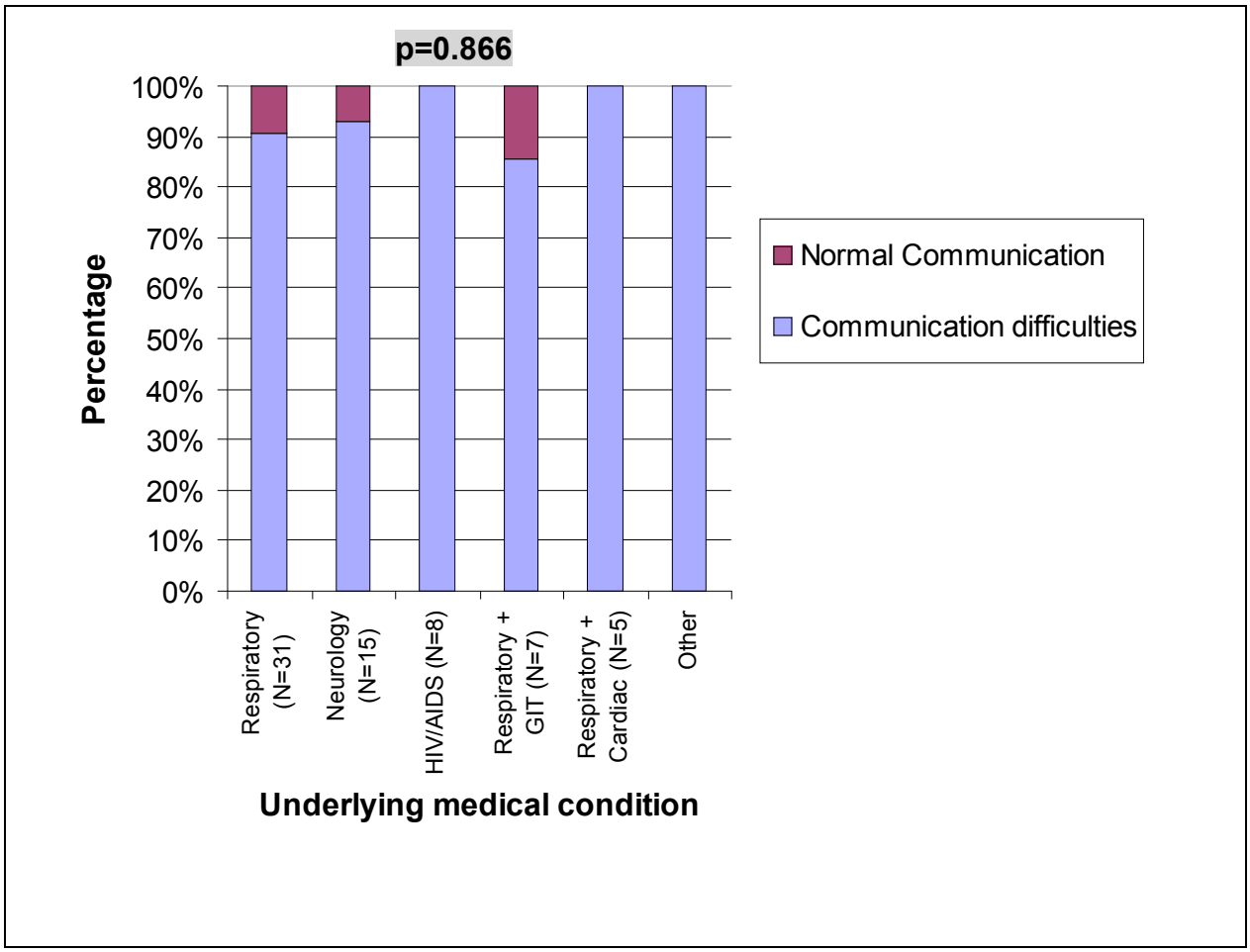

Figure 12. Incidence of communication difficulties in each underlying medical condition in the sample population of infants and toddlers with tracheostomies (N=70)

Over 90% of participants in all the underlying medical conditions, except for Respiratory + GIT, had communication difficulties, while 85% of participants in the Respiratory + GIT group had communication difficulties (Figure 12). There was therefore no significant association between the underlying medical condition and the incidence of communication difficulties. The small numbers of participants within each category may have influenced the analysis. However, it

is clear from the results that the incidence of communication difficulties in infants and toddlers with tracheostomies is very high and therefore requires early assessment and intervention by a speech-language therapist, regardless of the underlying medical condition.

The results of the study have reported the incidence and described the nature of dysphagia and communication difficulties in infants and toddlers with tracheostomies in the South African context. The results support the need for speech-language therapy intervention with this population. The present study has recorded similar results to previous studies on the topic, although there was variation in the different studies' reported incidences. The nature of dysphagia and communication difficulties was described and was of interest, as limited literature was available. It appeared that the multiple risk factors experienced by the study population had a noticeable impact on feeding and communication skills, as well as the presence of the tracheostomy. Conclusions and implications of the study will be discussed in the following section.

4. CONCLUSIONS AND IMPLICATIONS

This study provided quantitative information in the form of the incidence of paediatric dysphagia and communication difficulties in this specific population. It also provided qualitative information in the description of the nature of both dysphagia and communication difficulties experienced by infants and toddlers with tracheostomies. Finally, the study attempted to determine possible correlations between underlying medical conditions and the incidence of dysphagia and communication difficulties in the sample population (Leedy & Ormrod, 2004). This information is essential in planning and improving service delivery, training of clinicians and further research in the specific clinical area of infants and toddlers with tracheostomies. The following sections will discuss conclusions based on the results of the study, critically evaluate the study, and discuss clinical and research implications of the study.

4.1 CONCLUSIONS

The results of this study demonstrated a high incidence (80%) of dysphagia-related difficulties in the sample population of infants and toddlers with tracheostomies. Difficulties in the oral (81.25%) and oesophageal (79.7%) phases of swallowing were more common than pharyngeal phase (60.9%) difficulties. This may have indicated that the underlying medical condition and associated risk factors in this particular population and the South African context,

such as a history of prematurity and LBW (Hall, 2001), long-term non-oral feedings (Morris & Klein, 2000) and associated medical conditions, such as GOR (Field et al., 2003; Rommel et al., 2003), played a role in the swallowing and feeding difficulties experienced by infants and toddlers with tracheostomies.

According to the available literature the pharyngeal phase of swallowing is most affected by the presence of a tracheostomy tube (Abraham & Wolf, 2000; Rosingh & Peek, 1999), however the participants in the present study had a lower reported incidence of difficulties in the pharyngeal phase than the oral and oesophageal phases. This should, however, be considered with caution, as 60.9% of the study population experienced difficulties in the pharyngeal phase, with 25% having documented aspiration at some point, which increases the risk for negative effects on health status (Arvedson & Brodsky, 2002).

Although no statistically significant association could be determined between the underlying medical condition and the incidence of dysphagia, more than 85% of the participants in each of the following categories presented with dysphagic symptoms: *Neurology, HIV and AIDS, Respiratory and GIT,* and *Respiratory and Cardiac.* Infants and toddlers in the *Respiratory/ENT* category had the lowest incidence of dysphagia, which may be an indication that infants and toddlers with tracheostomies that have an isolated *Respiratory/ENT*–related underlying medical condition necessitating a tracheostomy have better feeding outcomes

after tracheostomy, than those with other categories of underlying medical conditions.

The results have confirmed that the records of infants and toddlers with tracheostomies who participated in this study demonstrated the need for a swallowing and feeding assessment, and intervention by a speech-language therapist. There was however little association between the underlying medical condition and the presence of dysphagia, indicating that all infants and toddlers with tracheostomies should be referred to a speech-language therapist for assessment.

Information regarding the communication skills of 70 of the 80 participants was available. Ninety-four percent of this sample had communication difficulties, which is higher than incidences reported in studies that excluded neurologically impaired children (Jiang & Morrison, 2003), as well as studies that did not include speech production difficulties (Arvedson & Brodsky, 1992; Simon et al., 1983).

Speech production difficulties were recorded in 78% of the sample population and may impact on language development (Bleile et al., 1993), as well as interaction-attachment (Adamson & Dunbar, 1991; Aradine, 1983) and later cognitive and academic progress (Rossetti, 2001).

Receptive (87%) and expressive (96%) language delays were recorded in the sample population (N=70). These incidences appeared higher when compared with other studies, such as Ross (1982) who reported no receptive language delay in toddlers following tracheostomy in infancy to specific language delays reported by others (Hill & Singer, 1990; Jiang & Morrison, 2003; Kaslon and Stein, 1985). Infants and toddlers with tracheostomies have multiple risk factors for having or developing communication delays or difficulties, namely repeated hospitalizations, infant-caregiver separation, periods of aphonia, the underlying medical condition, and associated risks for hearing loss and developmental delay.

Additional risk factors associated with communication difficulties in the present study included hearing loss (18), developmental delay (34) and neurological underlying medical conditions (17) (Billeaud, 1998; Rossetti, 2001). It is important to take note of these factors when considering the reported incidence of communication difficulties in the study population. However, those infants and toddlers with additional risk factors should not be excluded from the reported incidence, as this is representative of the paediatric population with tracheostomies at RCCH, and possibly South Africa, and therefore needs to be used to inform clinical practice and develop clinical guidelines. The results clearly supported the need for early intervention by a speech-language therapist for infants and toddlers with tracheostomies.

The results confirm that the records of infants and toddlers with tracheostomies who participated in this study demonstrated the need for a communication assessment and intervention by a speech-language therapist. Although there was little association between the underlying medical condition and the presence of communication difficulties, over 90% of the participants had a communication difficulty, indicating that all infants and toddlers with tracheostomies should be referred to a speech-language therapist for assessment and intervention.

Considering the health, developmental and long-term implications of difficulties in both feeding and communication it is essential that a speech-language therapist assess infants and toddlers with tracheostomies, providing intervention as necessary, and monitoring of the development of feeding and communication skills.

4.2 CRITICAL EVALUATION OF THE STUDY

It is important to critically evaluate the study in order to reflect on both the value and limitations of the results of the study. This is the first study to report on dysphagia and communication difficulties in infants and toddlers with tracheostomies in South Africa or a developing country. It can therefore provide useful information for clinicians working in similar contexts in developing countries, as well as a foundation for future research on the topic.

The study was retrospective in nature and the results may therefore have been affected by incomplete information in the reviewed medical records (Leedy & Ormrod, 2004). Communication information was not available for all participants because of the age of participants, mortality or transfer before assessment. The speech-language therapist was a member of the multidisciplinary team involved in the Tracheostomy Home Care Programme and a referral protocol had already been established at the hospital, so that the majority of the participants had been assessed by a speech-language therapist, resulting in accurate record-keeping. Researcher bias was controlled for through the development of the checklist based on the best available literature, and only information previously recorded in the participants' medical records was used to complete the checklist (De Vos, 1998; McMillan & Schumacher, 2001). The retrospective nature of the study therefore also controlled for researcher bias, as the information that was collected by the researcher had been recorded before the start of the study (Leedy & Ormrod, 2004).

The study provided support to the limited existing literature regarding swallowing and feeding in the paediatric tracheostomy population, by demonstrating the high incidence (80%) of dysphagia in the sample population. It also described the nature of dysphagia symptoms, and reported interesting results, not only related to the effects of the tracheostomy tube on swallowing, but the multiple risk factors contributing to dysphagia, which will be useful information for clinicians when planning assessment and intervention for this population.

The heterogeneity of the study population due to the underlying medical conditions, history of prematurity and LBW, additional risk factors for dysphagia and communication difficulties associated with repeated or long hospitalization, developmental delay and hearing loss may cause readers uncertainty regarding the causality between a tracheostomy and the presence of dysphagia and/or communication difficulties. However, the heterogeneous nature of the study population was representative of infants and toddlers with tracheostomies in a developing country and therefore provides clinicians with information regarding the possible profile of a paediatric patient with a tracheostomy that may form part of a speech-language therapist's caseload, including the multiple risk factors placing them at even greater risk for dysphagia and/or communication difficulties.

The information extracted from the records of the participants does not provide information regarding treatment and outcomes, as the aim of the study was to report incidence and nature of both dysphagia and communication difficulties in the study population. While incidence and descriptions of the nature of dysphagia and communication difficulties documented in the sample population provides a foundation for developing referral and treatment protocols for infants and toddlers with tracheostomies, more detailed information regarding treatment techniques and outcomes would be valuable to clinicians. Treatment techniques and therapy outcomes should therefore be investigated in future research on infants and toddlers with tracheostomies.

Participants' communication was assessed using a combination of language samples and the Rossetti Infant-Toddler Language Scale (Rossetti, 1990). No assessment for the ECI population has been standardized on the South African population, which may be considered a criticism of the study. This is however not considered a limitation, as Rossetti (2001) supports the use of criterion-referenced tests and checklists, in preference to norm-referenced tests, in the ECI population. They provide the assessor with information regarding behaviours that have been mastered, provide targets for intervention and a monitoring tool to evaluate progress (Rossetti, 2001).

A statistically significant association between the underlying medical condition and the presence of either dysphagia or communication difficulties was not found. A limitation of this part of the study was that the number of participants representing the presence or absence of difficulties within each category was too small to have statistical significance. Future studies with larger samples should therefore attempt to determine whether the underlying medical condition influences the incidence of dysphagia and/or communication difficulties in infants and toddlers with tracheostomies.

Finally, it was a cross-sectional study, in that all the data was collected at one time, only providing a snapshot of information on the participants (Leedy & Ormrod, 2004). A longitudinal study would provide information regarding long-term outcomes of both feeding and communication skills, and guide clinicians in

providing appropriate intervention (Bland, 2001). A cross-sectional design was however suited to this particular study, as the aim was to determine whether the medical records of infants and toddlers with tracheostomies indicated a need for speech-language therapy intervention, which was accomplished with this design.

Based on the critical evaluation, the present study has achieved the aims set out in the methodology, and the results have provided the first information regarding swallowing and communication skills of infants and toddlers with tracheostomies in South Africa. While a larger sample size, longitudinal study and a description of therapy techniques and outcomes would provide useful information for clinicians, the results presently obtained have provided an appropriate starting point for the education and training of speech-language therapists, healthcare professionals, students and parents. The results can also be used to inform clinical practice, develop assessment and treatment protocols, and form the basis for further research. The clinical implications of the study will be discussed in the following paragraphs.

4.3 CLINICAL IMPLICATIONS

The results of research are important in informing clinical practice. The results of this study can be used to provide speech-language therapists and health professionals working with infants and toddlers with tracheostomies, as well as parents, with useful information, namely referral protocols, a checklist for assessment and monitoring of feeding and communication skills, treatment guidelines and training.

Considering the high incidence of both dysphagia and communication difficulties in infants and toddlers with tracheostomies reported in this study, and supported by previous studies (Arvedson & Brodsky, 1993; Jiang & Morrison, 2003; Rosingh & Peek, 1999), it is recommended that all infants and toddlers with tracheostomies be referred to a speech-language therapist for assessment soon after cannulation. The first tracheostomy tube change is generally done 7 – 10 days after surgery, to allow for a tract to form and oedema to settle (Booth, 2005). Oral feeding may have been established during this time, but it is recommended that a speech-language therapist assess the swallowing and feeding of new infants and toddlers with tracheostomies soon after the first tracheostomy change, to establish oral feeds or an appropriate intervention programme. Once the patient is medically stable and the caregiver is being trained in the homecare programme, issues of communication should be addressed. In toddlers and children who have already established speech or

communication it is essential that an appropriate means of communication be established as soon as possible to prevent frustration and facilitate communication development and social interaction (Kertoy, 2002).

The Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies (Appendix E) was adapted for the clinical setting (Appendix F). It may be used by speech-language therapists working with infants and toddlers with tracheostomies as an assessment and monitoring tool, to guide therapy goals.

It is proposed that the Speech-Language Therapy Assessment and Therapy Guidelines Flowchart for Infants and Toddlers with Tracheostomies (Figure 13) may be used to assist speech-language therapists working with this population. The aim of this flowchart is to guide the speech-language therapist working with infants and toddlers with tracheostomies through a logical, clinical and research-based framework for the comprehensive assessment, treatment and management of swallowing, feeding and communication skills. The Speech-Language Therapy Assessment and Therapy Guidelines Flowchart for Infants and Toddlers with Tracheostomies (Figure 13) was developed by the researcher based on clinical practice, the results of the present study and available literature (Adamson & Dunbar, 1991; Abraham & Wolf, 2000; Arvedson & Brodsky, 2002; Arvedson & Lefton-Greif, 1998; Billeaud, 1998; Bleile et al., 1993; Field et al., 2003; Hall, 2001; Hill & Singer, 1990; Kertoy, 2002; Red Cross Children's

Hospital, 2005; Rommel et al., 2003; Rossetti, 2001; Simon et al., 1983; Wolf & Glass, 1992).

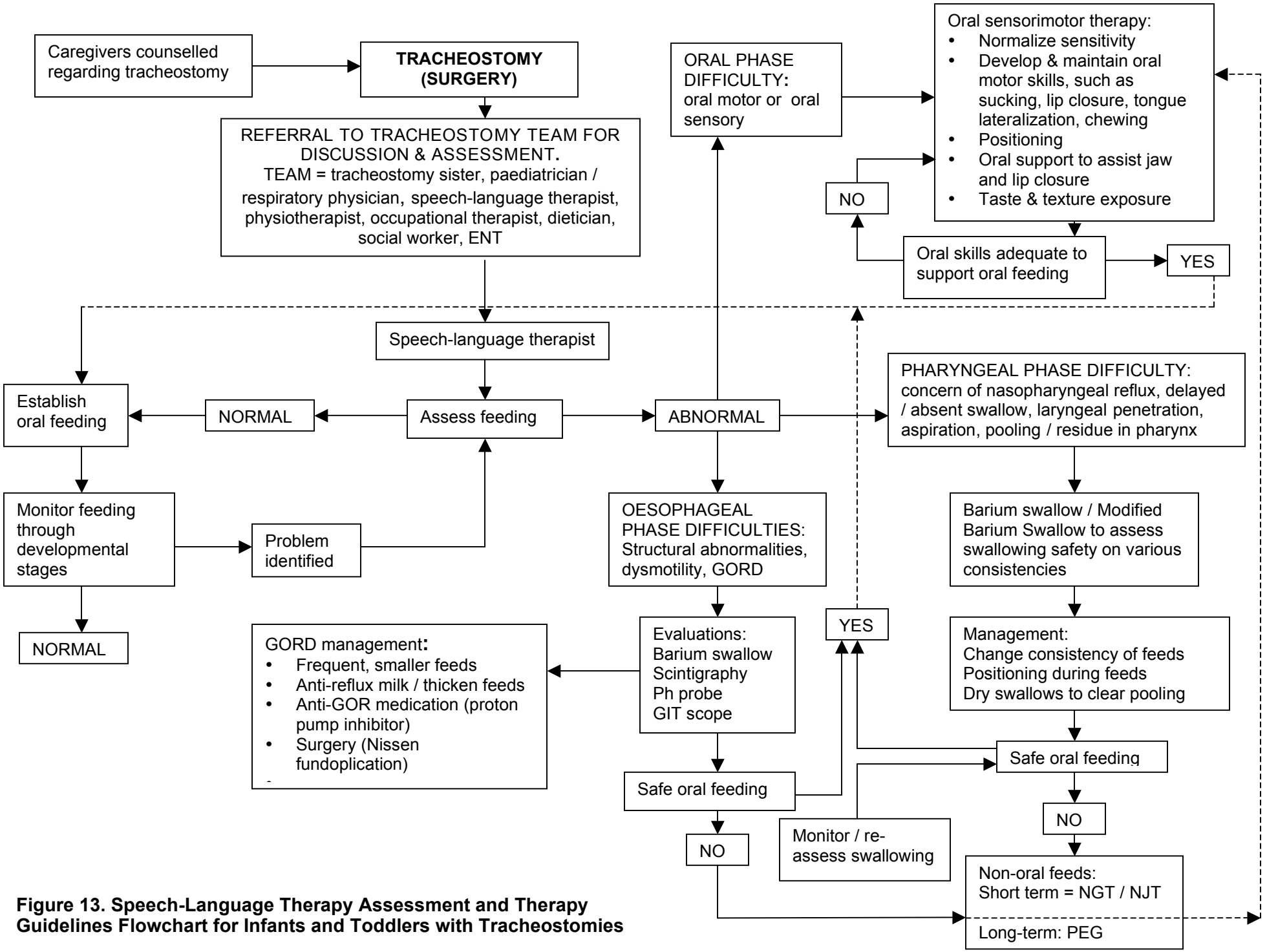

Figure 13. Speech-Language Therapy Assessment and Therapy Guidelines Flowchart for Infants and Toddlers with Tracheostomies

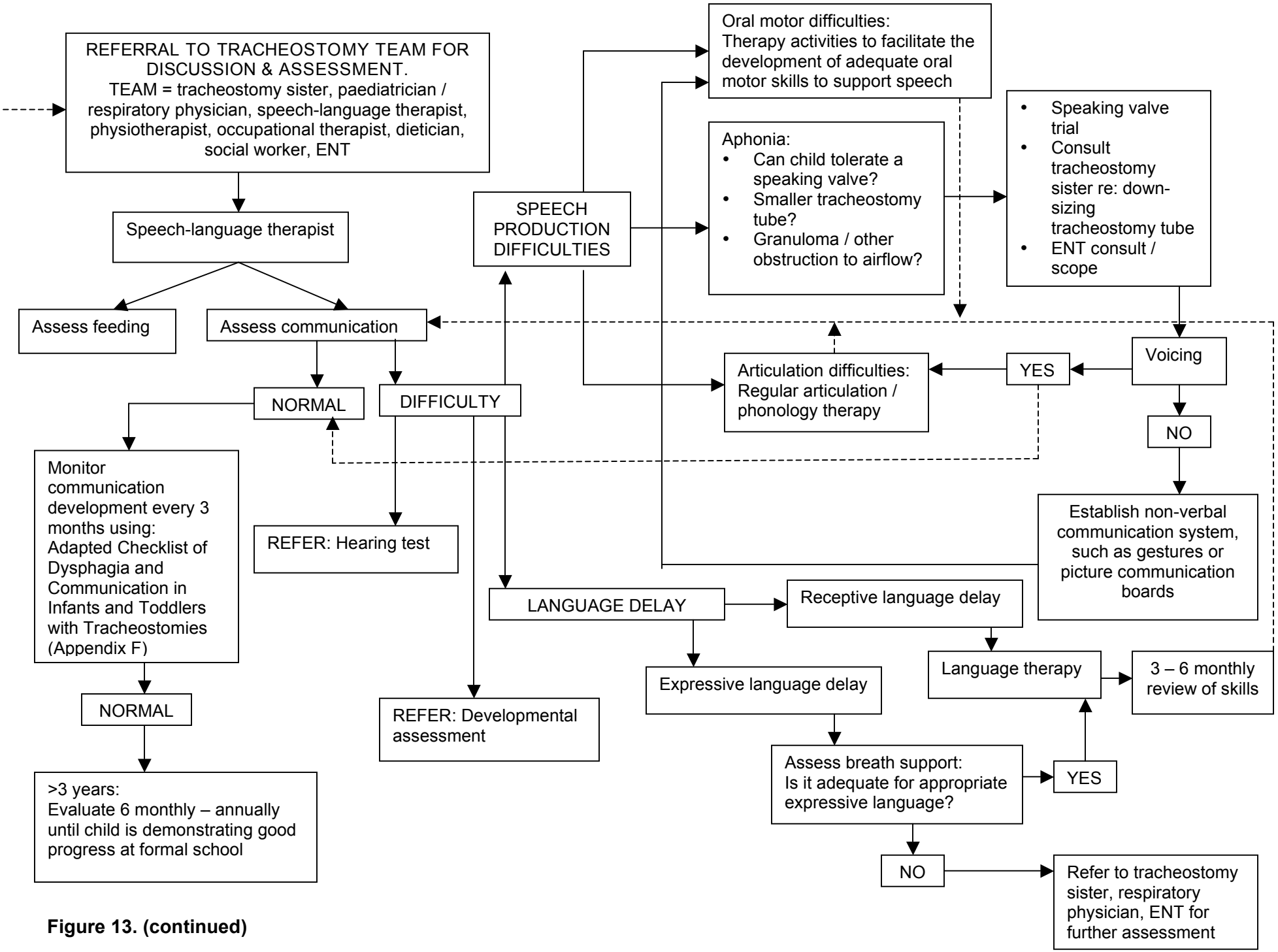

Figure 13. (continued)

4.4 RESEARCH IMPLICATIONS

It is important to consider topics identified in the present study for future research. This study has provided information regarding the incidence and nature of feeding and communication difficulties in the sample population in the South African context, but future research should assess the long-term outcomes of feeding and communication in infants and toddlers with tracheostomies or a history of tracheostomy, including scholastic progress. This will be useful, as there is limited local and international literature on the long-term outcomes of feeding and communication development following tracheostomy. This will guide clinicians in appropriate long-term management of children with tracheostomies (Kertoy, 2002).

Further research needs to assess various intervention strategies and programmes in order to identify evidence-based treatment protocols, as the present study, and those reviewed, have focused on identifying problem areas, but not on developing evidence-based management (Reilly, 2004a).

Future research with larger sample sizes should elaborate on the nature of difficulties experienced in this population (Kertoy, 2002) in an attempt to determine possible causal relationships with underlying medical conditions or other risk factors associated with the paediatric tracheostomy

population. This will assist clinicians in developing prevention and intervention programmes for the earliest possible intervention. Clinicians working in the area of paediatric tracheostomies should collaborate in order to research larger samples and develop standardized, evidence-based assessment and treatment protocols for this specialized clinical area in speech-language therapy (Kertoy, 2002; Reilly, 2004a).

4.5 FINAL COMMENTS

Infants and toddlers with tracheostomies, particularly in the South African context, have multiple risk factors for having or developing various health-related and developmental difficulties. This population and their families therefore require early intervention from a multidisciplinary team that can provide specialized assessment, treatment and management to prevent difficulties from developing, maximize their abilities and provide them with the best quality of life. A speech-language therapist skilled in the specific management of infants and toddlers with tracheostomies should be considered an essential team member, as swallowing, feeding and communication difficulties have been identified and described in this study, and the literature, thereby demonstrating the need for ECI by a speech-language therapist.

5. REFERENCES

1. Abraham, S.S. (2000). Babies with tracheostomies: The challenge of Providing Specialized Clinical Care. The ASHA Leader. http://professional.asha.org
2. Abraham, S.S. and Wolf, E.L. (2000). Swallowing Physiology of Toddlers with Long-Term Tracheostomies: A Preliminary Study. *Dysphagia*, 15:206-212.
3. Adamson, L.B. and Dunbar, B. (1991). Communication Development of Young Children with Tracheostomies. *AAC Augmentative and Alternative Communication*, 7:275-283.
4. Altman, D.G. (1991). *Practical Statistics for Medical Research*. Chapman & Hall/CRC, London.
5. Aradine, C.R. (1983). Young Children with Long-Term Tracheostomies: Health and Development. *Western Journal of Nursing Research*, 5(2):115 -124.
6. Arvedson, J.C. and Brodsky, L. (1992). Pediatric Tracheotomy Referrals to Speech-Language Pathology in a Children's Hospital. *International Journal of Pediatric Otorhinolaryngology*, 23:237-243.
7. Arvedson, J.C. and Brodsky, L. (2002). *Pediatric Swallowing and Feeding: Assessment and Management (2nd Ed)*. Singular Thomson Learning, Canada.

8. Arvedson, J.C. and Lefton-Greif, M.A. (1996). Anatomy, Physiology and development of Feeding. *Seminars in Speech and Language,* 17(4):261-268.

9. Arvedson, J.C. and Lefton-Greif, M.A. (1998). *Pediatric Videofluoroscopic Swallow Studies.* Communication Skill Builders, Texas.

10. ASHA. (2002). Knowledge and Skills Needed by Speech-Language Pathologists Providing Services to Individuals with Swallowing and/or Feeding Disorders. *ASHA Supplement* 22:81-88.

11. Babbie, E. and Mouton, J. (2001). *The Practice of Social Research*. Oxford University Press, Cape Town, SA.

12. Beukelman, D.R. and Mirenda, P. (1998). *Augmentative and Alternative Communication: Management of Severe Communication Disorders in Children and Adults (2nd Ed)*. Paul H Brookes Publishing Co., Maryland.

13. Billeaud, F.P. (1998). *Communication Disorders in Infants and Toddlers: Assessment and Intervention (2nd Ed)*. Butterworth-Heinemann, Boston.

14. Bland, M. (2000). *An Introduction to Medical Statistics (3rd Ed).* Oxford University Press, New York.

15. Bleile, K.M. (1993). Children with Long-Term Tracheostomies. In Bleile, K.M. *The Care of Children with Long-Term Tracheostomies*. San Diego, California: Singular Publishing Group, Inc.

16. Bleile, K.M., Stark, R.E. and McGowan, J.S. (1993). Speech Development in a Child after Decannulation: Further Evidence that Babbling Facilitates Later Speech Development. *Clinical Linguistics and Phonetics*, 7(4):319-337.

17. Booth, J. (2005). *Personal Communication*. Red Cross Children's Hospital, Rondebosch, Cape Town, SA.

18. Brodsky, L. (1997). Dysphagia with Respiratory / Pulmonary Presentation: Assessment and Management. *Seminars in Speech and Language*, 18(1):13-23.

19. Carron, J.D., Derkay, C.S., Strope, G.L., Nosonchuk, J.E. and Darrow, D.H. (2000). Pediatric Tracheostomies: Changing Indications and Outcomes. *The Laryngoscope*, 110:1099-1104.

20. Cho Lieu, J.E., Muntz, H.R., Prater, D. and Stahl, M.B. (1999). Passy-Muir Valve in Children with Tracheotomy. *International Journal of Pediatric Otorhinolaryngology*, 50:197-203.

21. Comrie, J.D. and Helm, J.M. (1997). Common Feeding Problems in the Intensive Care Nursery: Maturation, Organization, Evaluation and Management Strategies. *Seminars in Speech and Language*, 18(3):229-261.

22. Craig, G.M., Scambler, G and Spitz, L. (2003). Why Parents of Children with Neurodevelopmental Disabilities Requiring Gastrostomy Feeding need more Support. *Developmental Medicine and Child Neurology*, 45:183-188.

23. Davis-McFarland, E. (2000). Language and Oral-Motor Development and Disorders in Infants and Young Toddlers with Human Immunodeficiency Virus. *Seminars in Speech and Language*, 21(1):19-34.

24. Dellert, S.F., Hyams, J.S., Treem, W.R. and Geertsma, M.A. (1993). Feeding Resistance and Gastroesophageal Reflux in Infancy. *Journal of Pediatric Gastroenterology and Nutrition*, 17: 66-71.

25. Department of Health (2001). *Recommendations for managing HIV infection in children – draft.*

26. De Vos, A.S. (1998). *Research at Grass Roots: A Primer for the Caring Professions.* Van Schaik Publishers, Pretoria.

27. Dunn, S.L., Van Kleeck, A. and Rossetti, L.M. (1993). Current Roles and Continuing Needs of Speech-Language Pathologists Working in Neonatal Intensive Care Units. *American Journal of Speech-Language Pathology*, May:52-64.

28. Editors Inc. (2003). *SA 2003-2004: South Africa at a Glance.* United Litho, South Africa.

29. Farran, D.C. (2000). Another Decade of Intervention for Children who are Low Income or Disabled: What Do We Know Now? In Shonkoff, J.P. and Meisels, S.J. *Handbook of Early Childhood Intervention (2nd Ed)*. Cambridge University Press, USA.

30. Field, D., Garland, M. and Williams, K. (2003). Correlates of Specific Childhood Feeding Problems. *Journal of Pediatrics and Child Health*, 39:299-304.

31. Friedman, B and Frazier, J.B. (2000). Deep Laryngeal Penetration as a Predictor of Aspiration. *Dysphagia*, 15:153-158.

32. Fus, L.A. and Wacker, D.P. (1993). The Role of Vocalizations on Social Behaviours of a Tracheostomized Toddler. *Infant-Toddler Intervention*, 3(4):237-244.

33. Garbarino, J. and Ganzel, B. (2000). The Human Ecology of Early Risk. In Shonkoff, J.P. and Meisels, S.J. *Handbook of Early Childhood Intervention (2nd Ed)*. Cambridge University Press: USA.

34. Gereau, S.A., Navarro, G.C., Cluterio, B., Mullan, E., Basila, M. and Ruben, R.J. (1996). Selection of Pediatric Patients for use of the Passy-Muir Valve for Speech Production. *International Journal of Pediatric Otorhinolaryngology*, 35:11-17.

35. Guerriere, D.N., McKeever, P., Llewellyn-Thomas, H. and Berall, G. (2003). Mothers' Decisions about Gastrostomy Tube Insertion in Children: Factors contributing to uncertainty. *Developmental Medicine and Child Neurology*, 45:470-476.

36. Guralnick, M.J. (1997). *The Effectiveness of Early Intervention.* Paul H Brookes Publishing Co: Baltimore.

37. Hadfield, P.J., Lloyd-Faulconbridge, R.V., Almeyda, J., Albert, D.M. and Bailey, C.M. (2003). The Changing Indication for Paediatric Tracheostomy. *International Journal of Pediatric Otorhinolaryngology*, 67(7):7-10.

38. Hall, K. D. (2001). Pediatric Dysphagia: Resource Guide. Singular Thomson Learning: Canada.

39. Halpern, R. (2000). Early Intervention for Low Income Children and Families. In Shonkoff, J.P. and Meisels, S.J. *Handbook of Early Childhood Intervention (2nd Ed)*. Cambridge University Press: USA.

40. Halvorsen, R.A., Moelleken, S.M.C. and Kearney, A.T. (2003). Videofluoroscopic Evaluation of HIV/AIDS Patients with Swallowing Dysfunction. *Abdominal Imaging*, 28:244-247.

41. Handler, S.D. (1993). Surgical Management of the Tracheostomy. In Bleile, K.M. *The Care of Children with Long-Term Tracheostomies.* Singular Publishing Group, Inc., California.

42. Haney, M. and Klein, M.D. (1993). Impact of a Program to Facilitate Mother-Infant Communication in High-Risk Families of High-Risk Infants. *Journal of Childhood Communication Disorders*, 15(1):15-22.

43. Harris, G., Blisset, J. and Johnson, R. (2000). Food Refusal Associated with Illness. *Child Psychology and Psychiatry Review*, 5(4):148-155.

44. Hawdon, J.M., Beauregard, N., Slattery, J. and Kennedy, G. (2000). Identification of Neonates at Risk of Developing Feeding Problems in Infancy. *Developmental Medicine and Child Neurology*, 42:235-239.

45. Hill, B.P. and Singer, L.T. (1990). Speech and Language Development after Infant Tracheostomy. *Journal of Speech and Hearing Disorders*, 55:15-20.

46. Hodges, S. and Harris, R. (2000). The Feeding Clinic. In Southall, A. and Schwartz, A. *Feeding Problems in Children.* Radcliffe Medical Press.

47. Huggins, P.S., Tuomi, S.K. and Young, C. (1999). Effects of Nasogastric Tubes on the Young, Normal Swallowing Mechanism. *Dysphagia* 14(3):157-161.

48. Jiang, D. and Morrison, G.A.J. (2003). The Influence of Long-Term Tracheostomy on Speech and Language Development in Children. *International Journal of Pediatric Otorhinolaryngology*, 67S1:S217-S220.

49. Kamen, R.S. and Watson, B.C. (1991). Effects of Long-Term tracheostomy on Spectral Characteristics of Vowel Production. *Journal of Speech and Hearing Research*, 34:1057-1065.

50. Karnak, İ, Şenocak, M.E., Tanyel, F.C. and Büyükpamukçu, N. (2001). Achalasia in Childhood: Surgical Treatment and Outcome. *European Journal of Pediatric Surgery*, 11:223-229.

51. Kaslon, K.W. and Stein, R.E. (1985). Chronic Pediatric Tracheotomy: Assessment and Implications for Habilitation of Voice, Speech and Language in Young Children. *International Journal of Pediatric Otorhinolaryngology*, 9:165-171.

52. Katzenellenbogen, J.M., Joubert, G. and Abdool Karim, S.S. (1997). *Epidemiology: A manual for South Africa.* Oxford University Press, South Africa.

53. Kedesdy, J.H. and Budd, K.S. (1998). *Childhood Feeding Disorders: Biobehavioral Assessment and Intervention*. Paul H Brookes Publishing Co.: Baltimore.

54. Kertoy, M.K. (2002). *Children with Tracheostomies: Resource Guide*. Singular Thomson Learning: Canada.

55. Kertoy, M.K., Guest, C.M., Quart, E. and Lieh-Lai, M. (1999). Speech and Phonological Characteristics of Individual Children with a History of

Tracheostomy. *Journal of Speech, Language and Hearing Research*, 42(3):621-635.

56. Kertoy, M.K. and Waters, R. (1995). Communicative Intentions of Three Prelinguistic Children with a History of Long-Term Tracheostomy. *Infant-Toddler Intervention*, 5(3):301-314.

57. Klein, M.D. and Briggs, M.H. (1987). Facilitating Mother-Infant Interaction in Mothers of High-Risk Infants. *Journal of Childhood Communication Disorders*, 10(2):95-106.

58. Kritzinger, A. (2000). Establishing a Computer-Based Data System for Early Communication Intervention in South Africa. D.Phil Thesis, University of Pretoria.

59. Kummer, A.W. (2001). *Cleft Palate and Craniofacial Anomalies: Effects on Speech and Resonance.* Singular Thomson Learning: Canada.

60. Leedy, P.D. and Ormrod, J.E. (2004). *Practical Research: Planning and Design.* Pearson Prentice Hall: New Jersey.

61. Locke, J.L. and Pearson, D.M. (1990). Linguistic Significance of Babbling: Evidence from a Tracheostomized Infant. *Journal of Child Language*, 17:1-16.

62. Louw, B. (1997). Guidelines for Speech-Language Therapists and Audiologists: Early Communication Intervention. SASLHA: Ethics and Standards Committee.

63. Louw, B. (2003). *Personal Communication: Training of speech-language therapy students in tracheostomies.* University of Pretoria, South Africa.

64. McMillan, J.H. and Schumacher, S. (2001). *Research in Education: a conceptual introduction (5th Ed).* Addison Wesley Longman Inc.: New York.

65. McNeilly, L.G. (2005). HIV and Communication. *Journal of Communication Disorders*, 38(4):303-310.

66. Manikam, R. and Perman, J.A. (2000). Pediatric Feeding Disorders. *Journal of Clinical Gastroenterology*, 30(1):34-46.

67. Manley, S.B., Frank, E.M. and Melvin, C.F. (1999). Preparation of Speech-Language Pathologists to Provide Services to Patients with a Tracheostomy Tube: A Survey. *American Journal of Speech-Language Pathology*, 8:171-180.

68. Mathisen, B., Worrall, L., Masel, J., Wall, C. and Shepherd, R.W. (1999). Feeding Problems in Infants with Gastro-Oesophageal Reflux Disease: A Controlled Study. *Journal of Pediatric Child Health*, 35:163-169.

69. Medical Research Council of South Africa (2001) Guidelines on Ethics in Medical Research www.mrc.ac.za

70. Meisels, J.S. and Shonkoff, J.P. (2000). Early Childhood Intervention: A Continuing Evolution. In Shonkoff, J.P. and Meisels, S.J. *Handbook of Early Childhood Intervention (2nd Ed)*. Cambridge University Press: USA.

71. Midwinter, K.I. Carrie, S. and Bull, P.D. (2002). Paediatric Tracheostomy: Sheffield Experience 1979 –1999. *Journal of Laryngology and Otology*, 116:532-535.

72. Morris, S.E. and Klein, M.D. (2000). *Prefeeding Skills* (2nd Edition). Therapy Skill Builders: USA.

73. Murray, K.A. and Brzozowski, L.A. (1998). Swallowing in Patients with Tracheostomies. *AACN: Clinical Issues: Advanced Practice in Acute and Critical Care*, 9(3).

74. Nash, M. (1988). Swallowing Problems in the Tracheostomized Patient. *Otolaryngologic Clinics of North America*, 21 (4):701-709.

75. Northern, J.L. and Downs, M.P. (1991). *Hearing in Children (4th Ed).* Williams and Wilkins: Baltimore, USA.

76. Oliver, P.E., Forcht, S. and Lawrence, D.G. (1998). Prolonged Ventilation Effects on Swallowing and Feeding in Premature Infants. *Infant-Toddler Intervention*, 8(3):211-225.

77. Owens, R.E. (2001). *Language Development: An Introduction*. *(5th Ed).* Allyn and Bacon: USA.

78. Parrish, M. (1997). Family Adaptation to a Child's Swallowing and Feeding Disorder: A Social Work Perspective. *Seminars in Speech and Language*, 18 (1):71-78.

79. Paul, R. (2001). *Language Disorders from Infancy through Adolescence: Assessment & Intervention (2nd Ed).* Mosby: USA.

80. Pressman, H. (1992). Communication Disorders and Dysphagia in Pediatric AIDS. *ASHA*, January:45-47.

81. Red Cross Children's Hospital (2005). *Clinical Guidelines for Gastro-oesophageal Reflux and Dysphagia; Departments of Dietetics, Gastroenterology and Speech-Language Therapy – unpublished.*

82. Reilly, S. (2004a). The Move to Evidence-Based Practice within Speech Pathology. In Reilly, S., Douglas, J. and Oates, J. (2004). *Evidence Based Practice in Speech Pathology*. Whurr Publishers: London.

83. Reilly, S. (2004b). The Evidence Base for the Management of Dysphagia. In Reilly, S., Douglas, J. and Oates, J. (2004). *Evidence Based Practice in Speech Pathology*. Whurr Publishers: London.

84. Rommel, N., De Meyer, A., Feenstra, L. and Veereman-Wauters, G. (2003) The Complexity of Feeding Problems in 700 Infants and Young Children Presenting to a Tertiary Care Institution. *Journal of Pediatric Gastroenterology and Nutrition,* 37:75-84.

85. Romski, M. and Sevcik, R.A. (2005). Augmentative Communication and Early Intervention: Myths and Realities. *Infants and young Children*, 18(3):174-185.

86. Rosingh, H.J. and Peek, S.H.G. (1999). Swallowing and Speech in Infants Following Tracheostomy. *Acta oto-rhino-laryngologica Belgica*, 53(1):59-63.

87. Ross, G.S. (1982). Language Functioning and Speech Development of Six Children Receiving Tracheostomy in Infancy. *Journal of Communication Disorders*, 15:95-111.

88. Rossetti, L.M. (1990). *The Rossetti Infant-Toddler Language Scale: A measure of communication and interaction.* Linguisystems: Illinois.

89. Rossetti, L.M. (2001*). Communication Intervention: Birth to Three* (2nd Edition). Singular Thomson Learning: Canada.

90. Rudolph, C.D. and Link, D.T. (2002). Feeding Disorders in Infants and Children. *Pediatric Clinics of North America*, 49(1):97-12.

91. Rutter, M. (2000). Resilience Reconsidered: Conceptual Considerations, Empirical Findings and Policy Implications. In Shonkoff, J.P. and Meisels, S.J. *Handbook of Early Childhood Intervention (2nd Ed)*. Cambridge University Press: USA.

92. SAHIMS (The Southern African Humanitarian Information Network for a coordinated disaster response). www.SAHIMS.net, accessed 25/09/2005.

93. Sell, D. and MacCurtain, F. (1988). Speech and Language Development in Children with Acquired Subglottic Stenosis. *The Journal of Laryngology and Otology*, Supplement 17:35-8.

94. Shaker, R., Milbrath, M., Ren, J., Campbell, B., Toohill, R. and Hogan, W. (1995). Deglutive Aspiration in Patients with Tracheostomy: Effect of tracheostomy on the duration of vocal cord closure. *Gastroenterology,* 108:1357-1360.

95. Shinkwin, C.A. and Gibbin, K.P. (1996). Tracheostomy in Children. *Journal of the Royal Society of Medicine*, 89:188-192.

96. Shonkoff, J.P. and Marshall, P.C. (2000). The Biology of Developmental Vulnerability. In Shonkoff, J.P. and Meisels, S.J. *Handbook of Early Childhood Intervention (2nd Ed).* Cambridge University Press: USA.

97. Simon, B.M., Fowler, S.M. and Handler, S.D. (1983). Communication Development in Young Children with Long-Term Tracheostomies: Preliminary Report. *International Journal of Pediatric Otorhinolaryngology*, 6:37-50.

98. Singer, L.T., Kercsmar, C., Legris, G., Orlowski, J.P., Hill, B.P. and Doershuk, C. (1989). Developmental Sequelae of Long-Term Infant Tracheostomy. *Developmental Medicine and Child Neurology*, 31:224-230.

99. Singer, L.T., Wood, R. and Lambert, S. (1985). Developmental Follow-Up of Long-Term Tracheostomy: A preliminary report. *Developmental and Behavioural Pediatrics*, 6(3):132-136.

100. Singh, S.A. (2003). *Personal Communication: Training of speech-language therapy students in tracheostomies.* Department of Communication Sciences and Disorders, University of Cape Town, South Africa.

101. Stoel-Gammon, C. and Herrington, P.B. (1990). Vowel systems of normally developing and phonologically disordered children. *Clinical Linguistics and Phonetics*, 4(2):145-160.

102. USAID (2005). USAID's Strategy in South Africa. www.usaid.gov, accessed 26/10/2005.

103. Uys, K. (2000). Oral Feeding Skills in Premature Infants. Unpublished Master's Thesis. Department of Communication Pathology, University of Pretoria.

104. Van der Merwe, A. (2003). *Personal Communication: Training of speech-language therapy students in tracheostomies.* Department of Communication Pathology, University of Pretoria, South Africa.

105. Ward, R.F., Jones, J. and Carew, J.F. (1995). Current Trends in Pediatric Tracheotomy. *International Journal of Pediatric Otorhinolaryngology*, 32:233-239.

106. Wilson, D., Naidoo, S., Bekker, L., Cotton, M. and Maartens, G. (2002). *Handbook of HIV Medicine*. Oxford University Press: South Africa.

107. Wolf, L. and Glass, R. (1992). *Swallowing and Feeding Disorders in Infancy*. Therapy Skill Builders: Arizona.

108. Woodnorth, G.H. (2004). Assessing and Managing Medically fragile Children: Tracheostomy and Ventilatory Support. *Language, Speech and Hearing Services in Schools,* 35(4):363-372.

109. www.journ-aids.org November / December 2003.

110. www.journ-aids.org accessed, November 2005.

111. Zalar, A.E., Olmos, M.A., Piskorz, E.L. and Magnanini, F.L. (2003). Esophageal Motility Disorders in HIV Patients. *Digestive Diseases and Sciences*, 48(5):962-967.

6..APPENDICES

Appendix A:

University of Cape Town Faculty of Health Sciences' Research Ethics Committee approval letter

Appendix B:

University of Pretoria Faculty of Humanities Research Proposal and Ethics Committee approval letter.

Appendix C:

Letter from medical superintendent to review medical folders of infants and toddlers with tracheostomies.

APPENDIX D:

Description of participants

REF	M/F	Age at Tracheostomy	Category of underlying medical condition	Reason for tracheostomy	Caregiver trained
1	M	1 day	Respiratory + GIT	UAO	Mother
2	M	-1 week	Respiratory	UAO	Mother
3	M	10 month	Respiratory + GIT	UAO	Mother
4	M	2 weeks	Respiratory	UAO	Gran
5	M	- 8weeks	Respiratory + Cardiac	UAO	Mother
6	M	1.6 years	Neurology	UAO	Mother
7	F	4 month	Other (Cystic hygroma)	UAO	Mother
8	M	2 month	Respiratory	UAO	Mother
9	M	6 month	Respiratory	UAO	Father
10	M	4 month	Respiratory + Cardiac	UAO + Toilet	Mother
11	M	1 month	Respiratory	UAO	Mother
12	F	6 month	Respiratory	UAO	Mother
13	F	2 month	Respiratory	UAO	Mother
14	F	4 month	Respiratory	UAO	Mother
15	M	14 month	Other (Burns)	UAO	Mother
16	M	<1 month	Respiratory + GIT	UAO	Mother
17	M	9 month	Respiratory + GIT	UAO	Mother
18	M	1 month	Respiratory	UAO	Mother
19	F	1 month	Respiratory + GIT	Ventilation + UAO	Mother
20	F	9 month	HIV	UAO	Mother
21	M	5 days	Respiratory	UAO	Mother
22	F	22 month	Respiratory	Ventilation	Mother

23	M	3 month	Respiratory	UAO	Mother
24	M	2 month	Respiratory	UAO	Mother
25	F	18 month	Neurology	UAO	Mother
26	M	22 month	Neurology	Ventilation + Toilet	Mother
27	F	19 month	Neurology	Ventilation	Mother
28	M	1 month	Respiratory	UAO	Mother
29	M	20 month	HIV	UAO	Mother
30	F	3 month	Neurology	UAO	Mother
31	M	4 days	Respiratory	UAO	Mother
32	M	1.2 years	Respiratory	UAO + Ventilation	Mother
33	M	2 weeks	Respiratory	UAO	Mother
34	M	3.8 years	Neurology	UAO + Toilet	Mother
35	M	2.5 month	Respiratory	UAO	Mother
36	M	9 days	Respiratory	UAO	Mother
37	M	14 month	HIV	UAO	Mother
38	F	1 week	Respiratory + GIT	UAO	Mother
39	F	3.7 years	Respiratory	UAO	Mother
40	F	2 years	Neurology	Ventilation	Mother
41	M	8 days	Respiratory + GIT	UAO	Mother
42	M	19 month	HIV	Ventilation	Mother
43	M	2.10 years	Neurology	UAO	Mother
44	M	6 month	Respiratory	UAO	Mother
45	F	17 month	Other (poison ingestion - burns)	UAO	Mother
46	M	10 month	Neurology	UAO	Mother
47	F	4 month	HIV	UAO	Mother

48	M	1.1 years	HIV	UAO	Mother
49	M	4 month	Respiratory	UAO	Mother
50	M	3 month	Respiratory + Cardiac	Ventilation	Mother
51	M	1 year	Respiratory	UAO	Mother
52	M	10 month	Neurology	UAO	Mother
53	F	3.11 years	Neurology	Ventilation + Toilet	N/A (died before trained)
54	M	9 month	Respiratory + GIT	UAO	Gran
55	M	<1 month	Respiratory	UAO	N/A (abandoned – care facility trained)
56	F	1 day	Respiratory + Cardiac	UAO + Ventilation	Mother
57	M	1 month	Respiratory + GIT	UAO + Ventilation	N/A (Died before trained)
58	F	2 month	Respiratory + Cardiac	UAO	N/A (died before trained)
59	M	8 month	HIV	UAO + Toilet	Mother
60	M	2.2 years	Respiratory	Ventilation	Mother
61	M	7 month	Respiratory	UAO	Mother
62	M	2 weeks	Neurology	Ventilation	Mother
63	M	5 month	Neurology	Ventilation	Mother
64	M	6 days	Respiratory + GIT	UAO	Mother
65	M	3 month	Neurology	Ventilation	Mother
66	M	9 month	Neurology	UAO	Mother
67	F	-1 month	Respiratory	UAO	Mother
68	F	18 month	HIV	UAO	Gran
69	M	<1 month	Respiratory + Cardiac	UAO + Ventilation	Mother

70	M	<1 month	Respiratory	UAO + Ventilation	Mother
71	F	2 month	Respiratory + Cardiac	UAO	Mother
72	M	1 month	Respiratory	UAO	N/A (abandoned – care facility trained)
73	F	18 month	Respiratory	UAO	Mother
74	M	3 month	Neurology	UAO	Mother
75	F	20 month	Neurology	Ventilation	Mother
76	F	1.1 year	HIV	UAO	Mother
77	M	3 month	Respiratory + Cardiac	UAO + Ventilation	Mother
78	M	18 month	Other (cardiac)	UAO	Mother
79	F	2 month	Respiratory	UAO	Mother
80	F	1 year	Respiratory	Ventilation	Mother

APPENDIX E

CHECKLIST FOR DYSPHAGIA AND COMMUNICATION DIFFICULTIES IN INFANTS AND TODDLERS WITH TRACHEOSTOMIES

This checklist was compiled from a variety of resources available in the literature: Adamson & Dunbar, 1991; Arvedson & Brodsky, 2002; Arvedson & Lefton-Greif, 1998; Billeaud, 1998; Bleile, 1993; Bleile et al., 1993; Carron et al., 2000; Hall, 2001; Hill & Singer, 1990; Kamen & Watson, 1991; Kaslon & Stein, 1985; Katzenellenbogen et al., 1997; Kertoy, 2002; Kertoy et al., 1999; Locke & Pearson, 1990; Midwinter et al., 2002; Morris & Klein, 2000; Rossetti, 2001; Simon et al., 1983; Wolf & Glass, 1992.

1. Reference number		
2. Age at cannulation		
3. Primary underlying medical condition		
4. Indication for tracheostomy		
	Present	Absent
5. Dysphagia – related symptoms / difficulties		
5.1. Structural defects		
5.2. Oral phase		

5.2.1. Oral motor difficulties		
5.2.2. Oral sensory difficulties		
5.3. Pharyngeal phase		
5.3.1. Delayed / absent swallow response		
5.3.2. Nasopharyngeal backflow		
5.3.3. Laryngeal penetration		
5.3.4. Aspiration		
5.3.5. Pooling/residue in valleculae/pyriform sinuses		
5.4.Oesophageal phase		
5.4.1. Inadequate UOS opening		
5.4.2. Structural abnormalities		
5.4.3. GOR		
5.4.4. Oesophageal dysmotility		
6. Feeding method		

7. Communication skills		
7.1. Speech production difficulties	Present	Absent
7.1.1. Aphonia		
7.1.2. Indistinct / unintelligible		
7.2. Communication		
7.2.1. Non-verbal communication system		
7.2.2. Receptive language delay		
7.2.3. Expressive language delay		
8. Hearing status		
8.1. Conductive hearing loss		
8.2. Sensorineural hearing loss		
9. Developmental delay		

Appendix F:

Adapted Checklist for Dysphagia and Communication Difficulties in Infants and Toddlers with Tracheostomies

NAME: _____ **FOLDER NUMBER:** _____
DATE of BIRTH: _____ **ADDRESS:** _____
CONTACT NUMBERS: _____ **CAREGIVER:** _____

INFORMATION	JUSTIFICATION	DETAILS
Age at cannulation:	The age at which patients are cannulated is important when considering feeding and communication development.	
Primary underlying medical condition:	It is important to consider the primary underlying medical condition when assessing feeding and communication skills in infants and toddlers with tracheostomies, as the underlying medical condition may affect these skills in addition to the presence of the tracheostomy.	
Indication for tracheostomy	The indication for a tracheostomy is relevant because it is related to the underlying medical condition, and may also impact on feeding and communication development.	

INFORMATION	JUSTIFICATION	DATE							
1.**Dysphagia:** related symptoms/difficulties assessed clinically and/or instrumentally.									
1.1. Structural defects e.g. cleft palate	1.1. Structural abnormalities may result in swallowing and feeding difficulties.								
1.2. Oral phase: 1.2.1. Oral motor difficulties e.g. poor sucking, poor lip closure, reduced tongue movement.	1.2.1. Oral motor skills are essential for optimal swallowing and feeding								
1.2.2. Oral sensory difficulties e.g. oral hypo/hypersensitivity, oral aversion.	1.2.2. Oral sensory disorders may result in impaired oral motor function and suboptimal feeding skills.								
1.3. Pharyngeal phase: 1.3.1. Delayed / absent swallow response.	1.3.1. Delayed or absent swallow response is an increased risk for aspiration.								
1.3.2.Nasopharyngeal backflow	1.3.2. Nasopharyngeal backflow indicates a lack of co-ordination of swallowing and may compromise breathing.								
1.3.3. Laryngeal penetration	1.3.3. Laryngeal penetration occurs when material enters the laryngeal vestibule above the vocal cords and increases the risk of								

	aspiration.								
1.3.4. Aspiration	1.3.4. Aspiration occurs when the swallow response is inco-ordinated and there is inadequate airway protection, resulting in material entering the trachea and possibly the lungs.								
1.3.5. Pooling in valleculae & pyriform sinuses; residue in pharynx.	1.3.5. Pooling of material in the pharynx before or after a swallow increases the risk of aspiration.								
1.4. Oesophageal phase: 1.4.1. Delayed / insufficient upper oesophageal sphincter opening	1.4.1. Upper oesophageal sphincter dysfunction may result in aspiration, nasopharyngeal backflow, pooling in the pharynx, and may be indicative of a neurological cause or structural abnormality.								
1.4.2. Structural abnormalities e.g. stricture, obstruction, tracheoesophageal fistula.	1.4.2. Structural abnormalities of the oesophagus may result in swallowing and feeding difficulties.								
1.4.3. Gastro-oesophageal reflux (GOR)	1.4.3. GOR may cause dysphagia, respiratory complications and failure to thrive.								
1.4.4.Oesophageal dysmotility	1.4.4. Oesophageal dysmotility may result in retrograde movement of material and subsequent aspiration, as well as associated pain, which may also affect feeding.								

2. Feeding method: Oral, Nasogastric tube, Nasojejunal tube, Gastrostomy tube, Combination oral + tube	2. Infants and toddlers with swallowing and feeding problems may require alternative feeding. While non-oral feeding may provide a safe method of feeding, or provide adequate nutrition that cannot be attained orally, the use of alternative feeding methods may affect development of sensorimotor skills necessary for feeding and speech.								
3. Communication skills	3. Communication skills may be affected because of the underlying medical condition, or as a result of the tracheostomy and the associated effects on communication.								
3.1.1. Oral motor skills	3.1.1. Adequate oral motor skills are necessary for speech production.								
3.1.2. Aphonia	3.1.2. The inability to produce voice may affect the normal development of speech.								
3.1.3.Indistinct/unintelligible speech production	3.1.3.. The clarity of speech may be affected by a long-term tracheostomy tube.								
3.1.4. Articulation	3.1 4. Articulation deficits may be present during cannulation, and after decannulation.								
3.2. Means of Communication	3.2. During periods of aphonia it may be necessary to introduce a non-verbal means of communication to facilitate								

	the development of communication.								
3.3. Receptive language skills	3.3. Delays in the receptive skills of infants and toddlers with tracheostomies have been reported in the literature.								
3.4. Expressive language skills	3.4. Delays in the expressive language skills of infants and toddlers with tracheostomies have been reported in literature.								
4. Hearing status	4. Hearing loss will affect speech and language development.								
5. Developmental delay	5. The infant and toddler with a tracheostomy is at risk for developmental delay because of the underlying medical conditions, health status and possible long-term / repeated hospitalisations.								