The Feeding and Swallowing Impact Survey (FS-IS): cross-cultural adaptation for the South African context

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Declaration

I, Candice Bestenbier, hereby declare that this dissertation is based on my original work (except where acknowledgements indicate otherwise) and have used the American Psychological Association system of referencing. I declare that neither the whole work or any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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Abstract

Background: Feeding and swallowing difficulties (FSD) are found in typically developing children and children with complex medical and developmental conditions. These difficulties may have negative health consequences which can be stressful for caregivers as they are required to provide care for their children in the home environment. The Feeding and Swallowing Impact Survey (FS-IS) is a subjective rating scale used to determine the health-related quality of life (HRQoL) of caregivers of children diagnosed with FSD. However, this scale is not yet available in any of the official South African languages (except for English), and has not yet been culturally or linguistically adapted for the South African context.

Research aims: The study aimed to cross culturally adapt and validate the FS-IS for the South African context by 1) describing the content validity of the FS-IS in a South African context; 2) describing the cultural and linguistic appropriateness of the English, isiXhosa and Afrikaans versions of the FS-IS; and 3) describing the experiences caregivers of children have in caring for their child with FSD using the FS-IS, in a pilot study.

Methodology: A descriptive exploratory design was used to cross-culturally adapt and pilot the FS-IS, which consists of 3 subsections related to daily activities, worrying and problems with feeding. Five expert speech-language therapist (SLT) participants were identified to review the FS-IS for content validity. The FS-IS was then translated into Afrikaans and isiXhosa using the forward and back translation process. Caregivers (n=15) were identified at feeding clinics to determine the cultural and linguistic appropriateness of the FS-IS in English (n=5), Afrikaans (n=5) and isiXhosa (n=5). Their recommendations were taken into consideration and changes made. The pilot study included caregivers of children with FSD attending feeding clinics at two institutions (n=32) who completed the FS-IS. The participants in the pilot study included parents as primary caregivers (n=28; 88%), grandparents (n=2; 6%), as well as foster parents (n=2; 6%). Thirty-one participants were female with 14 English speaking, 9 isiXhosa and 9 Afrikaans speaking. The caregivers were the primary caregivers of children with a variety of FSD including non-oral feeds, oral feeds with specific modifications and picky or selective eaters.

Results: The FS-IS was found to have content validity as experts and caregiver participants judged it to be contextually relevant for the South African context. Caregivers considered the items on the FS-IS important, clear and appropriate for speakers of their native language as well as for fellow South African families, with minor changes suggested for the isiXhosa translated version. The tool has high internal consistency (Cronbach's alpha = 0.827) as well as excellent intra and inter-rater reliability (100% agreement). Daily activities that caregiver participants found most difficult included getting help from others (50%, n=16) and leaving their child in the care of others as they are scared to have others feed or take care of their child (62.5%, n=19). The majority of caregiver participants reported concerns related to their child's general health (84%, n=27) and whether they were doing enough to help with their child's FSD (50%, n=16). Few caregivers reported difficulties with feeding, with 87.5% (n=28) reporting no difficulties as a result of the time taken to prepare meals and 72% (n=23) reported no difficulty due to professionals or family having differing opinions about how to feed their child with FSD.

Conclusion*:* The results confirm that the FS-IS is a reliable and valid tool for the identification of caregivers with reduced HRQoL related to caring for their child with FSD in a South African context. The adapted and translated FS-IS can therefore be used to identify caregivers who may need additional support or referral for further management from the multidisciplinary team. The results highlighted the complexity of caring for a child with FSD and the effects of the burden of care on caregivers. Early identification of the HRQoL of caregivers will not only benefit the caregivers but

also the child they are caring for as the HRQoL of caregivers impacts on the QoL of the child with FSD.

Keywords: Feeding and swallowing difficulties, health-related quality of life, cross-cultural adaptation, Feeding and Swallowing Impact Survey (FS-IS), paediatric dysphagia, caregivers, South Africa.

Author's note

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Referencing style:

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

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Glossary

Aspiration

The entering of a bolus (e.g. food, liquid, saliva) into the airway below the level of the true vocal folds, into the trachea and lungs (Andrew, Parr, & Sullivan, 2012; Arvedson, 2008; Dodrill & Gosa, 2015; Jadcherla, 2016).

Behavioural Feeding Difficulties

Feeding difficulties that occur when a child is unwilling to consume food/liquid despite their sufficient ability to do so physically. These difficulties may co-occur with dysphagia (Dodrill & Gosa, 2015).

Cerebral Palsy

Cerebral palsy (CP) is a permanent, static neurological condition as a result of a brain injury before cerebral development is completed and is the most common motor disability in childhood. CP affects movement and posture and can range from mild to severe (Arvedson, 2013; Marques & Sá, 2016; Umay, Gündoğdu, & Öztürk, 2019).

Congenital heart disease (CHD)

Structural defects of the heart that are represented as serious malformations that manifest in the new born (de Queiroga et al., 2017).

Construct Validity

The extent to which a test or tool measures what it is intended to measure (Bruce, Pope, & Stanistreet, 2017).

Growth faltering

The term used to describe slower weight gain in childhood than is typically expected for a child's age (Gonzalez-Viana, Dworzynski, Murphy, & Peek, 2017).

Feeding and Swallowing Disorder/Difficulties (FSD)

A range of difficulties in the area of eating and swallowing. They may include food refusal, disruptive behaviour during mealtimes, delays in the achievement of age-appropriate feeding skills as well as feeding and swallowing difficulties/disorders (Arvedson, 2008). FSD may present as inadequate growth, prolonged feeding times as well as delayed feeding milestones (Arvedson, 2013).

Health-related Quality of Life (HRQoL)

Quality of life (QoL) as it relates to diseases or treatments people experience (Bonomi, Patrick, Bushnell, & Martin, 2000; Ruperto et al., 2000).

Quality of Life (QoL)

A term used to describe the multidimensional concept that focuses on an individual's evaluation of all aspects of their life as well as the way in which they live, expectations of life and standard of living (Bonomi et al., 2000; Swan, Speyer, Heijnen, Wagg, & Cordier, 2015).

Abbreviations

OA-TOF	Oesophageal Atresia- Tracheo-oesophageal Fistula
FS-IS	Feeding and Swallowing Impact Survey
FSD	Feeding and Swallowing Disorders
GORD	Gastro-oesophageal reflux disease
HPCSA	Health Professions Council of South Africa
HRQoL	Health Related Quality of Life
RCWMCH	Red Cross War Memorial Children's Hospital
SLT	Speech-Language Therapist
TBH	Tygerberg Hospital
TBI	Traumatic Brain Injury
QoL	Quality of Life
VFSS	Video Fluoroscopic Swallow Study
VLBW	Very low birth weight

1 Introduction

Feeding and swallowing difficulties (FSD) in the paediatric population are associated with negative health consequences such as malnutrition, dehydration and respiratory illness (Rogers & Arvedson, 2005; Vesey, 2013). Eating, swallowing and respiration are essential functions of the body through which life and growth are sustained (Garg, 2003; Sharp, Jaquess, Morton, & Herzinger, 2010). The prevalence of FSD has increased as the survival rates of premature infants and children with chronic medical conditions increase (Kakodkar & Schroeder, 2013).

FSD impact on children and their caregivers in many ways. Caregivers are faced with increasing stress related to the care of their child with FSD. However, there is limited understanding of the impact of taking care of children with FSD, and tools used to measure the concerns of caregivers are lacking (Lefton-Greif et al., 2014). Caregivers have stated a variety of concerns and difficulties related to caring for a child with FSD such as the impact on their work hours, income, leisure time and lack of emotional support (Hatzmann, Maurice-Stam, Heymans, & Grootenhuis, 2009; Lefton-Greif et al., 2014). Caregivers are required to learn to care for their child with FSD in the home environment which can increase caregiver burden (Lutz, 2012). The impact of caring for a child with a chronic condition is referred to as caregiver burden (Nogueira, Rabeh, Caliri, Dantas, & Haas, 2012). The burden related to the care of children with FSD frequently impacts caregiver stress, quality of life (QoL) and Health-related Quality of Life (HRQoL) and caregivers benefit from both formal as well as informal support while they care for their child with FSD (Azios, Damico, & Roussel, 2016; Erasmus, van Hulst, Rotteveel, Willemsen, & Jongerius, 2012).

Lefton-Greif et al. (2014) developed and validated a tool, the Feeding/Swallowing-Impact Survey (FS-IS), to measure the HRQoL of caregivers of children with FSD to determine the impact of these difficulties on carers in the United States (US). However, a contextually relevant tool measuring HRQoL of caregivers of children with FSD in South Africa is currently lacking. Contextually relevant resources are resources that are available for health professionals to use with a specific population in a specific setting, and which have been developed with that population and setting in mind (Pascoe & Norman, 2011). Many resources used by health care professionals in South Africa have been developed in countries such as the United Kingdom (UK), US and Australia and are not contextually relevant for South Africa's multilingual, multicultural population (Pascoe & Norman, 2011). It is important to use validated and contextually relevant resources as they address the needs of the population they are created for (Dekker, Dallmeijer, & Lankhorst, 2005), and the use of such tools follows guidelines of the Health Professions Council of South Africa (HPCSA, 2019) for speech-language therapists (SLTs) working with linguistically and culturally diverse populations.

South Africa has eleven official languages and ethical guidelines for practice suggest that a language mismatch should not be the cause for denying intervention or a lesser quality of intervention (Pascoe & Norman, 2011) . The process of translation, validation and cross-cultural adaptation is beneficial when adapting a tool for a different context as it allows the researcher to adapt and adjust items in the tool to suit the context in which it will be used as simple forward translation is not sufficient (Epstein, Santo, & Guillemin, 2015; Padua, 2003; Pascoe & Norman, 2011; van Widenfelt, Treffers, de Beurs, Siebelink, & Koudijs, 2005).

Insight into the contributions of factors that affect the HRQoL of the caregivers of children with FSD may benefit children and their caregivers by providing guidance to healthcare professionals about the care and support these caregivers require as they care for their child with FSD. Exploring the impact of the FSD on family stress and HRQoL will contribute to the research field as these aspects have not been well studied (Garro, Thurman, Kerwin, & Ducette, 2005). Translation, validation and cross-cultural adaptation of a tool that measures HRQoL, such as the FS-IS, can therefore make an important contribution to families and health professionals in the South African context. Ongoing research in this field will assist with determining how caregivers are coping with the care of their child with FSD as well as the provision of the necessary services and support for the caregivers (Lefton-Greif et al., 2014).

2 Literature review

Feeding is a basic need, an instinctive and essential part of life which begins at birth (Horton, Atwood, Gnagi, Teufel, & Clemmens, 2018; Smithard, 2015). In the paediatric population it is associated with appropriate weight gain in early infancy and during the first few years of life. Although natural and instinctive, it requires co-ordination between swallowing and breathing (Delaney & Arvedson, 2008). Feeding impacts all aspects of a child's life, including development, health, growth and even independence and social skills (Goday et al., 2019; Sharp et al., 2010). Feeding also serves to encourage interaction between children and their caregivers (Delaney & Arvedson, 2008; Rybak, 2015), and provides opportunities for the development of independence as well as socialisation (Smithard, 2015). FSD refers to the disruption in one or more of the areas integrated in typical feeding and swallowing such as medical, nutritional, feeding skills and psychosocial aspects during early development.

FSD integrates a range of aspects in early childhood development and impacts on these aspects in varying degrees. It can impact medical and nutritional aspects, as well as feeding skills and psychosocial aspects (Bryant-Waugh, Markham, Kreipe, & Walsh, 2010; Dodrill & Gosa, 2015; Goday et al., 2019; Laud, Girolami, Boscoe, & Gulotta, 2009; van den Engel-Hoek, de Groot, de Swart, & Erasmus, 2015). The range of aspects that are impacted by FSD can greatly impact a child and his/her caregiver as any one aspect can be affected and subsequently affect other aspects.

FSD can occur in otherwise typically developing children (Gisel, 2008; Laud et al., 2009; Voulgarakis & Forte, 2015) but are more frequently present in infants and children who are 'at-risk' such as those with medical conditions and neurodevelopmental disabilities (Andrew & Sullivan, 2010; Rogers & Arvedson, 2005). FSD are typically associated with underlying medical conditions, particularly those conditions that affect the structure and function of the cardiopulmonary, gastrointestinal (GI) and neurological systems (Dodrill & Gosa, 2015; Estrem et al., 2016; Goday et al., 2019; Voulgarakis & Forte, 2015). These underlying medical conditions place infants and children at greater risk for FSD which in turn increases their risk for the associated negative health consequences of FSD, such as aspiration which affects respiratory health (Lefton-Greif & Arvedson, 2016; Tutor & Gosa, 2012); and reduced intake which affects optimal growth and nutrition (Andrew & Sullivan, 2010; Benfer et al., 2015). Nutrition is a fundamental aspect of development in children as the attainment of adequate nutrition ensures optimal physical growth and development.

Normal nutritional status improves QoL (Quitadamo, Thapar, Staiano, & Borrelli, 2016), and feeding serves as the means for obtaining nutrients for growth (Horton et al., 2018). Impaired oral intake can affect a child's ability to meet their daily hydration and nutritional requirements, affecting their ability to grow and thrive (Andrew & Sullivan, 2010; Goday et al., 2019; Heckathorn, Speyer, Taylor, & Cordier, 2016; Laud et al., 2009; Voulgarakis & Forte, 2015). Furthermore, malnutrition has a negative impact on the functional outcomes, growth and development of children (Mehta et al., 2013). Skill-based dysfunction in FSD refers to dysfunction in the safety, age-appropriacy and efficiency of the intake of the child (Goday et al., 2019). These impairments may be due to increased or decreased (hyper or hypotonicity) muscle tone, heightened sensitivity to texture, an aversive response or difficulty with jaw and tongue control (Bryant-Waugh et al., 2010; Willging, 2020). These difficulties may result in the child failing to eat adequately in conjunction with weight loss, or significant failure to gain weight (not directly related to another medical or psychological condition) as well as aspiration and respiratory difficulties (Bryant-Waugh et al., 2010).

The psychosocial components of FSD include developmental, mental, and behavioural health problems, social factors and environmental factors that negatively influence a child's nutritional intake (Berlin, Lobato, Pinkos, Cerezo, & LeLeiko, 2011; Goday et al., 2019). These are present in children who are unwilling to consume liquids or foods orally, despite their physical ability to do so, although this may coincide with medical conditions (Dodrill & Gosa, 2015). The 'red flags' for the psychosocial components include but are not limited to: avoidance behaviours such as food selectivity/fixation, food refusal, inappropriate caregiver management of the feeding and nutritional needs of the child, forceful feeding, abrupt cessation of feeding after a triggered event, anticipatory gagging, failure to thrive and the disruption of social functioning and the caregiver-child relationship (Berlin et al., 2011; Goday et al., 2019; Kerzner et al., 2015; Williams, Field, & Seiverling, 2010). These psychosocial components often result in FSD and impact on the development of the child as well as their social development and relationship with their caregivers.

Many challenges related to FSD are universal, but the nature of eating and cultural components related to mealtimes vary between cultures (Mais, Warkentin, Latorre, Carnell, & Taddei, 2015), therefore investigating FSD in different settings is important. There has been limited research in South Africa surrounding FSD. A study completed by Hewetson and Singh (2009) pointed to the need for continued research in the area of FSD and its effects on the caregivers of children with FSD in the South African context. This adds to the rationale for the validation and cross-cultural adaptation of the FS-IS for the South African context.

FSD reduces the opportunities children have to practice and develop age-appropriate feeding skills as they are frequently limited to certain consistencies or textures that are safe and recommended, (Borowitz & Borowitz, 2018), resulting in their feeding skills being inappropriate for their age (Goday et al., 2019). This consequently affects the growth of the child and their development of age-appropriate skills thus missing out on critical periods of development (Andrew & Sullivan, 2010; Dodrill, 2014; Fischer & Silverman, 2007; Lefton-Greif & Arvedson, 2016). Furthermore, the timing of the attainment of the missed earlier developmental milestones may impact on the achievement of later milestones, thereby having a compounding effect (Park, Knafl, Thoyre, & Brandon, 2015). For example, delays in the initiation of a pureed diet as a result of aspiration or poor oral motor skills, results in subsequent skills such as chewing being further delayed. Characteristics of FSD vary from one child to the next and are reported in children with a variety of medical diagnoses. However, to date, the data and prevalence estimations of FSD in the paediatric population are limited (Arvedson, Clark, Lazarus, Schooling, & Frymark, 2010; Berlin et al., 2011; Bhattacharyya, 2015; Goday et al., 2019; Jadcherla, 2016). Using the characteristics of FSD, the prevalence and effects of FSD will be discussed next.

2.1 Prevalence and effects of FSD

The prevalence of FSD in South Africa has not been established. A study conducted in the US reported that 0.9% of typically developing children, between the ages of 3 and 17 years of age, presented with some form of FSD, suggesting that half a million typically developing children, in the US, have some form of FSD, although the majority of paediatric FSDs are thought to occur in children younger than two years of age (Andrew & Sullivan, 2010; Bhattacharyya, 2015; Jadcherla, 2016) suggesting that this may therefore be an under-representation. Laud et al. (2009) reported the prevalence of FSD in the paediatric population is high with 20 to 40% of all children presenting with some form of the condition. It is reported that these typically developing children are diagnosed with mild and transient FSD resulting in few affected children receiving treatment (Bhattacharyya, 2015; Borowitz & Borowitz, 2018). While FSD can be found in typically developing children, the condition is more prevalent in those diagnosed with medical conditions (Rogers & Arvedson, 2005), therefore there is an expected rise in the prevalence of FSD in younger children with complex and or chronic medical conditions. This expected rise in FSD in children is likely due to the increase in survival rates of children with prematurity, complex medical conditions and significant developmental disabilities (Ancel et al., 2006; Fischer & Silverman, 2007; Kakodkar & Schroeder, 2013; Rommel, De Meyer, Feenstra, & Veereman-Wauters, 2003; Stoner, Bailey, Angell, Robbins, & Polewski, 2006). Children at an increased risk of FSD include those with complex medical conditions,

developmental disabilities and those with neurological impairments, with cerebral palsy (CP) being the most common (Andrew & Sullivan, 2010; Durvasula, O'Neill, & Richter, 2014; Fischer & Silverman, 2007; Sharp et al., 2010; van den Engel-Hoek et al., 2015; van den Engel-Hoek, Harding, van Gerven, & Cockerill, 2017). It is reported that 25–80% of children with developmental disabilities present with FSD (Arvedson, 2008; Manikam & Perman, 2000) while 61.5% of children with complex medical conditions, some of which may include gastroesophageal reflux disease (GORD), cleft lip and palate and congenital heart disease (CHD) (Rybak, 2015; Sharp et al., 2010) and 30–40% of children with neurological impairments (Andrew & Sullivan, 2010; van den Engel-Hoek et al., 2015) are diagnosed with FSD. A range of children are diagnosed with FSD, and furthermore, the effects of FSD on these children may vary.

The prevalence of FSD in the paediatric population with complex and/ chronic medical conditions is high and underrepresented in the literature as few studies have defined FSD consistently and there has not been consensus about the definition. FSD in children may cause stress as well as stressful interactions for both the children and their caregivers (Andrew & Sullivan, 2010; Lefton-Greif & Arvedson, 2016; Rybak, 2015). The care of a child with FSD may be a cause of stress for caregivers due to the monitoring of daily activities of their child as well as managing any emergencies that may arise (Zelman & Ferro, 2018). Negative behaviours and feeding habits can contribute to feelings of distress for the caregiver, and anxiety which may in turn contribute to the stressful feeding interaction between the child and caregiver (Didehbani, Kelly, Austin, & Wiechmann, 2011; Phalen, 2013). Feeding-related behavioural difficulties are frequently associated with reduced participation and social interaction, thus impacting on the caregiver-child interaction during meals (Andrew et al., 2012). These psychosocial impairments can affect feeding development negatively and contribute to FSD (Berlin et al., 2011). This subsequently affects caregiver-child bonding and caregiver-child interactions, resulting in food refusal and disruptive mealtime behaviours (Willging, 2020).

The recent advances in treatment, health care and its delivery, together with increases in child survival rates, has resulted in an increased number of children with chronic medical conditions receiving care at home (Balling & McCubbin, 2001). This in turn requires caregivers of children with FSD to be trained in the care of their child as they resume full caretaking in the home environment (Lutz, 2012). The challenges associated with the care of a child with FSD have an impact on the everyday life of those involved, and may impact on caregiver burden and QoL (Azios et al., 2016; Erasmus et al., 2012).

2.2 Caregiver burden and quality of life

Burden refers to the impact that the act of caregiving has on caregivers (Nogueira et al., 2012). Burden changes as the demands and extent of caregiving management changes (Chou, 2000) and the transition of healthcare to the home increases the demands placed on family members, as the caregiving needs can be intense and stressful for all parties involved (Mahant, Pastor, DeOliveira, Nicholas, & Langer, 2011; Raina et al., 2004; Stoner et al., 2006). The burden of care is frequently placed on the primary caregiver, most commonly the mother, who reportedly experiences more daily challenges than mothers of typically developing children, as the roles of both child and caregiver are altered (Azios et al., 2016; Estrem, Thoyre, Knafl, Pados, & Van Riper, 2018; Lutz, 2012; Winston, Dunbar, Reed, & Francis-Connolly, 2010). Burden may have an impact on the caregivers' physical, psychological, social and financial well-being, as they are required to care for their child with FSD in the home environment and have many responsibilities to perform in this regard (Dambi, Jelsma, & Mlambo, 2015; Nogueira et al., 2012; Sabzevari & Nematollahi, 2016; Winston et al., 2010).

Winston et al. (2010) provide insight into the perception of mothers and their occupations when mothering a child with FSD. They described the perception of a child's illness and effect on their caregivers as their caregivers are faced with increased caregiving demands. The study by Winston et al. (2010) described a shift from the mothering role to a mothering occupation as the arrival of a child with a condition such as FSD brings added responsibility in terms of maternal work within their daily occupations, roles and routines. The study comprised mothers, at least 18 years of age, who were parenting children between the ages of 12 and 36 months and found that due to the complex nature of FSD, caregivers experience reduced QoL due to the complex occupational responsibilities that are associated with caring for children with FSD.

Caring for typically developing children as well as those with disabilities can be time consuming and physically exhausting. However, caregivers of children with disabilities undertake tasks that are important, difficult and unusual and are required to attend frequent hospital visits and therapy sessions (Winston et al., 2010). For example, caregivers of children receiving feeds enterally must fulfil time and treatment commitments and responsibilities such as proper use and care of the tubes used for feeding (Pedersen, Parsons, & Dewey, 2004). The daily responsibilities and constant burden of care for a child with FSD may add stress to the lives of caregivers (Lefton-Greif et al., 2014). Increased levels of stress, depression and anxiety are linked to reduced health rates and QoL (Iconomou, 2001), which could inevitably negatively affect the QoL of both the child with FSD and their caregiver (Hatzmann et al., 2009; Lefton-Greif et al., 2014). The improvement of their child's

health as well as their QoL are frequently prioritized by caregivers of children with FSD (Simione et al., 2020). Caregivers may minimize personal issues or difficulties that may arise in the care of their child with FSD as they are committed to their child's care (Raatz, Ward, Marshall, Afoakwah, & Byrnes, 2020). Therefore, caregiver burden impacts on caregiver stress and acts as a determining factor in the QoL of caregivers of children with FSD. As stress increases so the QoL is affected (Huang, Chang, Chi, & Lai, 2014; Jeong, Myong, & Koo, 2015; Lefton-Greif et al., 2014).

QoL is a multidimensional concept that focuses on an individual's evaluation of all aspects of their life as well as the way in which they live, expectations of life and standard of living (Bonomi et al., 2000; Swan et al., 2015). Table 1 highlights the domains encompassed in QoL including: general health, physical symptoms, emotional functioning, social components and relationships (Vesey, 2013). If any of these domains are affected the QoL of the individual can be influenced (Dardas & Ahmad, 2015).

TABLE 1: DOMAINS OF QOL

Domains affected by QoL	Examples
General, Physical and Mental Health	- Exhaustion due to caring for child and limited and disrupted sleep due to caring responsibilities
Emotional Functioning	- Psychological impact - Expectations
Social Components	- Isolation and difficulty maintaining social and building social relationships. - Time
Relationships	- Difficulty in making time for families and family holidays as well as pressure on marital relationships

The term health related quality of life (HRQoL) refers to QoL as it is related to diseases or treatments people experience (Bonomi et al., 2000; Ruperto et al., 2000). Poor HRQoL may be associated with increased strain, anxiety, depression and/or stress, as the caregiving burden impacts on all the domains of HRQoL (Dambi et al., 2015; Iconomou, 2001; Nogueira et al., 2012). Caregivers have been reported to experience stress, anxiety (Azios et al., 2016) low moods and depression (Andrew & Sullivan, 2010) in association with their child's FSD. Caregiver HRQoL has also been correlated with their subjective perception of their child's limitation by illness in daily life, psychosocial strains, and ways of coping (Wiedebusch et al., 2010). Exploring and understanding the HRQoL of caregivers would contribute to the improvement of the quality and appropriateness of treatment provided to the child with a chronic feeding difficulty and their family (Garro et al., 2005; Heidemann et al., 2014; Ruperto et al., 2000). Increased caregiver stress results in reduced QoL which has been reported in

caregivers of children with FSD as they are faced with additional stressors in caring for their child with multiple additional needs and specific management, this is discussed further in the following section on caregiver stress.

2.2.1 Caregiver stress

When providing care for children with chronic conditions or illnesses, it is vital to address the caregiver stress that may be experienced (Didehbani et al., 2011). Sources of stress can stem from factors that are individual to each medical condition and family system. Caregivers of children with FSD may experience stress directly related to their child's FSD or management of these, the psychological impact, underlying medical condition, and associated financial burden related to the care of their child (Azios et al., 2016; Howe, Sheu, Wang, & Hsu, 2014; Simione et al., 2020).

2.2.1.1 Feeding

Feeding a child with FSD is a common source of stress for caregivers (Rogers, 2004; Schwarz, 2003; Sharp et al., 2010). Caregivers are concerned with the safety of oral intake as there is a risk of aspiration and choking during feeding (Rybak, 2015). They are therefore taught to adapt feeding techniques or change the consistency of the food to reduce the risk of aspiration and episodes of choking. These specific feeding strategies may add stress to the already stressful feeding regime of a child with FSD (Azios et al., 2016; Marques & Sá, 2016). Caregivers also experience frustration related to difficulties with behaviour during mealtimes (Borowitz & Borowitz, 2018). These mealtime stressors may result in feelings of anger or frustration (Rogers, 2004; Schwarz, 2003; Sharp et al., 2010).

Caregivers may feel as though feeding is a priority for their child with FSD due to the role of feeding in nutrition, growth, and development (Andrew et al., 2012; Lutz, 2012; Winston et al., 2010). The growth of a child is an indicator of their nutritional intake as well as feeding skills (Dodrill, 2014). Nutritional status supports optimal neurodevelopment as sufficient energy and nutrition is essential in the development of appropriate cognitive and physical development in children (Dodrill, 2014; Estrem et al., 2018). Nutritional deficits are one of the complications that may arise in the paediatric population with FSD (Andrew et al., 2012; Andrew & Sullivan, 2010; Estrem et al., 2018; Redle, 2007; Rybak, 2015). Children with FSD are dependent on their caregivers to meet their nutritional needs which impacts on caregiver confidence and increases the stress that caregivers experience in caring for their child (Dusick, 2003; Powers et al., 2002; Sharp et al., 2010). In addition, caregivers often feel that healthcare workers focus on the nutritional status and weight of the child (Azios et al., 2016), which may subsequently result in mothers feeling as though feeding has a dominant role in their

daily lives. They feel liable for poor growth of their children (Craig, 2013; Rogers, 2004), which may further compound the stress associated with feeding (Andrew et al., 2012).

In addition to the stress related to feeding safety and nutrition, the scheduling, preparation, and administration of oral feeds may be time consuming, taking caregivers between 30 to 60 minutes to complete a meal. Caregivers often report feeding their child for hours while they are awake due to the specificity of their meal as well as manner of intake (Andrew et al., 2012; Craig, Scambler, & Spitz, 2003; Lutz, 2012; Rogers, 2004; Schwarz, 2003; Winston et al., 2010). Caregivers are required to incorporate various considerations into the care of their child such as scheduling tube feeds, preparing specific meals, attending appointments as well as adjusting family schedules and routines to meet the needs of the child with FSD (Winston et al., 2010). These feeding-related tasks place a great demand on caregivers resulting in them planning their lives around the mealtimes of their child with FSD (Hewetson & Singh, 2009). The scheduling of the needs of a child with FSD may in turn result in reduced time and interactions with other family members (Sabzevari & Nematollahi, 2016). The preparations and scheduling may add to caregiver stress causing them to feel overwhelmed with the care they are required to provide their child. These include the daily responsibilities and lack of time they have in completing personal daily tasks which may subsequently affect caregivers psychologically (Winston et al., 2010).

2.2.1.2 Psychological

There is a psychological impact on the caregivers of children with chronic medical conditions, including children diagnosed with FSD (Anderson, Loughlin, Goldberg, & Laffel, 2001). Caregivers often express their difficulty coping with the daily demands of the responsibilities of home, work and family life (Lowes, Clark, & Noritz, 2016). The severity and extent of the care required with the disorder, dependence of the child on their caregiver, behaviour of the child, social factors and characteristics of the caregiver are psychological factors that contribute to caregiver stress (Pedersen et al., 2004; Raina et al., 2004). The psychological functioning of caregivers impacts the health outcomes of children (physical and mental) as it affects the adherence to care (Commodari, 2010) and the care provided for their child (Pinquart, 2018). Caregivers with higher levels of stress experience poorer psychological health (Raphael, Zhang, Liu, & Giardino, 2010). The specificity of the care required to provide nutrition for a child with FSD is frequently placed solely on the primary caregiver, who is usually the mother (Azios et al., 2016). These additional stressors and psychological effects of caring for a child with FSD impact on the QoL of caregivers which may subsequently lead to caregivers experiencing a range of emotions. The range of emotions experienced may vary from one caregiver to the next and further impact each one in a different way.

The caregivers of children with FSD may feel incompetent and experience feelings of guilt, blame and failure if their child is not able to feed orally or has difficulty meeting their nutritional needs (Craig, 2013). Mothers report feeling judged or blamed by extended family members for the care they provide for their child, particularly their inability to feed their child, as well as a general lack of understanding in public settings (Azios et al., 2016; Craig, 2013). The feeling of judgement often overwhelms mothers when their child experiences growth faltering irrespective of the manner of nutritional intake (Hewetson & Singh, 2009). Caregivers of children with FSD have reported feelings of anxiety around their child's ability to eat orally and whether their child will be able to have their feeding tube removed (Tregay et al., 2017).

Providing the nutritional needs of a child is an important aspect of the initial caregiver-child interaction and influences the first caregiver-child interaction (Didehbani et al., 2011; Franklin & Rodger, 2003; Rybak, 2015). In addition to the physical effects of FSD on the child's growth, health and development, the feeding experience impacts the relationship and interactions between the caregiver and child (Andrew & Sullivan, 2010; Horton et al., 2018). This interaction alters when feeding becomes more of a medical task than a typical caregiving interaction, as mothers are required to shift their role as a mother to a nurse in the transition of care from the hospital to the home environment (Hewetson & Singh, 2009; Tregay et al., 2017). Frequently, in the presence of FSD, the feeding relationship between a caregiver and child is interrupted (Didehbani et al., 2011) or disrupted due to negative experiences during feeding times (Franklin & Rodger, 2003). The limited or reduced interaction between the caregiver and child with FSD during mealtimes violates the expectations caregivers have of parenting as it impacts on their ability to bond with their child (Franklin & Rodger, 2003; Lutz, 2012). Their bonding experience may be further negatively affected by the focus on their child's weight rather than on the feeding experience or interaction (Borowitz & Borowitz, 2018; Swift & Scholten, 2010) which may then negatively affect their bonding experience (Hewetson & Singh, 2009). The psychological aspects that affect caregivers include difficulties with daily demands in the care of their child, feelings of judgment or incompetence as well as caregiver-child interactions, all of which have further effects on the HRQoL of the caregiver and subsequently on the health outcomes of the child.

2.2.1.3 Medical condition

The life of the child diagnosed with a chronic condition is affected as well as the life of their caregivers (Marques & Sá, 2016) as there are overwhelming emotions these caregivers may experience (Kolaitis, Meentken, & Utens, 2017). Caregivers of children with chronic conditions and disabilities are vulnerable to caregiving stress as they are confronted with new and unexpected experiences (Chaturvedi, Ojha, & Tiwari, 2014). When a child has been diagnosed with a chronic

condition or disability, such as CHD or CP, attention is frequently focused on the child, while caregivers also require assistance in coping with stress related to the care of their child (Chaturvedi et al., 2014). CHD is a chronic condition that can be stressful for caregivers (Kolaitis et al., 2017) as the disease manifests differently and has varying severities and treatments that require frequent medical follow ups (de Queiroga et al., 2017; Solberg et al., 2011). The same is true for CP and although care may form part of the caregiving role, there can be an increased burden when the care requirements are excessive and longer lasting, such as the care that may be required for children with FSD (Marrón et al., 2013). This increased burden associated with the care required for children with complex medical conditions increases the level of stress caregivers experience in caring for their child in the home environment (Besser, 2018; Cowpe, Hanson, & Smith, 2014), despite education and training provided to adapt to their new situation (Du, McGrath, Yiu, & King, 2010; Fischer & Silverman, 2007; Meleski, 2002; Sanchez, Spittle, Allinson, & Morgan, 2015; Sharp et al., 2010). These increased levels of stress related to the medical conditions and co-morbidities may impact on the QoL of these caregivers (Lowes et al., 2016).

Caregivers may experience stress related to the medical consequences of FSD as well as the underlying medical condition. The most common medical consequences of FSD include malnutrition and aspiration (Emond, Drewett, Blair, & Emmett, 2007; Garg, 2003; McDougall, Drewett, Hungin, & Wright, 2009; Redle, 2007; Reilly, Skuse, Wolke, & Stevenson, 1999; Schwarz, 2003; Shields, Wacogne, & Wright, 2012; Staiano & Martinelli, 2013). Children with FSD may be deemed medically fragile, and the risks of aspiration are then added stressors for caregivers of children with FSD (Anderson et al., 2001; Besser, 2018; Wu, Franciosi, Rothenberg, & Hommel, 2012) as permanent damage to developing lungs may arise (Tutor & Gosa, 2012). Chronic aspiration may result in aspiration pneumonia (Arvedson, 2008), reactive airway disease (Schwarz, 2003), respiratory issues such as bronchiectasis as well as progressive or chronic lung disease (Boesch et al., 2006; de Benedictis, Carnielli, & de Benedictis, 2009). GORD is included as one of the complications that may co-occur with FSD (Arvedson, 2008; Schwarz, 2003) and may also contribute to aspiration (Boesch et al., 2006).

The risk of medical complications arising in the home environment are high for children with chronic medical conditions (Garro et al., 2005; Sabzevari & Nematollahi, 2016; Van Exel, Bobinac, Koopmanschap, & Brouwer, 2008; Wiedebusch et al., 2010) causing caregivers to constantly be concerned about their child's health and fear regarding their child's survival (Batchelor, 2007; Franklin & Rodger, 2003; Mahant et al., 2011; Winston et al., 2010). These risks may result in additional hospital visits due to the increased need for medical attention (Howe et al., 2014). Additionally, caregivers are expected to attend each medical appointment and be present for each

admission. These may result in caregivers feeling overwhelmed by the medical condition of their child as it takes time out of their schedules frequently disrupting their work and home life and the sense of normalcy, furthermore, affecting their QoL.

In addition to the health consequences of FSD such as aspiration and poor nutrition, most children with FSD have underlying or associated chronic medical conditions and/or developmental conditions which also contribute to caregiver stress (Berlin et al., 2011). Caregivers have to adapt to the chronicity of their child's condition as well as any co-morbidities that may be present (Brett, 2002). Fishbein, Benton, and Struthers (2016) used the *Parenting Stress Index – Short Form* (PSI-SF) to determine the overall stress level of caregivers of children with FSD. The study compared the stress experienced by caregivers of children with FSD, those with and those without co-morbidities. They reported that caregivers of children without co-morbidities scored lower on the PSI-SF, indicating that caregiving stress was directly related to, and increased by, the presence of comorbidities in their child with FSD (Fishbein et al., 2016). This study by Fishbein et al. (2016), supports the premise that the health condition of a child affects the QoL of their caregiver as their medical condition causes additional stress and subsequent decrease in HRQoL. The effects of the health condition of a child with FSD therefore impact on the HRQoL of their caregivers due to the increase in stress as a result of additional caregiver burden.

2.2.1.4 Financial burden

The financial burden that families with children with a chronic illness face is a global issue that has not been characterised thoroughly (Connor, Kline, Mott, Harris, & Jenkins, 2010). Health care costs related to intervention can be considerable for children with chronic conditions (Eunson, 2015). Due to the complex medical conditions and co-morbidities associated with FSD, children often require recurrent and frequent hospitalisations as well as clinic visits, placing a financial burden on the caregivers (Anderson et al., 2001; Bandstra, Crist, Napier-Phillips, & Flowerdew, 2011; Lutz, 2012). Transport costs related to frequent medical visits (Anderson et al., 2001) and additional costs related to the care, specialised feeds and equipment required for tube feeding add to the financial concerns (Craig, 2013; Simione et al., 2020). Furthermore, frequent medical check-ups and therapy sessions occupy a significant amount of time for caregivers which may result in the main caregiver not being able to work and remaining at home to care for their child with FSD (Connor et al., 2010; Eunson, 2015; Howe et al., 2014; Sloper & Turner, 1992; Winston et al., 2010). The caregiver that continues working may be required to work extra hours to provide for their family (Sabzevari & Nematollahi, 2016). These changes in employment may result in financial constraints as there is a decrease in the income received in the household, which may be even more apparent in single caregiver families (Connor et al., 2010).

2.2.2 Caregiver quality of life

Caregiver QoL is affected by the stress caregivers experience in the care of their child with FSD, which may impact their employment, physical health, emotional wellbeing, and social life. Caregivers are frequently required to take time off work (Anderson et al., 2001) as well as rearrange their work schedules to care for their child with FSD (Meleski, 2002). This absence from work or education as well as the number of doctor visits were highlighted as factors that directly relate to caregiver and family functioning (Heidemann et al., 2014), as this may have an impact on employment status (Hewetson & Singh, 2009) and ultimately place financial constraints on the family causing stress and ultimately affecting the QoL of these caregivers (Connor et al., 2010).

Nordheim, Rustøen, Solevåg, Småstuen, and Nakstad (2018) determined that the QoL of caregivers of children with very low birth weight (VLBW) reduced as their stress increased. The burden of caring for a child with a disability can have negative effects on the health of their caregivers (Lima, Cardoso, & Silva, 2016). In a cross sectional study by Cowpe et al. (2014) caregivers reported that their physical well-being was affected especially in the early stages after receiving their child's diagnosis. Caregivers experience reduced QoL due to the physical demands of caring for their child with FSD (Cousino & Hazen, 2013). Mothers reported that caring for a child with FSD is exhausting (Follent et al., 2017) and feeding children with FSD caused them to tire easily (Hewetson & Singh, 2009). In addition, nasogastric tube (NGT) and gastrostomy feeds may require feeding schedules that could lead to exhaustion as caregivers are required to feed their children every few hours (Mahant et al., 2011). Caregivers may find the feeding demands of their child with FSD results in frequent feeding attempts which subsequently leads to sleep deprivation, and places a significant demand on the caregiver especially when there are other children to care for (Tregay et al., 2017). Fatigue in caregivers may also be as a result of having to sleep in places that are not very comfortable, such as hospitals for repeat admissions (Winston et al., 2010). These caregiving activities may result in caregivers changing their lifestyle which in turn compromises their health status affecting their QoL (Nogueira, Rabeh, Caliri, & Dantas, 2016).

Family stress can be operationally defined by Abidin's Family Stress Model (1997). According to this framework, stresses of various aetiologies (e.g. financial, health, job dissatisfaction, lack of social support) can cause caregivers emotional stress (Raphael et al., 2010). Responses to these stresses can disrupt caregiving and the interactions between caregiver and child (Raphael et al., 2010). The medical and psychosocial complications of FSD place a considerable burden on caregivers, as they care for their child because they require various care routines to ensure adequate health, nutrition and development (Horton et al., 2018).

Caregivers feel a range of emotions when caring for their child with FSD (Winston et al., 2010) and these emotions can be complex and conflicting (Azios et al., 2016; Batchelor, 2007). Emotions tend to fluctuate as the health condition of the child changes. Feelings may range between feelings of guilt, hopefulness and gratitude (Lutz, 2012). In a study completed by Raphael et al. (2010) the National Survey of Children's Health 2003–2004 was used to determine the prevalence of caregiving stress in the US. It was reported that households in which caregivers had emotional support had lower levels of caregiving stress than those without (Raphael et al., 2010).

The complex care regimens caregivers are faced with in the care of their child with FSD may result in caregivers questioning their capabilities and competence as mothers when they may be required to feed their child enterally instead of orally and experiencing feelings of frustration (Anderson et al., 2001; Hewetson & Singh, 2009; Pedersen et al., 2004). The majority of caregivers, especially mothers, associate successful feeding with feelings of competency and are therefore prone to placing blame upon themselves for their child's inability to feed and failure to thrive, despite their best efforts, which may result in anxious caregivers who experience a sense of failure (Andrew et al., 2012; Andrew & Sullivan, 2010; Batchelor, 2007; Besser, 2018; Cowpe et al., 2014; Craig, 2013). This may consequently lead to self-doubt, and feelings of rejection and place further additional stress on caregivers (Auslander, Netzer, & Arad, 2003). The increased stress and anxiety caregivers experience in relation to feelings of blame, failure and self-doubt may result in reduced emotional QoL (Lowes et al., 2016).

The overall emotional concern caregivers experience in caring for their child with FSD has an impact on their QoL, frequently reducing it (Lowes et al., 2016). There is a ripple effect on the family system, marriage, siblings and extended family relationships, as caregivers experience a range of emotions (Anderson et al., 2001; Lutz, 2012). The demanding treatments for children with FSD are noted to negatively impact family functioning (Cousino & Hazen, 2013). Marital relationships are either strengthened or negatively impacted by the involvement of caregivers, or lack thereof, in the care of a child with FSD (Hewetson & Singh, 2009). Positive family functioning has the potential to improve caregiving stress (Raphael et al., 2010). Some mothers may feel that their spouse is not providing enough emotional support which may result in disagreements (Swift & Scholten, 2010). In addition, arguments between caregivers of children with FSD often occur due to different opinions about invasive interventions, worsening health and setbacks in feeding (Lutz, 2012). Increased anxiety and depression in caregivers may result in reduced marital satisfaction (Lowes et al., 2016). This could subsequently affect the emotional QoL of caregivers as a lack of mutual support from partners contributes to strain between couples (Swift & Scholten, 2010).

The social aspects associated with the care of children with FSD are not frequently explored, despite the time commitments and treatment responsibilities caregivers are required to perform (Azios et al., 2016; Pedersen et al., 2004). Due to the increased demand of responsibilities, caregivers have a reduced amount of time available for their personal activities (Hewetson & Singh, 2009; Pedersen et al., 2004). Caregivers may feel as though they are no longer able to participate in social activities as their child's FSD may not be socially accepted. For example, messy eating, feeding intolerance and enteral feeding within usual social settings, such as restaurants, may not be suitable as feeding is challenging and stressful (Andrew et al., 2012; Craig, 2013; Mahant et al., 2011). The lack of time caregivers have for social interactions and activities may result in these caregivers feeling isolated which may subsequently contribute to a reduced QoL. In addition caregivers may feel misunderstood by other caregivers, family and friends, as children with FSD are frequently set apart due to their dietary requirements (Azios et al., 2016; Lutz, 2012). Furthermore, caregivers of children with FSD may feel judged by others and stigmatised in social settings when they receive uncomfortable glances, stares and are often asked intrusive questions about their child (Lutz, 2012; Mahant et al., 2011). Stigma may result in caregivers hiding feeding tubes and equipment when in public or avoiding leaving home with a child that is enterally fed (Mahant et al., 2011). These experiences frequently occur in a variety of contexts and may affect social participation, causing caregivers to adapt their environment as well as their lifestyle to accommodate their child's FSD which may subsequently lead to self-isolation and negatively affect the QoL of the caregivers (Balling & McCubbin, 2001; Batchelor, 2007; Craig, 2013; Hewetson & Singh, 2009; Mahant et al., 2011).

The adaptations caregivers are required to make to their lives as they care for their child with FSD may result in these caregivers requiring support as they adjust to the care of their child. Due to the additional burden and subsequent caregiver stress, these caregivers may benefit from various forms of caregiver support, formal and informal, depending on their specific needs.

2.2.3 Caregiver support needs

Support for caregivers of children with FSD is essential as it can reduce stress and improve QoL (Charpentier, Morgan, & Harding, 2020; Swift & Scholten, 2010). Addressing caregiver goals and expectations, their perceptions, obtaining clarification and the provision of interventions and support needs regarding their child's FSD all contribute to the reduction of caregiver stress levels (Garro et al., 2005). Professional support in the form of services, education, information and training, psychological counselling as well as informal support are reported to reduce caregiver stress related to caring for a child with FSD. Satisfaction with the support provided from professionals was described as a contributing factor to caregivers' ability to cope with their stress related to the care of their child (Franklin & Rodger, 2003).

2.2.3.1 Professional support

Caregivers identified professionals as important in their lives as well as the life of their child with FSD. Therapists play a vital role in the support provided for families and facilitate the best possible outcome for a child with FSD (Brett, 2002). Families therefore valued positive working relationships between themselves and the professionals and expressed their desire for a partnership with the professionals involved in the care of their child with FSD (Brett, 2002; Cowpe et al., 2014). Supportive relationships enable caregivers to learn the necessary skills and seek advice from professionals in caring for their child (Bond & Moss, 2003). However, some caregivers have reported insufficient professional support (Lutz, 2012) and support that does not address the long term needs and future plans of children with FSD, or caregivers' fears, resulting in them feeling undervalued (Azios et al., 2016). These barriers to support may cause caregivers to feel oppressed by their child's impairment (Brett, 2002) and experience high levels of anxiety, frustration, distress and feelings of being unheard (Cowpe et al., 2014). Providing support for caregivers of children with chronic health conditions is beneficial (Hsiao, 2018) and when caregiver support needs are met with contextualized support, the experience of stress is decreased and the QoL of caregivers is improved (Azios et al., 2016; Garro et al., 2005). Caregivers would therefore appreciate relevant and appropriate support in the form of services, education, information, and training as well as psychological counselling as they care for their child with FSD as summarised in Table 2.

TABLE 2: CAREGIVER SUPPORT NEEDS

Caregiver support needs	
Professional support	- Accessibility to services - Education, information, and training - Professional qualities i.e., communication - Psychological counselling
Informal support	- Peer support - Additional carers for child

2.2.3.1.1 Services

Access to suitable and opportune FSD management is essential for the child and their family (Raatz et al., 2020). However, time, staffing and flexibility of service delivery for a child with FSD are three concerning factors caregivers mentioned surrounding their ability to access services (Cowpe et al., 2014). There are frequent appointments to attend due to the complex care regimen of children with FSD and they are seen by a team of professionals (Craig, 2013; Sloper & Turner, 1992), including gastroenterologists, SLTs (Andrew & Sullivan, 2010) mental health professionals (Bryant-Waugh et al., 2010) such as paediatric psychologists (Fischer & Silverman, 2007), paediatricians and dieticians (Rybak, 2015). Once discharged from the hospital caregivers have reported difficulties accessing all

these services (Besser, 2018; Lutz, 2012). Furthermore, the number of professionals required to see a child with FSD may be overwhelming for caregivers (Craig, 2013) as well as the lack of integrated services that places an additional demand on caregivers. For professionals to provide family-centred care effectively they need to be aware of the potential stressors families experience (Swift & Scholten, 2010).

Caregivers have reported difficulties accessing services which may affect the care a child with FSD receives (Lutz, 2012) as services required for FSD are frequently provided at specialised facilities or tertiary institutions which are usually in urban areas (Raatz et al., 2020). Caregivers found it difficult to travel to hospital visits due to distance, the disruption of family life, transport complexities and fear of infection in the hospital (Mahant et al., 2011). It was also reported that scheduled meeting times at the hospital often clashed with their already set feeding schedules and that staff were insensitive to their stress and scheduling concerns (Swift & Scholten, 2010). Services for children with FSD should be coordinated to ensure that patients attend as few appointments as possible, which reduces the stress and travel for caregivers, which will likely reduce the risk for missed appointments (Raatz et al., 2020).

2.2.3.1.2 Professional qualities

It is beneficial for professionals to be empathic towards caregivers of children with FSD, as they have to deal with the stress of having a child with a chronic condition as well as the complex care regimens (Sabzevari & Nematollahi, 2016). Professionals should consider the work commitments of caregivers and feeding schedules of children. A collaborative approach to the care of a child with FSD was an important factor for caregivers (Lutz, 2012) and they therefore appreciate proactivity from the multidisciplinary team (MDT) regarding their various needs including emotional and physical health requirements (Cowpe et al., 2014). The interdisciplinary and multidisciplinary approach is beneficial in the management of children with FSD as it encourages co-ordination between professionals ensuring adequate focus on the child, in conjunction with their caregivers (Rybak, 2015) as well as meaningful intervention for both the child and their caregivers; it also encourages generalisation of the therapy in a home environment (Dodrill, 2014).

Caregivers have reported unequal power relationships between themselves and the professionals involved in the care of their child (Brett, 2002). Caregivers feel that professionals believe that they are the experts and “know best”, and as such caregivers may experience feelings of disempowerment as professionals “take charge” of the child’s health care while the caregivers become passive partners in the care of their child (Brett, 2002; Hewetson & Singh, 2009). A comprehensive history including the description of family feeding management and perceptions of

the family and of the diagnosis of FSD, will provide a foundation for the development of appropriate interventions (Estrem et al., 2018).

Some caregivers report their feelings, opinions or preferences were not valued by the health care professionals (Lutz, 2012), and therefore, they appreciate professionals who value their concerns and listen to their opinions on the care provided for their child with FSD (Stoner et al., 2006). Caregivers often feel they had little to no input in the decision making surrounding the care and services their child receives (Brett, 2002). Stoner et al. (2006) noted that caregivers felt frustrated when their concerns were dismissed by professionals; they felt disregarded when receiving recommendations from their MDT about the appropriateness of management and treatment of their child's FSD (Craig et al., 2003). Comprehensive health care for children with chronic medical conditions is essential, and should focus on caregiver well-being, family relationships and optimal child health outcomes (Anderson et al., 2001).

2.2.3.1.2.1 Communication

Caregivers appreciated open and honest communication between themselves and the professionals involved in the feeding management of their child with FSD (Stoner et al., 2006). Decisions made surrounding alternative methods of feeding such as long term enteral feeding should be discussed with the family as the feeding methods are complex (Azios et al., 2016). The involvement of caregivers in the management plan of children with FSD is vital for the advancement of proper feeding (Besser, 2018; Swift & Scholten, 2010). The therapist should be sensitive to the needs of the child and family, and aim to empower the family to manage their child's FSD confidently as caregivers hold the key to accessing the experiences of their child and are able to provide insight into the world of their child and their needs (Brett, 2002; Starr, 2006). Considering family views is essential as the majority of healthcare aims to reduce symptoms, minimise disability and improve QoL, aspects which only patients and their families can assess (Black, 2013). The majority of the care burden falls on the family of the child with FSD and they are therefore vital for any or all decisions regarding the care of the child.

Cowpe et al. (2014) found parents noted that poor communication created barriers between parents and their child's MDT and emphasized the need for effective communication within the team, which should include caregivers in the decision-making process. This notion was supported in a study by Craig et al. (2003) as not all professionals were in accord regarding their recommendations surrounding oral feeding in a child with FSD, which may subsequently affect relationships between caregivers and their MDT.

There have been reports from caregivers that the lack of communication in their child's MDT had an impact on their well-being and subsequently the well-being of their child (Cowpe et al., 2014; Lutz, 2012). The well-being of these caregivers is affected through their innate responses to barriers they experience. These responses frequently include elevated anxiety levels, frustration as well as feelings of being unheard by their child's MDT (Cowpe et al., 2014). Poor collaboration and/or communication between team members caring for a child with FSD may subsequently lead to distrust, frustration and stress (Lutz, 2012). Part of what caregivers experience is feelings of being unheard and/or undermined in the care provided for their child which may cause stress (Cowpe et al., 2014).

Caregivers appreciate those professionals that listen to them and value their opinions (Batchelor, 2007; Cowpe et al., 2014). The involvement of caregivers in the treatment process of FSD is important to ensure caregivers feel understood, supported and invested in the diagnosis and management of their child's condition, thus influencing the caregiver's trust of the healthcare providers (Cowpe et al., 2014; Wu et al., 2012). It is essential to empower caregivers, encouraging them to contribute to the care of their child (Brett, 2002) and although caregivers value the knowledge professionals provide on the care of their child they preferred to be acknowledged as the expert on their child (Cowpe et al., 2014). Health care practitioners are encouraged to reassure caregivers that they are part of the solution to the feeding challenges of their child (Rogers, 2004). For example, caregivers can be encouraged to spend special/bonding time with their child in various other activities, such as bathing, play and bedtime routines (Craig, 2013). These caregivers may benefit from advice surrounding mealtime management in the family context as caregivers frequently report their desire for family meals and eating together and tube-feeding becomes a barrier, as mealtimes provide opportunities for conversation, inclusion and participation (Craig, 2013).

2.2.3.1.2.2 Education, information and training

Caregivers require education, information and training to ensure they are able to provide their child with adequate care in the home environment. These caregivers benefit from education as they are required to learn new skills in the care of their child with FSD and when professionals fail to provide credibility and understanding to these caregivers, it may be an added source of stress and confusion (Brett, 2002). Caregivers of children with FSD expressed frustration when professionals provided inaccurate prognoses for their children, informing caregivers that their child will never advance to oral feeding causing caregivers to relinquish cherished dreams that they have had about their child (Stoner et al., 2006). Enteral feeding is often considered a supplement to oral feeds and the caregivers of children fed enterally required considerable support and education surrounding the

care required for their child (Bond & Moss, 2003; Burdall, Howarth, Sharrard, & Lee, 2017; Starr, 2006). Caregivers may feel reluctant to accept advice from professionals regarding their child's ability to feed orally and while they may agree to tube feed their child, they may not be convinced about its full potential and still prefer to feed their child orally (Craig et al., 2003).

Caregivers may feel as though they do not receive adequate information surrounding the care they are required to provide for their child with FSD. It is essential to provide caregivers with sufficient and relevant information as they struggle to comprehend the swallowing mechanism, their child's FSD and the rationale for adaptive or enteral feeding (Hewetson & Singh, 2009). Caregivers should be provided with post-discharge information regarding their child's feeding in the home environment (Hewetson & Singh, 2009). Information sharing, identifying a need for up-to-date, jargon free information was an aspect caregivers appreciated in professionals which maximised their understanding and involvement in the care of their child with FSD (Cowpe et al., 2014). Positive experiences with healthcare professionals and their expert knowledge contributed to an increase in the caregiver's knowledge surrounding their child's FSD (Cowpe et al., 2014). Education of caregivers may assist in reducing their stress (Hsiao, 2018).

The manner in which information is provided to caregivers affected the ability of caregivers to cope with their new role in the home environment (Hewetson & Singh, 2009). Members of the MDT should communicate with each other and the caregiver, asking them how they experienced previous suggestions, before making new suggestions or changing the intervention (Swift & Scholten, 2010). This emphasises that the information caregivers receive surrounding the care of their child and the management in the home environment should be clear and consistent across disciplines as conflicting or differing perspectives and aims between professionals and caregivers may exacerbate already stressful circumstances (Rouse, Herrington, Assey, Baker, & Golden, 2002) which may also lead to distrust (Lutz, 2012).

Some tasks caregivers are expected to perform on their child are uncomfortable or painful (Sabzevari & Nematollahi, 2016), therefore ongoing support should be provided to caregivers to assist in the implementation of feeding plans and the improvement oral feeding (Bond & Moss, 2003). Information and training should also be provided constantly to ensure the follow-up of care as or when the child improves. Caregivers of children who are fed enterally are particularly concerned about the normalisation of feeding, mothering and the development of their child (Petersen, Schmidt, & Bullinger, 2006). Some caregivers may feel that eating orally provides the child with pleasure as they are able to explore tastes in the oral cavity (Craig, 2013). Caregivers of children who had undergone open heart surgery, reported professionals did not create plans or goals to

improve the child's FSD or to remove their feeding tube (Tregay et al., 2017). It is thus vital for the therapist to assist caregivers in providing meaningful and therapeutic input that will assist caregivers in providing pleasure and movement in and around the mouth of their child during tube feeds such as massage, kissing, touching and taste exposure for children who are fed enterally (Craig, 2013; Starr, 2006).

Caregivers should be enabled in the management of home-based care instead of simply being expected to cope with the emotional and practical components of care for their child with FSD (Hewetson & Singh, 2009). It is important to ensure that information and guidance is provided to caregivers continually as the child develops and the effect these developmental changes may have on feeding and nutrition (Lutz, 2012; Speyer, Cordier, Parsons, Denman, & Kim, 2018). The manner in which caregivers are trained is also essential as caregivers have reported that their training is rushed (Hewetson & Singh, 2009). When providing information and training, health professionals should avoid the use of words that add to the stress and feelings of incompetency or place blame on caregivers such as 'failure to thrive' and 'malnourished' (Craig, 2013). In Cowpe et al. (2014) caregivers appreciated jargon-free information to ensure they adequately understood the terminology and involvement in the care they are required to provide for their child.

2.2.3.1.2.3 Psychological counselling

All health professionals should identify stressors affecting caregivers of children with FSD to ensure appropriate support and coping strategies are offered (Garro et al., 2005). Support provided for caregivers of children with chronic conditions such as FSD will assist in the reduction of caregiver stress and subsequently improve their QoL (Swift & Scholten, 2010). The support provided by professionals in the form of education and psychological support positively influences caregiver HRQoL (Zelman & Ferro, 2018).

Families of children with FSD often receive inept and disjointed care as the psychological and family aspects of comprehensive care are often excluded (Anderson, 2001). Professionals should be sensitive to the caregivers of children with FSD, as insensitive remarks or behaviour may cause caregivers to feel frustrated and angry (Lutz, 2012).They should also be sensitive to the psychological stressors caregivers of children with FSD may be experiencing (Stoner, 2016). The management of FSD should therefore be guided by principles that include more than the simple medical model and professionals are urged to be sensitive to the needs of the caregivers of children with FSD (Azios et al., 2016; Stoner et al., 2006). This is vital and can be used to reduce their stress to assist in optimizing outcomes for their children with FSD (Hsiao, 2018).

Kolaitis et al. (2017) found that caregivers of children with chronic health conditions would like to be referred to mental health professionals. Many need psychological support due to them feeling overwhelmed and having some negative emotions (Brett, 2002). Through information training and psychoeducation, the role of caregivers can be strengthened in the care of their child and caregivers can receive psychological support for the stress and burden of care they may be experiencing (Kolaitis et al., 2017).

2.2.3.2 Informal Support

In addition to professional support, caregivers have identified that informal support such as family support and caregiver-to-caregiver support, such as support groups, is helpful and empowering (Cowpe et al., 2014). Mothers of children with a chronic condition or illness may have difficulties in their social and personal lives (Sabzevari & Nematollahi, 2016) and lack of support contributed to the caregiver's feeling of stress (Winston et al., 2010). Support improves and reduces the level of stress caregivers experience, but it is not always readily available (Swift & Scholten, 2010).

Professionals should be encouraged to assist caregivers in accessing support groups and counselling groups (Hsiao, 2018), as social support has a positive impact on caregivers as well as families of children (Robinson, Weiss, Lunsky, & Ouellette-Kuntz, 2016). Social support refers to the material and psychological resources caregivers find available to them through their interpersonal relationships which may prevent or mitigate stressful situations (Lima et al., 2016). Support groups provide caregivers with the opportunity to share with other caregivers and have caregiver-caregiver interactions that many appreciate as health professionals often do not have first-hand experience in caring for a child with a chronic condition.

Aside from caregivers having difficulty in the social context, they find co-ordinating the care of their child with FSD, challenging (Estrem et al., 2018). Caregivers find it difficult leaving their child in the care of others due to the amount of meticulous care needed to care for their child with FSD (Anderson et al., 2001). They are often concerned others will be incapable of addressing the mealtime difficulties of their child (Andrew & Sullivan, 2010; Craig, 2013). It can be difficult to find someone suitable to care for a child with FSD (Anderson et al., 2001; Murphy, Christian, Caplin, & Young, 2007), as carers, babysitters and other family members are often not fit or capable to care for a child with specific needs or prepare foods in a very particular way (Winston et al., 2010). The lack of additional carers and the mistrust caregivers have in others caring for their child, makes it difficult for caregivers to leave home (Mahant et al., 2011). These feelings impact on the psychological stress caregivers experience in the care of their child with FSD as positive family support and functioning aids in the improvement and reduction of caregiving stress (Raphael et al., 2010).

2.3 Measuring HRQoL

Measuring HRQoL or coping strategies of the caregivers of children with FSD is helpful in identifying stresses and support needs and allowing clinicians to provide appropriate support, not only for FSD, but to support needs of caregivers. FSD-related studies commonly focus on the QoL of the child (Heidemann et al., 2014). It is essential to investigate how satisfied caregivers are with the healthcare they are provided with particularly in hospital settings. This typically includes how satisfied caregivers are with the information they have received with regards to their child's condition (Sigurdardottir, Garwick, & Svavarsdottir, 2017). Exploring the impact of the dysphagia on family stress and HRQoL will contribute to the research field as these aspects have been underrepresented in the literature (Garro et al., 2005). Research in this field will assist with early detection, intervention and the implementation of appropriate management of these children and the provision of the necessary services to their caregivers (Lefton-Greif et al., 2014).

Caregivers of children with FSD experience high levels of stress that subsequently impact their HRQoL. Taking the accounts and the meanings caregivers associate with feeding into consideration can provide vital information on how best healthcare practitioners can provide support (Craig, 2013). Through determining the HRQoL of caregivers, clinicians would be able to identify those caregivers in need of additional support in the care of their children with FSD, thus improving the care provided to these children (Lefton-Greif et al., 2014). Tools can be used to assess the HRQoL of those affected by health-related stressors (Slattery et al., 2011) such as patient reported outcomes (PROs). PROs are measures that aid in patient (or caregivers) decision-making processes and create awareness of their needs for health professionals (Anthoine, Moret, Regnault, Sebille, & Hardouin, 2014). The concept of PROs can be used for caregivers of children with FSD. It is essential that clinicians are able to interpret and use the results obtained from surveys and questionnaires (Slattery et al., 2011).

For a clinician to determine the best tool to use in a clinical setting, they need to be able to select a tool that has been validated, and that has been proven to measure what it intends to measure (Spittle, Doyle, & Boyd, 2008)., Questionnaires/tools should be straightforward, efficient and specific for the target population (Speyer, Kertscher, & Cordier, 2014). Several stress measures exist that evaluate the stress and HRQoL of caregivers of children with chronic conditions including FSD, for example the Parenting Stress Scale (PSS), which is an 18-item scale that focuses on the perception of caregiving stress and the impact children with chronic conditions have on the caregiving role (Zelman & Ferro, 2018). However, unlike the FS-IS, the PSS is not specifically related to caregivers of

children with FSD and assesses the general stress caregivers experience as they care for their children. It was therefore not appropriate for use in this study.

The FS-IS, designed in the US, used data of 164 caregivers of children with dysphagia in the validation process (Lefton-Greif et al., 2014). It is an instrument aimed at assisting clinicians in the identification of factors that may impact the HRQoL of primary caregivers of children with dysphagia (Lefton-Greif et al., 2014). The FS-IS results were correlated with the results obtained on the Paediatric Quality of Life Inventory Family Impact Module (PEDS-QL FIM) to determine concurrent validity (Lefton-Greif et al., 2014). Although the FS-IS has been validated for use in the US, little information is available for similar tools in the South African context that measure the HRQoL of caregivers of children with FSD. Therefore, tools may need to be translated, validated and cross-culturally adapted for the context.

While Hewetson and Singh (2009) completed a study describing the daily experiences of caregivers of children with FSD in South Africa, there has not yet been a study conducted to validate a tool to use for these caregivers. Determining the HRQoL of primary caregivers will be advantageous in the South African context as the study completed by Hewetson and Singh (2009) established that caregivers and families of children with FSD would benefit from family-centred intervention. The cross-cultural adaptation and validation of the FS-IS in South Africa creates a bridge between the availability of tools used to determine the HRQoL of caregivers of children with FSD as well as the need for additional interventions.

2.4 Cross-cultural adaptation of tools

Beaton, Bombardier, Guillemin, and Ferraz (2000) and Slattery et al. (2011) provide guidelines including recommended steps for the cross-cultural adaptation of tools. These stages include translation, synthesis of translation, expert committee review, the submission of documentation as well as pre-testing; these stages can be adapted for various contexts. The initial translation of a tool into a target language should include a forward translation, synthesis of the translations by translators discussing any discrepancies between translations followed by back translation (Beaton et al., 2000). Back translations create an opportunity for validity checking assisting with discrepancies, inconsistencies or errors that may have occurred in the translation process (Beaton et al., 2000).

Guidelines provided for an expert committee include semantic, idiomatic, experiential, and conceptual equivalence. Semantic equivalence refers to the meaning of the words used within the tool; grammatical alterations are necessary to ensure the desired meaning is carried over (Beaton et

al., 2000). Conceptual equivalence refers to the validity of the concept that is to be explored; as the concepts may not be carried over from the culture of origin into the target culture(Beaton et al., 2000). Hereafter, pre-testing or pilot testing is recommended using the translated tool and is ideally administered on a separate group of participants other than those who participated in data collection (Beaton et al., 2000; Slattery et al., 2011). When validating a tool for another context, such as South Africa, it is beneficial to follow these guidelines to ensure that the translated versions of the original tool is contextually relevant for the context in which it is intended to be measured.

The validation of a tool ensures that it measures what it was intended to measure (Epstein et al., 2015). It is important to validate tools in the context in which they will be used, guided by the context in which the construct is being measured (Dekker et al., 2005). The process of cross-cultural adaptation involves the measurement of the same/equivalent phenomenon in different cultures. It is conducted to explore the same/equivalent question in the respective cultures as it considers the differences between the original culture and the target culture and aims to maintain equivalence in meaning (Epstein et al., 2015; Ruperto et al., 2000). The adaptation of a tool can be problematic as the adaptation can have very different meanings due to non-equivalent words or idiomatic expressions. For example, the translation of the English word “difficult” could be translated to the Afrikaans “delikaat” or “lastig” or “moeilik” or “opdraand” or “swaar” which may not elicit the same answer or response when used. Therefore, questionnaires that are intended to be used in a different culture, should be translated and adapted to that context (Epstein et al., 2015; Padua, 2003). This type of adaptation is required when the target population differs from the original population (Geisinger, 1994; Pascoe & Norman, 2011) as it seeks to ensure that reliable instruments may be obtained for use in different countries despite differing socio-economic conditions, religion, weather, electricity and varying stages of social development (Pascoe & Norman, 2011; Ruperto et al., 2000).

Mealtimes can be complex rituals full of cultural and social significance as families eat together and share food (Adams, Verachia, & Coutts, 2020). These mealtimes provide opportunities for social interactions and expressions of both individual as well as family identity (Lam & Keller, 2015) as each family will have their own routines surrounding mealtimes (Adams et al., 2020). The comprehensive feeding practices questionnaire (CFPQ) by Musher-Eizenman and Holub (2007) was used to measure parental feeding practices and was cross-culturally validated and adapted for use in Brazil by Mais et al. (2015). It was found that the cross-culturally validated and adapted version of the questionnaire contained slight modifications most likely due to cultural differences. The adaptation project addresses the complexities surrounding the cultural components of mealtimes and the varieties

between cultures. These differences may also play a role in the manner in which caregivers address FSD.

Adapted versions of questionnaires (or other tools) should be evaluated according to basic measurement properties such as reliability and validity (Grotle, Brox, & Vollestad, 2003). A well translated and culturally adapted questionnaire maintains the content validity of the original instrument across different cultures (Beaton, Bombardier, Guillemin, & Ferraz, 2002). For example the study completed by Arslan et al. (2018), measuring the reliability and validity of the Turkish version of the FS-IS, found the translated and adapted version to be reliable and valid, and the tool could therefore be applied in the clinical setting. Cross-cultural adaptation also aims to ensure consistency in the content and face validity between the original and target versions of the original tool (Beaton et al., 2000).

Translation is the single process of producing a document in the target language from the source language (Epstein et al., 2015). When translation focuses solely on the linguistic translation it does not automatically provide a valid measure of another culture's health, and this should be verified carefully as this may threaten the content validity (Beaton et al., 2000; Bornman, Sevcik, Romski, & Pae, 2010) and is not sufficient in ensuring that the tool is contextually and culturally appropriate (Pascoe & Norman, 2011). Simple forward and back translations may not take ways of expression from the target culture into consideration (van Widenfelt et al., 2005) and are not sufficient in the adaptation of a tool, because of language and cultural differences (Guillemin, Bombardier, & Beaton, 1993; van Widenfelt et al., 2005). It is important to translate, validate and cross-culturally adapt tools to make them valid in a different culture (Beaton et al., 2000) as only focusing on the linguistic translation may threaten the content validity of a tool (Bornman et al., 2010).

Cross-cultural adaptation and validation of the FS-IS in the South African context will allow professionals to use this tool to determine the HRQoL of caregivers of children with FSD. Professionals will be able to identify the factors that need to be addressed with regards to the difficulties caregivers experience in caring for children with FSD; and therefore, provide appropriate and effective treatment in the management of these patients. Clinicians need to have access to tools that have been validated and proven to measure what they set out to measure (Spittle et al., 2008). To date there is no valid or reliable tool available in the South African context for evaluating HRQoL of caregivers of children with FSD.

2.5 Contextually relevant resources in South Africa

South Africa has a multicultural and multilingual population which can impact the outcomes of assessments (Bornman et al., 2010) if these assessments or tools are not cross-culturally adapted

and validated for the context. Tools developed for other countries may need adaptation (Carter et al., 2005). For data to be relevant the context should be taken into consideration (Naidu & Sliep, 2011). A challenge faced in the healthcare setting is the lack of culturally relevant resources in the South African context (Pascoe, Rogers, & Norman, 2013). Researchers have not yet embarked on the cross-cultural adaptation process in South Africa related to the HRQoL of caregivers of children with FSD.

The studies completed by Smit, Van den Berg, Bekker, Seedat, and Stein (2006), Morris, Grimmer-Somers, Louw, and Sullivan (2012), Tuthill et al. (2014) and Bresick, Sayed, le Grange, Bhagwan, and Manga (2015) followed the process of cross-cultural adaptation of various instruments for the South African context. Each instrument was translated using the forward-back translation process. Experts, or expert committees and user focus groups or informal discussions with key members of the community were used to ensure semantic equivalence of the translated versions.

Smit et al. (2006) described the process of cross-cultural adaptation of a mental health battery for South Africa: The Center for Epidemiology Depression Scale (CES-D) to measure depression, The Alcohol Use Disorders Identification Test (AUDIT) to measure alcohol use disorders and the Harvard Trauma Questionnaire (HTQ) to measure Post-traumatic Stress Disorder (PTSD). These tools were translated from English to isiXhosa. A committee consensus meeting was held by a group of bilinguals in which any discrepancies were discussed during the translation process.

Morris et al. (2012) cross-culturally adapted and validated the South African PCS (SA-PCS) among English, Afrikaans and isiXhosa speaking patients with fibromyalgia living in Cape Town, South Africa. The cross-culturally adapted versions showed good face and content validity, internal consistency as well as test-retest reliability, and the SA-PCS is therefore considered a simple, efficient, valid, and reliable tool. However, it was noted that the adaptations and validation of the tool may not be acceptable for other English, Afrikaans and isiXhosa speaking ethnic groups in the rest of South Africa, as the SA-PCS was adapted and validated for the Western Cape region.

Another example of a cross-culturally adapted tool is the Iowa Infant Feeding Attitudes Scale (Breastfeeding Self-Efficacy Scale-Short Form) which was cross-culturally adapted in August 2012 by Tuthill et al. (2014) in Kwazulu-Natal, South Africa. It was found to be culturally relevant and maintained content validity and semantic equivalence of the target version. A challenge described by Tuthill et al. (2014) in the adaptation of the chosen tool in their study was item development – not applicable to the cross cultural adaptation and validation of the FS-IS in the SA context. Items were developed to capture context specific themes identified by researchers through extensive research as well as qualitative data analysis of qualitative reports from caregivers within the target

context. Item development is required to address a deficiency in content in a particular tool (Tuthill et al., 2014). The original FS-IS addressed the areas of concern typically identified in literature as common concerns caregivers of children with FSD may experience as they provide the necessary care for their child, therefore it was not imperative to develop novel items for the FS-IS in the South African context.

Culturally relevant resources are essential in the healthcare setting of South Africa and the translation, validation and cross-culturally adapted HRQoL resources would be beneficial for SLTs to use in this context to measure the HRQoL of caregivers of children with FSD. The processes used by these studies and the guidelines suggested by Beaton et al. (2000) informed the process used to translate and cross-culturally validate the FS-IS for the South African context. In addition, this study also included a pilot study as suggested by Beaton et al. (2000).

2.6 The Feeding and Swallowing Impact Survey

The FS-IS (Lefton-Greif et al., 2014) can be used to measure the care provided in the FSD population as well as the effects of care on the HRQoL of caregivers. The FS-IS used data of 164 caregivers of children with dysphagia in the validation process (Lefton-Greif et al., 2014). The results were correlated with the results obtained on the PEDS-QL FIM to determine concurrent validity (Lefton-Greif et al., 2014). Concurrent validity was obtained which indicates that the HRQoL of caregivers was impacted by caring for children with FSD (Lefton-Greif et al., 2014). The FS-IS was subsequently administered by Fracchia et al. (2017) to the caregivers of 35 children with laryngeal clefts and aspiration at the Pediatric Aero-digestive center in Boston, US. The study concluded that the FS-IS is a valid instrument that can be used in assessing the improvement in FSD after laryngeal repair and the effects of the FSD on the caregivers of these children.

The challenges related to contextually relevant resources are not unique to the South African context (Pascoe et al., 2013). The FS-IS has been translated and adapted for use in the Turkish language. The FS-IS was translated using the forward, backward, forward translation method and 117 caregivers of children with CP and some form of dysphagia were included in the study (Arslan et al., 2018). The internal consistency, reliability, construct and discriminant validity of the T-FS-IS was measured and found to be a reliable and valid instrument to measure the impact of swallowing disorders of children with CP on their caregivers (Arslan et al., 2018). Arslan, Demir, Karaduman, Tanyel, and Soyer (2019) used the T-FS-IS to assess the concerns of caregivers of children with oesophageal atresia-tracheo-oesophageal fistula (OA-TOF) related to feeding-swallowing difficulties. It was found that caregivers of these children experience an additional burden in caring for their child with OA-TOF and feeding concerns and established the validity of the T-FS-IS.

It is important to validate the FS-IS in the context of South Africa as selecting a tool to assess the HRQoL should be guided by the context in which the construct is being measured (Dekker et al., 2005). Validating and cross-culturally adapting the FS-IS in South Africa will allow for professionals to use this tool to determine the HRQoL in this context, while taking linguistic and cultural diversity into account. Professionals will be able to adapt their intervention to ensure that treatment is appropriate and effective for the family (Feinstein, 1983; Lefton-Greif et al., 2014; Turner-Stokes, Williams, & Siegert, 2010), thus benefitting and improving the quality of patient care (Dekker et al., 2005).

The FS-IS is a useful tool to use in the South African context to assist with the identification of caregivers with reduced HRQoL, requiring additional support in their care with their child with FSD. There is no tool currently available to determine the HRQoL of caregivers of children with FSD in the South African context, therefore the adaptation and validation of the original FS-IS will benefit caregivers and provide health care professionals with insight into the needs of the caregivers attending their sessions.

3 Methodology

3.1 Aims and Objectives

Aim: To adapt the FS-IS (Lefton-Greif et al., 2014) for a South African context, and pilot it with caregivers of children with dysphagia.

Objectives:

1. To describe the content validity of the FS-IS in a South African context.
2. To describe the cultural and linguistic appropriateness of the English, isiXhosa and Afrikaans versions of the FS-IS.
3. To describe the experiences of caregivers of children with feeding and swallowing difficulties, related to stress and coping, using the adapted FS-IS.

3.2 Research design

A descriptive exploratory research design was used in this study. A descriptive research design outlines characteristics of a population (Tredoux & Smith, 2006). However, the aim was to develop a cultural and linguistically relevant version of the FS-IS to be used in the South African context, as generalisability is an important part of the descriptive design (Tredoux & Smith, 2006). In order to conduct the study, the FS-IS needed cross-cultural adaptation for the South African context, the steps taken to conduct the cross-cultural adaptation were described by Beaton et al. (2000) and included 1) expert review, 2) translation 3) establishing cultural and linguistic appropriateness of the translated versions of the FSIS followed by 4) a pilot study using the cross-culturally adapted and validated FS-IS in the South African context.

This research design focuses on measures of central tendency as well as variability (Colorafi & Evans, 2016). A descriptive design is used to describe the nature of the information and the relationships between variables (Du Plooy, 2009; Leedy & Ormrod, 2005). The descriptive exploratory design was used to investigate the ideas and experiences of the caregivers of the children with dysphagia (Terre-Blanche, Durrheim, & Painter, 2006). The HRQoL of caregivers of children with FSD is described in a South African context.

An exploratory design was chosen to encourage the exploration and description of phenomena that have little to no investigation, as this design yields qualitative information (Durrheim, 2006). The exploratory design allows for in-depth investigation into the HRQoL of caregivers of children with dysphagia, as there is a limited amount of information available surrounding this phenomenon (Terre Blanche, 2006; Willig, 2008).

A standardised set of guidelines should be used for the cross-cultural adaptation of HRQoL measures (Grotle et al., 2003; Guillemin et al., 1993). To be successful a systematic approach was required to the translation and cross-cultural adaptation process of HRQoL measures (Guillemin et al., 1993). The guidelines for cross cultural adaptation consist of five stages described by Beaton et al. (2000) and Slattery et al. (2011). These stages include translation, synthesis of translation, expert committee review, the submission of documentation as well as pre-testing.

3.3 Study location

The research sites included two tertiary level hospitals, Red Cross War Memorial Children's Hospital (RCWMCH) and Tygerberg Hospital (TBH), in the Western Cape, which have SLT departments that provide services to children with FSD and their families. These sites were ideal due to the large catchment areas, thus ensuring optimal chances of recruitment to the study**.**

3.4 Research process

Ethics approval was obtained from the University of Cape Town Faculty of Health Sciences' Human Research Ethics Committee (HREC: 049/2018; Appendix A) before the study began. The research was conducted in 4 main phases and Table 3 provides an overview of the research process followed.

TABLE 3: OVERVIEW OF RESEARCH PROCESS

Overview of Research Process

	Objective	**Participants**	**Procedure**	**Beaton Guideline** (Beaton et al., 2000)
Phase 1	To describe the content validity of the FS-IS in a South African context.	Five experienced SLTs in South Africa, working with children with dysphagia	Expert review of FS-IS for SA context 1. Consent to participate in the study (See Appendix A) 2. Participants were given a questionnaire to complete (See Appendix B)	Expert Committee Review
Phase 2	Translate the FS-IS		1. Translation of the FS-IS into Afrikaans and isiXhosa	Translation/Synthesis of translation
Phase 3	To describe the cultural and linguistic appropriateness of the English, isiXhosa and Afrikaans versions of the FS-IS	Caregivers of children with dysphagia (n=15). (Five English, five isiXhosa and five Afrikaans)	Key informant (caregiver) feedback on cultural and linguistic appropriateness of translated FS-IS 1. Consent to participate in the study (See Appendix C) 2. The researcher and research assistant assisted the participants during the completion of the questionnaire (See Appendix D)	Cross-cultural and linguistic appropriateness
Phase 4	To describe the experiences of caregivers of children with feeding and swallowing difficulties related to stress and coping.	Thirty-two caregivers of children with FSD, attending the dysphagia clinic at tertiary hospitals in the Western Cape	Pilot study with adapted FS-IS 1. Consent was obtained to participate in the study (See Appendix E) 2. The FS-IS was piloted in the three languages (English, isiXhosa and Afrikaans)	Pre-testing

3.5 Phase 1

This phase involved obtaining key informant feedback regarding the content of the FS-IS for the SA context by SLTs.

3.5.1 Participants

3.5.1.1 Selection criteria

SLTs who provided key information regarding the content validity of the FS-IS in the South African context were required to have a minimum of 5 years clinical experience in the field of paediatric FSD in South Africa to ensure that they had adequate experience working with caregivers of children with FSD in the local context.

3.5.1.2 Recruitment strategy

The SLTs were identified by the researcher's supervisor as experts in the field of paediatric FSD in South Africa. These experts needed experience in the context of South Africa as the FS-IS has been validated in the country of origin (US). They were invited to participate and sent the *Consent form for SLT* (Appendix B) and provided informed consent via email.

3.5.1.3 Sampling

Non-probability, purposive sampling was used to select the SLTs. The researcher identified those individuals who met the inclusion criteria of the study (Daniel, 2012). Purposive sampling is a strategy used to focus on those individuals who meet the inclusion criteria and provide the most valuable insight into the research question (Devers & Frankel, 2000). For the purpose of this study, SLTs who worked with the paediatric FSD population were identified.

3.5.1.4 Sample size

Potential SLTs with experience in paediatric FSD were identified and invited to participate in the study as part of the objective to describe the content validity of the FS-IS in South Africa (Gosselin, Bourgault, Lavoie, Coleman, & Méziat-Burdin, 2014). Five SLTs who met the inclusion criteria agreed to participate. According to Lynn (1986, as cited in Hyrkäs, Appelqvist-Schmidlechner, and Oksa (2003), 5 to 10 experts is an acceptable number of experts that should be included in a validity study.

3.5.2 Procedures

3.5.2.1 Step 1

Five experts (SLTs) in the field of dysphagia were recruited by the researcher and her supervisors. Identified experts were contacted via email, provided with information regarding the study and invited to participate. Consent forms were given to each willing participant and completed (Appendix B).

3.5.2.2 Step 2

The *Questionnaire for Experts* (Appendix C) was sent to each participant, along with the FS-IS. The participants were required to return the completed questionnaire to the researcher after a period of one week.

3.5.3 Materials and instrumentation

3.5.3.1 The Feeding and Swallowing Impact Survey (FS-IS)

The FS-IS (Appendix D) is a condition specific tool used to measure the HRQoL of caregivers of children with FSD (Lefton-Greif et al., 2014). This tool consists of 3 subscales which examine the perspectives of caregivers and the effects of their child's FSD on their daily activities, worries related to their child as well as challenges related to the care they provide for their child's FSD. Each subscale consists of items scored with a Likert scale ranging from 1 to 5 indicating "never" and "almost always" respectively. The items within each subscale are averaged and higher scores indicate reduced HRQoL or greater problems (Madhoun, Crerand, O'Brien, & Baylis, 2020). The items of the FS-IS were developed in 3 phases. Phase 1 included content extraction from caregiver input into the feeding/swallowing clinic over a 20-year period. Phase 2 proceeded to review the content of the FS-IS and then consult experts in the field of dysphagia (i.e., SLTs and pulmonary specialists) involved in the care of those children with dysphagia. During the third phase, the items on the FS-IS were grouped into 3 major categories parallel to those subtests on the PEDS-QL test. A 5-point Likert scale is used to assess the responses of the caregivers (Lefton-Greif et al., 2014). In the original study, concurrent construct validity was determined by correlations between the FS-IS and the PEDS-QL FIM by using Pearson correlation coefficients while internal reliability was determined using Cronbach's alpha (Lefton-Greif et al., 2014).

3.5.3.2 Questionnaire for experts

The *Questionnaire for Experts* (Appendix C) was used to determine the content validity of the FS-IS. The questions posed in the questionnaire were designed to evaluate the content of the FS-IS in the SA context. The experts were provided with the opportunity to provide feedback and additional comments.

The *Questionnaire for Experts* (Appendix C) consisted of a checklist with 3 closed-ended questions related to each item on the FS-IS. These questions were used to determine the validity of the content of the FS-IS (i.e., will the FS-IS be successful in the identification of the HRQoL of caregivers of children with FSD in South Africa?). The items included in this questionnaire were based on guidelines by Beaton et al. (2000) and focus on the semantic and conceptual equivalence of the FS-IS in the South African context. Semantic equivalence refers to the meaning of the words used within the tool and conceptual equivalence refers to the validity of the concept that is to be explored, as

the concepts may not be carried over from the culture of origin into the target culture (Beaton et al., 2000).

3.5.4 Reliability and validity

The psychometric properties of reliability and validity were used to validate the FS-IS (Spittle et al., 2008). Internal reliability measures the extent to which causal conclusions can be drawn from collected data (Blanche, Durrheim, & Painter, 2006). Internal reliability was determined by the use of Cronbach's alpha. The internal reliability of the FS-IS in the original study completed in the US, was good with Cronbach's alpha above 0.7 (Lefton-Greif et al., 2014).

3.5.5 Data analysis

Data collected from the experts in this phase of the study was entered into an excel spreadsheet and analysed. Experts provided additional comments if they specifically felt certain items may not be relevant for caregivers. For example, in response to **It is hard for my family to make plans or go out to eat** one expert commented, *not appropriate for parents/caregivers, mostly because in government situations, socioeconomic status is often lower and even the idea of going out is a rare luxury. However, in private sector or amongst more affluent clients, it could be a consideration*. These comments were recorded and reported descriptively as this assisted in the analysis of the suggestions and recommendations made by the participants (Blair & Conrad, 2011). The suggestions and recommendations were addressed if more than 70% of the participants reported that an item should be changed in the translation of the adapted versions (Hyrkäs et al., 2003), so that they were refined and ready for use in the next phases of the study.

3.6 Phase 2

The FS-IS was translated into Afrikaans and isiXhosa following feedback from the SLTs. This phase did not include participants, only translators. Therefore, only a description of the procedures has been included.

3.6.1 Procedures

3.6.1.1 Step 1

Two translators were used as forward translators to translate the FS-IS conceptually into Afrikaans and isiXhosa respectively. The translators were bilingual and their mother tongue was the target language (Beaton et al., 2000). The translators were professionals in the health field.

3.6.1.2 Step 2

To demonstrate the linguistic equivalence of the FS-IS, each forward translation was translated back to the original language (Bornman et al., 2010), independently from one another (Guillemin et al., 1993). Therefore, the FS-IS was then translated back into English from Afrikaans and isiXhosa. This is a process of validity checking, to ensure the translated version reflected the same item content as

the original FS-IS (Beaton et al., 2002). These back translations should reflect the same content and response categories as the original FS-IS (van Widenfelt et al., 2005). Two translators were recruited to complete the translations of the FS-IS back into English without having seen the English version. These translators were first language speakers of the target language (English) but fluent in the other languages and were also from the health field.

3.6.1.3 Step 3

The forward and back translations were then compared, and any discrepancies were examined by the research team, namely, the researcher and her supervisors. The identification of discrepancies between the forward and back translations is important, as these need to be discussed and changes should be made where necessary (Beaton et al., 2000). Once discrepancies were identified, changes were made to the adapted tool.

3.7 Phase 3

Description of the cultural and linguistic appropriateness of the English, isiXhosa and Afrikaans versions of the FS-IS.

3.7.1 Participants

3.7.1.1 Selection criteria

Caregivers of children with FSD attending the feeding clinics at RCWMCH and TBH, were recruited to participate in phase 3 of the study. The caregivers were included on the basis of their attendance at the feeding clinics of the hospitals as the primary caregiver of a child with FSD. It was necessary to include isiXhosa, English and Afrikaans speaking caregivers. Caregivers identified for isiXhosa and Afrikaans were required to be first language speakers of the languages. Caregivers communicating in English were either primary or second language speakers of English, as many patients speak English with their health care providers, despite English not being their first language.

3.7.1.2 Recruitment strategy

Caregiver participants were recruited from the paediatric outpatient feeding clinics at both tertiary institutions, through personal requests from the SLTs at each institution. The SLTs at each institution provided those individuals who met the inclusion criteria with a description of the study and if the caregivers indicated that they were willing to participate, the researcher was informed.

3.7.1.3 Sampling

Non-probability, purposive sampling was used to identify those individuals who met the inclusion criteria of the study (Daniel, 2012). Purposive sampling is a strategy used to focus on those individuals who meet the inclusion criteria and were thought to provide the most valuable insight into the research question (Devers & Frankel, 2000). For the purpose of this study, I focused on

caregivers of children with dysphagia attending feeding clinics at the SLT departments, who were Afrikaans, isiXhosa or English speaking.

3.7.1.4 Sample size

Participants from each language were recruited to determine the cultural and linguistic appropriateness of the questionnaire. Five caregiver participants per language group were sourced, totalling 15 participants (n=15), as this sample size produces substantial improvements in reliability and in the detection of problems (Blair & Conrad, 2011). Smaller samples aid in the identification of draft survey questions (Blair & Conrad, 2011).

3.7.2 Research personnel

The research assistant and an isiXhosa translator were involved in the completion of the questionnaire with the caregiver participants to determine the cultural and linguistic appropriateness of the FS-IS. The research assistant was an SLT able to communicate effectively in English and Afrikaans, while the translator was fluent in English and isiXhosa to allow for the administration of the isiXhosa questionnaire.

3.7.3 Materials and instrumentation

The *Feedback from Caregivers* form (Appendix E, F and G) in English, Afrikaans and isiXhosa respectively, was used to determine the caregivers' understanding of the items on the FS-IS. The questionnaire allowed the caregivers to answer and provide suggestions. The questionnaire focused on the caregivers' understanding of terms and items used in the translated versions of the adapted FS-IS, as well as whether caregivers considered the content appropriate or whether they had suggestions for additions or changes. This step supports the conceptual, semantic and content equivalence of the translated version of the FS-IS (Sousa & Rojjanasrirat, 2011). The data collected from the caregivers was entered into an excel spreadsheet and was analysed. Changes or clarification to items on the FS-IS were made based on their feedback. A final version of the FS-IS was used in the pilot study.

3.7.4 Procedures

3.7.4.1 Step 1

After ethics approval was obtained, permission was obtained from the medical superintendents at RCWMCH and TBH (Appendix H and I), as well as from the head of the Speech Therapy departments at RCWMCH and TBH (Appendix J and K).

3.7.4.2 Step 2

Caregivers of children with FSD, attending the feeding clinic at RCWMCH and TBH were recruited to complete this phase of the study on the day that they were attending the feeding clinic. Consent was

obtained in the preferred language from those caregivers that met the criteria and were willing to participate (English –Appendix L; Afrikaans – Appendix M; isiXhosa – Appendix N).

3.7.4.3 Step 3

Caregiver participants were assisted by the researcher/research assistant in the completion of the caregiver feedback form (Appendices E, F and G) regarding the FS-IS in their preferred language. The researcher/research assistant administered the questionnaire to caregivers. This allowed the researcher/research assistant to ask for clarification on any suggestions provided. Caregivers were asked by the researcher/research assistant whether there were terms/items they had difficulty understanding (Sousa & Rojjanasrirat, 2011). Once these terms had been explained, they were provided with another opportunity to provide additional explanations or alternative vocabulary, as well as feedback on the appropriateness of the items on the FS-IS and whether they felt the items were appropriate/relevant for other caregivers or families in the South African context with children with FSD. The researcher/research assistant audio recorded the questionnaire process. The completed form, containing the participant's number corresponded with the number of the audio recording done for the completion of the questionnaire.

3.7.5 Data analysis

Caregiver participant responses were entered into an excel spreadsheet, analysed and reported quantitatively and descriptively to assist in the analysis of the terms, words, and clarity of sentences that were identified by caregiver participants as problematic (Blair & Conrad, 2011). Caregiver participants provided additional comments, such as, *You could just not go out* in response to the item, **It is hard for my family to make plans or go out to eat.** These comments were analysed and reported in the results descriptively. Further additional comments made by caregiver participants were analysed and compared, and suggestions and recommendations were considered, and changes made if more than 70% of the participants indicated that an item should be changed. Items with 70% agreement were deemed acceptable and retained (Hyrkäs et al., 2003).

3.8 Phase 4

3.8.1 Participants

3.8.1.1 Selection criteria

A second group of primary caregivers of children with dysphagia attending feeding clinics at the research sites was recruited to participate in the pilot study. Those individuals attending the clinics that were not primary caregivers of the children with dysphagia were excluded as they may not have been able to provide accurate information. It was necessary to include isiXhosa, English and Afrikaans speaking caregivers. Caregivers identified for isiXhosa and Afrikaans were required to be first language speakers of the languages. Caregivers communicating in English were either primary or

second language speakers of English, as many patients speak English with their health care providers, despite English not being their first language.

3.8.1.2 Recruitment strategy

Caregiver participants were recruited from the paediatric outpatient feeding clinics at both tertiary institutions. Resident SLTs informed those caregivers attending the clinic of the research study and provided them with the information sheet. Those caregivers willing to participate in the pilot study met with the researcher (and translator) for more information and completed a consent form (Appendices L, M and N). The researcher (and translator) completed the adapted and translated FS-IS with the caregiver participants in a private space on the same day as their appointment so as not to incur any extra costs or additional time requirements.

3.8.1.3 Sampling

Non-probability, purposive sampling was used to select the caregiver participants based on the inclusion criteria of the study (Daniel, 2012). Purposive sampling is a strategy used to focus on those individuals who meet the inclusion criteria and provide the most valuable insight into the research question (Devers & Frankel, 2000). For the purpose of this study, primary caregivers of children with dysphagia, attending feeding clinics at the SLT departments, were selected.

3.8.1.4 Sample size

Thirty-two caregiver participants formed part of the pilot study and were from both hospitals, this was an adequate sample size as, in descriptive pilot studies, 30–40 participants is recommended (Beaton et al., 2000).

3.8.2 Research personnel

The FS-IS was administered by the researcher or a research assistant trained in the administration of the FS-IS, through practicing administration of the tool in the different languages with the primary researcher prior to the data collection process. Both the researcher and research assistant are qualified SLTs, registered with the HPCSA. The researcher is able to speak English and Afrikaans, and the research assistant was fluent in English and isiXhosa. Another research assistant, fluent in Afrikaans and isiXhosa, assisted with the inter-rater reliability of the tool.

3.8.3 Materials and instrumentation

The adapted and translated versions of the FS-IS in English (Appendix O), Afrikaans (Appendix P) and isiXhosa (Appendix Q) were used. The original FS-IS has been described in section 3.4.7.1.

3.8.4 Reliability and validity

The reliability and validity of the revised translated versions is reported in the results. The aim of this study was to report on the reliability and validity of the adapted FS-IS. Inter-rater reliability evaluates whether data collected by two separate raters are in agreement with each other (Fink, 2008; Leedy

& Ormrod, 2005; Tredoux & Durrheim, 2002). To ensure inter-rater reliability, the researcher along with a research assistant completed the adapted versions of the FS-IS (Appendices O-Q) independently and thereafter, compared the results obtained. According to Curtis and Drennan (2013), 85% agreement is considered to be acceptable.

Intra-rater reliability evaluates how well the data captured can be reproduced when the researcher repeats the process (Leedy & Ormrod, 2005; Tredoux & Durrheim, 2002). The researcher randomly selected 5% of the study sample, one month post the initial completion of the questionnaire, blinded to the previous results, and then completed the questionnaire for a second time by listening to the audio recordings. The audio recordings provided another opportunity for the researcher to repeat the completion of the questionnaire process. The two sets of data were compared with the criterion level set at 95% agreement (Gomm, 2008; Jackson, 2015).

Construct validity was established with the original tool. Construct validity seeks to establish whether a test measures what it is intended to measure. The FS-IS has been validated in the US, showing good construct validity (Lefton-Greif et al., 2014). The reliability and validity of the FS-IS in SA is the main focus of this study and is therefore reported in the results.

3.8.5 Procedures

3.8.5.1 Step 1

Caregivers of children with FSD attending the feeding clinics at RCWMCH and TBH were recruited to complete the pilot study. Consent was obtained from those caregivers who met the inclusion criteria in their preferred language (English - Appendix R, Afrikaans - Appendix S and isiXhosa - Appendix T).

3.8.5.2 Step 2

Caregiver participants completed the FS-IS with the researcher/research assistant. When questions for clarity arose, the researcher assisted in addressing these.

3.8.5.3 Step 3

Data from the completed FS-IS were extracted and entered onto an excel spreadsheet for analysis. Participant responses in English, Afrikaans and isiXhosa, were collated from the Likert scale and the percentage of participant responses was obtained. Additional comments made in English and Afrikaans were transcribed (and translated into English) by the researcher, while comments made by caregiver participants in isiXhosa were translated and transcribed by the research assistant.

3.8.6 Data analysis

The data obtained from the pilot study were recorded and analysed quantitatively and descriptively. Measures of central tendency were used to analyse caregiver participant responses (Du Plooy, 2009;

Leedy & Ormrod, 2005). Frequency counts and proportions were used to record the data collected and quotes from caregiver participants were used to describe caregiver concerns and experiences related to their HRQoL as they care for their child with FSD.

The responses of the caregiver participants (n=32) in the pilot study were analysed and entered into a Microsoft Excel spreadsheet. The data were then entered into the SPSS version 27, and the mean for each subscale calculated and entered into a table for comparison. Items within each subscale of the FS-IS were added together, divided by the total number of items in the subscale to create an average subscale score. The 18 items were added and then divided by the total number of items on the tool (n=18) – this provided the researcher with the HRQoL score of each caregiver participant. The original study did not quantify the value of the HRQoL scores on the FS-IS. Descriptive statistics such as percentages, means and standard deviations were calculated and reported.

To determine inter-rater reliability, the researcher along with a research assistant completed a questionnaire (Appendix O, P and Q) independently and thereafter, compared the results obtained. According to Curtis and Drennan (2013), 85% agreement is considered to be acceptable and was thus set as the level of agreement for this study.

Intra-rater reliability was determined one month post the initial completion of the questionnaire. Blinded to the previous results, the researcher randomly selected 5% of the study sample and then completed the questionnaire for a second time by listening to the audio recordings. The two sets of data were compared with the criterion level set at 95% agreement (Gomm, 2008; Jackson, 2015).

The internal consistency of the adapted FS-IS was calculated using Cronbach's alpha. The internal consistency was measured to determine whether the adapted FS-IS was measuring what it was intended to measure, HRQoL. The statistical programme used to calculate the internal consistency was the statistical package for the social sciences (SPSS) version 27 in conjunction with Microsoft excel. Acceptable Cronbach's alpha values range between 0.70 to 0.95 (Tavakol & Dennick, 2011). The data was entered into an excel spreadsheet initially and then into SPSS which generated the results for Cronbach's alpha. Details regarding the results obtained are reported in the results section 5.4.

4 Ethical considerations

Ethical considerations for research that includes human participants are an important part of research (Jelsma & Clow, 2005). The Declaration of Helsinki (2013) developed by the World Medical Association (WMA) guided the ethical principles used in this research. There are four main principles that are taken into consideration, namely: autonomy, beneficence, non-maleficence and justice (Schüklenk, 2000). These ethical considerations ensure that the choices people make are respected, no harm is done and any medical intervention provided is done in a fair and ethical manner (Schüklenk, 2000).

4.1 Autonomy

Autonomy ensures that the decisions of individuals be respected and their participation in the research is voluntary and the information they receive with regards to the research is adequate (Diekema, 2009). The respect for informed consent is essential to autonomy, and should be taken prior to participants being enrolled in a study (Jelsma & Clow, 2005; Schüklenk, 2000). Autonomy was accounted for through the consent process. All potential participants were given the opportunity to make an informed decision regarding their desire to participate in the research study. All participants were informed that they were able to withdraw from the study with no negative consequences (Beauchamp & Childress, 2001).

Each participant was assured that their participation in the study would be treated in confidence. Confidentiality ensures that the researcher maintains anonymity and privacy of the participants (Blanche et al., 2006; Smith, 2003). Each participant was allocated a participant number; this number had no information related to the participant. A master list of participant names and participant numbers was kept on a password protected document. This document was needed to assist with reliability checks. Each audio recording was destroyed once they had been captured and checked to ensure anonymity.

4.2 Non-maleficence

Non-maleficence ensures that no harm comes to the participant in a research study (Beauchamp, 2007). For this research study, no direct intervention was given to participants or their dependents. There was no risk related to phase 1 of the study in which qualified SLTs provided feedback on the cultural and linguistic appropriateness of the FS-IS. In phases 3 and 4, caregivers of children with dysphagia completed the FS-IS which asked about their coping and stress related to caring for a child with dysphagia. There was a small risk that caregivers would feel uncomfortable or upset by reflecting on how they felt. If caregivers had become distressed during the completion of the questionnaires, they would have been referred to the appropriate healthcare professional at the

institution for further support (Jelsma & Clow, 2005). None of the participants required referral for additional support.

4.3 Beneficence

The principle of beneficence ensures that the health and well-being of the research participants are optimised, through minimising any harm and maximising the benefits (Blanche et al., 2006; Diekema, 2006). Information and suggestions received in phase 1 of the study were taken into consideration to ensure that the adapted tool was culturally and linguistically relevant to this population. Although the participants of the study may not directly benefit from any of the phases of the study, those who will use the tool in future may find it beneficial as it may assist future patients and their families by identifying support needs.

4.4 Justice

Justice ensures that the benefits of the research are distributed equally, including the selection of participants (Diekema, 2006; Terre-Blanche et al., 2006). Participants were identified by the inclusion criteria of the study. The results obtained in the study will be made available to the research sites and through publications, as well as on the UCT library website as an online resource.

5 Results

The results of the study have been organised according to the study aims and objectives.

5.1 Content validity of the FS-IS

The FS-IS was reviewed by SLT experts who provided feedback on the items specific to the contextual relevance for South Africa. The feedback from the experts, and subsequent modifications made to the FS-IS, are summarised in tables 4-6. Modifications to the FS-IS were implemented before the next phase of the study. Recommendations were considered and changes made if more than 70% of the experts indicated that an item should be changed. The results of the content validity will be presented according to three subsections: namely, expert feedback on the FS-IS of the items related to 1) carrying out daily activities, 2) worrying, and 3) concerns caregivers have related to feeding their children with FSD.

Table 4 summarises the expert participants' responses for the items related to caregivers carrying out their daily activities. Expert feedback indicated that all items were considered important. One item, **It is hard for my family to make plans or go out to eat** was highlighted by 2 (40%) experts suggesting the item be omitted and 3 (60%) of the experts considered it potentially unclear and inappropriate for South African families. One expert stated:

> *Although this item is relevant to many South African families that I currently see, this might not be a challenge that ALL South African families at large will identify with, especially people living in poverty or in a rural setting, which is the majority of our country. The reason I think these items should still remain in the tool, is that there would be families who this applies to*.

Another expert remarked:

> *Not appropriate for parents/caregivers, mostly because in government situations, socioeconomic status is often lower and even the idea of going out is a rare luxury. However, in private sector or amongst more affluent clients, it could be a consideration.*

Another expert found that the item was "Not always appropriate" and suggested that the item be modified to: "Perhaps eat in front of child." Although this item was highlighted by 3 experts as a potentially inappropriate item in some contexts, the criteria of 70% for removal was not reached and the item was thus retained.

TABLE 4: EXPERT FEEDBACK (N=5) ON THE FS-IS: ITEMS RELATED TO CARRYING OUT DAILY ACTIVITIES

	FS-IS Items Section 1	Feedback			Modifications suggested
		Important / appropriate given our knowledge and experience with paediatric dysphagia and its impact on families	Clear and appropriate for speakers of South African English (i.e., is spelling, word-choice and grammar optimal for our local context?)	Clear and appropriate for South African families (i.e., will this question relate to the experiences and everyday reality of South African families?)	
1.	**It is hard for me to do my job, go to school, or work around the house.**	100%	80%	80%	None
2.	**It is hard for me to get help from others because they are scared to feed or take care of my child.**	100%	100%	100%	None
3.	**It is hard for me to leave my child because I am scared to have other people feed or take care of my child.**	100%	80%	80%	None
4.	**It is hard for my family to make plans or go out to eat.**	100%	80%	60%	40% thought the item should be changed or omitted
5.	**I am too tired to do the things I want or need to do.**	100%	80%	100%	None

Table 5 summarises the responses from the expert participants for the items related to caregiver worrying. The experts felt that most of the items related to caregiver worrying were important, clear, and appropriate for speakers of South African English and South African families.

One expert felt that item 7, **I worry about how my child's feeding/swallowing problems affect others in my family,** was unclear and commented:

> *It is not clear to me what this question is targeting or how it is anticipated that the feeding difficulties could affect others in the family. The way it currently reads potentially suggests that the feeding difficulties could be contagious.*

Experts (n=3) commented on word choice, either stating that certain words/terms could be omitted or changed and provided suggestions or recommendations for change. The experts (n=3) highlighted 6 items related to word choice within the FS-IS. For example, in response to item 4, **I worry about how my child breathes when feeding and whether my child will choke,** one expert stated:

> *The word "choke" may need to be considered. I am not sure if the meaning would change on translation or whether another word like cough would be substituted?*

In response to item 3, **I worry about how others will react to my child's feeding/swallowing problems,** one of the experts felt that "others" should be changed to "Other People".

The phrasing of items contributed to the relevance of the items for the South African context and for caregivers of children with FSD. In response to item 6, **I worry about whether I am doing enough to help with my child's feeding /swallowing problems,** one expert suggested that **I worry about whether I am** should be changed to *I worry if I am*. While another expert thought this item could be omitted but did not state why they felt it should be omitted from the FS-IS.

TABLE 5: EXPERT FEEDBACK (N=5) ON THE FSIS: ITEMS RELATED TO CAREGIVER WORRYING

	FS-IS Items Section 2	Feedback			Modifications suggested
		Important/appropriate given our knowledge and experience with Paediatric dysphagia and its impact on families	Clear and appropriate for speakers of South African English (i.e. is spelling, word-choice and grammar optimal for our local context?)	Clear and appropriate for South African families (i.e. will this question relate to the experiences and everyday reality of South African families?)	
1.	**I worry about my child's general health.**	80%	60%	80%	None
2.	**I worry that my child does not get enough to eat or drink.**	80%	80%	80%	None
3.	**I worry about how others will react to my child's feeding/swallowing problems.**	80%	60%	80%	None
4.	**I worry about how my child breathes when feeding and whether my child will choke**	80%	60%	80%	None
5.	**I worry that my child will never eat and drink like other children.**	80%	80%	80%	None
6.	**I worry about whether I am doing enough to help with my child's feeding/swallowing problems**	60%	80%	80%	20% thought the item should be omitted
7.	**I worry about how my child's feeding/swallowing problems affect others in my family**	60%	60%	60%	None

Table 6 summarises the responses from experts related to caregiver concerns associated with feeding their children. One expert felt that either a few terms or items should be changed or omitted. In response to item 1, **It is hard to feed my child because it takes a long time to prepare liquids and foods, participant** 3 suggested: *The term liquids could be omitted here*.

Three experts made comments on the relevance of certain items within the FS-IS. Four comments were made in total: three comments mentioned that items may not be relevant for all South African families but can be retained as some families may find them relevant. In response to item 1: **It is hard to feed my child because it takes a long time to prepare liquids and foods,** one expert stated:

Again, many families in my current caseload of private health care clients will regards this as relevant. But I don't think the majority of South African parents will have access to blenders or even variety of foods in order to prepare foods "the right way" for their children. In my opinion, many parents especially mothers of children with cerebral palsy, when asked, will say that they use porridge, mash or yoghurt as these consistencies are easy. It appears that they don't even consider trying to blend meat or other food groups in order to get the consistency ready for the little one, as this is not an option for most families due to limited resources and financial constraints. The reason I think these items should still remain in the tool, is that there would be families who this applies to.

In response to item 3, **It is hard to feed my child because others give my child liquids or foods that are not allowed,** another expert felt:

This sentence isn't really clear – based on the questions above and other research in this area other people seldom feed children with dysphagia.

Another item that one of the experts felt was not relevant was item 4: **It is hard to feed my child because I don't know how long these problems will last** and stated.

I'm not sure that this is a relevant question that will change the scenario in any meaningful way. In my experience, the ease/difficulty related to feeding a child on the caregiver's part has not been centred on the duration of the problem but rather focused on the "here and now" as feeding is an immediate need providing nutrition for their children is usually foremost on a caregiver's mind.

One expert suggested that Section 3 item 2 be omitted, **It is hard to feed my child because I don't know how to prepare liquids and foods,** and commented:

I think this question could be omitted given that the question above implies that there is a 'right way' to prepare foods. It may increase caregiver anxiety.

One participant responded to section 3 item 5, **It is hard to feed my child because family members or professionals have different opinions about taking care of my child's feeding/swallowing problems**, noting that the item may increase caregiver anxiety and remarked:

I don't think that this would make it difficult to feed a child but caregivers could be asked if they would find it helpful if they were given verbal/written information about therapeutic techniques and/or alternative ways of feeding their child

TABLE 6: EXPERT FEEDBACK (N=5) ON THE FSIS: ITEMS RELATED TO CONCERNS CAREGIVERS HAVE RELATED TO FEEDING THEIR CHILDREN

	FS-IS Items Section 3	Expert Feedback			Modifications suggested
		Important/appropriate given our knowledge and experience with paediatric dysphagia and its impact on families.	Clear and appropriate for speakers of South African English (i.e., is spelling, word-choice and grammar optimal for our local context?)	Clear and appropriate for South African families (i.e., will this question relate to the experiences and everyday reality of South African families?)	
1.	**It is hard to feed my child because it takes a long time to prepare liquids and foods the "right" way.**	80%	60%	60%	20% felt this item should be omitted
2.	**It is hard to feed my child because I don't know how to prepare liquids and foods.**	60%	60%	60%	20% thought this item should be omitted
3.	**It is hard to feed my child because others give my child liquids or foods that are not allowed.**	80%	60%	60%	None
4.	**It is hard to feed my child because I don't know how long these problems will last.**	60%	80%	60%	20% thought this item should be omitted
5.	**It is hard to feed my child because I do not get enough information about how to get my child to eat and drink like other children.**	80%	80%	80%	20% of the experts involved in the study felt that this item should be omitted.
6.	**It is hard to feed my child because I do not get enough information about how to get my child to eat and drink like other children**	60%	60%	60%	

The experts provided valuable feedback on the appropriateness of the contextual relevance of the items on the FS-IS for the South African context, based on their experience in the field of FSD. The responses collated from the experts were insightful and relevant, however for each recommendation less than 70% of the experts felt the item was irrelevant, an item should be removed or that items should be changed or reworded. Therefore, in this phase of the study no items were edited or removed. Each item in the FS-IS was therefore determined to be contextually appropriate and relevant for the South African context by the experts. In the next phases of the study the FS-IS was translated into Afrikaans and isiXhosa, back translated, and then presented to caregivers of children with FSD to determine the cultural and linguistic appropriateness of the translated and English versions of the FS-IS.

5.2 Cultural and linguistic appropriateness of the FS-IS

Fifteen caregiver participants, five from each language - English, Afrikaans and isiXhosa - participated in phase 3 of the study and assisted in determining the cultural and linguistic appropriateness of the FS-IS for the South African context. Caregiver participants were required to indicate if they thought the items were culturally and linguistically appropriate and whether they felt an item should be changed or omitted. These caregiver participant responses were analysed, and recommendations were taken into consideration when more than 70% of the participants agreed that an item should be changed or removed.

5.2.1 English-speaking caregivers of children with FSD (n=5)

Table 7 summarises the feedback received from the English-speaking participants. All five (100%) of the English caregiver participants judged the items as important/appropriate given their knowledge and experience with FSD and its impact on them and their families. The same five participants thought the language and terminology used was clear and appropriate for English speakers, including spelling, word-choice, and grammar. They also considered the items to be clear and appropriate for South African families. Three (60%) of the English caregiver participants thought the FS-IS covered all the aspects they faced with a child with FSD while five (100%) of the caregiver participants understood all the terms used in the FS-IS and agreed that the FS-IS would be useful to help other caregivers whose children have FSD. Table 7 presents the specific items highlighted by English-speaking caregiver participants and the comments and recommendations they made for these items.

TABLE 7: ENGLISH-SPEAKING CAREGIVERS' FEEDBACK ON THE FSIS AND ITS CULTURAL AND LINGUISTIC APPROPRIATENESS FOR SOUTH AFRICAN FAMILIES WITH CHILDREN WITH FSD (N=5)

Original item relating to caregiver's comments		Number of participants who thought this was appropriate given their experience with FSD (n=5)	Comments	Modifications
Section 1 Item 4	It is hard for my family to make plans or go out to eat.	Three (60%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	"You don't have to eat out" "You could just not go out"	None
Section 1 Item 5	I am too tired to do the things I want or need to do.	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	One caregiver disagreed; "You should find time"	None
Section 2 Item 3	I worry about how others will react to my child's feeding/swallowing problems.	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	"Your child come first"	None
Section 2 Item 7	I worry about how my child's feeding/swallowing problems affect others in my family.	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.		None
Section 3 Item 2	It is hard to feed my child because I don't know how to prepare liquids and foods.	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	"You get taught by your healthcare team"	None
Section 3 Item 4	It is hard to feed my child because I don't know how long these problems will last.	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.		None
Section 3 Item 5	It is hard to feed my child because family members or professionals have different opinions about taking care of my child's feeding/swallowing problems.	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	"The professionals should be listened to"	None

5.2.2 Afrikaans-speaking caregivers of children with FSD (n=5)

Table 8 summarises the feedback received from Afrikaans-speaking caregiver participants. No item was removed. Four (80%) of the Afrikaans-speaking caregiver participants thought the FS-IS covers all the aspects caregivers face or have difficulty with daily, while 60% of these caregiver participants understood all the terms used in Afrikaans in the translated version of the FS-IS. All five (100%) of the caregiver participants felt that the FS-IS will be useful to help other caregivers who have children with FSD. The table highlights the items in which Afrikaans-speaking caregiver participants did not meet 100% agreement in their opinion of the importance or appropriateness of the items in the FS-IS. No specific comments or recommendations were made by the participants.

TABLE 8: AFRIKAANS-SPEAKING CAREGIVERS' FEEDBACK ON THE FSIS AND ITS CULTURAL AND LINGUISTIC APPROPRIATENESS FOR SOUTH AFRICAN FAMILIES WITH CHILDREN WITH FSD (N=5).

	Original item relating to caregivers' comments	Number of participants who thought this was appropriate given their experience with FSD (n=5)	Comments	Modifications
Section 1 Item 5	I am too tired to do the things I want or need to do. *Ek is te moeg om die dinge te doen wat ek wil of moet doen.*	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None
Section 2 Item 6	I worry about whether I am doing enough to help with my child's feeding /swallowing problems *Ek is bekommerd of ek genoeg doen om my kind te help met hom/haar eet/sluk probleme.*	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None
Section 2 Item 7	I worry about how my child's feeding/swallowing problems affect others in my family. *Ek is bekommerd oor hoe my kind se eet/sluk probleme ander in my gesin affekteer.*	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None
Section 3 Item 1	It is hard to feed my child because it takes a long time to prepare liquids and foods the "right" way. *Dit is moeilik om my kind te voed omdat dit 'n langtyd neem om die vloeistowwe en kos die "regte" manier voorteberei.*	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None
Section 3 Item 2	It is hard to feed my child because I don't know how to prepare liquids and foods. *Dit is moeilik om my kind te voed omdat ek nie weet hoe om die vloeistowwe en kos voorteberei nie.*	Three (60%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None
Section 3 Item 3	It is hard to feed my child because others give my child liquids or foods that are not allowed. *Dit is moeilik om my kind te voed omdat ander my kind vloeistowwe en kos gee wat nie toelaatbaar is nie.*	Three (60%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None
Section 3 Item 4	It is hard to feed my child because I don't know how long these problems will last. *Dit is moeilik om my kind te voed omdat ek nie weet hoe lank hierdie probleme sal aanhou nie*	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None

5.2.3 isiXhosa-speaking caregivers of children with FSD (N=5)

Table 9 collates the information received from the isiXhosa-speaking caregiver participants. Based on their responses, less than 70% of these caregiver participants agreed that any item should be changed or removed; therefore, these translated items were deemed acceptable. It was noted that **banemviwo** was reportedly not very clear as it inferred that doctors and other professionals have different "exams" for caring for a child's problem, and was thus changed to **banezimvo***,* which clarifies the translation to differing "opinions" in caring for a child's problems, for the pilot study.

All five (100%) of the caregiver participants thought that the FS-IS covered all the aspects they face and or have difficulty with daily. They also understood all the terms used in the translated version of the FS-IS. All the caregiver participants felt that the tool would be useful to help other caregivers who have children with FSD. The items in which all isiXhosa speaking caregiver participants did not reach 100% agreement on the importance or appropriateness of items are highlighted in table 9.

TABLE 9: ISIXHOSA-SPEAKING CAREGIVERS' FEEDBACK ON THE FSIS AND ITS CULTURAL AND LINGUISTIC APPROPRIATENESS FOR SOUTH AFRICAN FAMILIES WITH CHILDREN WITH FSD (N=5)

Original item relating to caregivers' comments		Number of participants who thought this was appropriate given their experience with FSD (n=5)	Comments	Modifications
Section 1 Item 1	It is hard for me to do my job, go to school, or work around the house. *Kunzima ukuba ndenze imisebenzi yam enjegokuya esikolweni okanye ukwenza umsebenzi endlini.*	Three (60%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None
Section 1 Item 4	It is hard for my family to make plans or go out to eat. *Kunzima ukuba mna nosapho lwam siphume siyotya kwezinye indawo okanye sizikhuphe*	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	This question could be asked to people who do not spend most of their time with their kids. OR rephrased "Is it difficult for your child to go out and eat with other people?" Another caregiver feels the question is unnecessary, because she knows what her child eats and cannot eat and therefore it is not a problem at all for her.	None
Section 2 Item 3	I worry about how others will react to my child's feeding/swallowing problems. *Ndiyaxhalaba ukuba abanye abantu bazoyibona njani ingxaki yomntwana wam yokutya okanye yokuginya.*	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None
Section 2 Item 4	I worry about how my child breathes when feeding and whether my child will choke. *Ndiyaxhalaba ukuba umtwana wam uphefumla njani xa esitya nokuba umntwana wam akazukomiwa na.*	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None

Section 2 Item 5	I worry that my child will never eat and drink like other children. *Ndiyaxhalaba ukuba umntwana wam akanoze aphinde akwazi ukutya nokusela njengabanye abantwana.*	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None
Section 2 Item 7	I worry about how my child's feeding/swallowing problems affect others in my family. *Ndiyaxhalaba ukuba ingxaki zomntwana wam zokutya nokuginya ziluchaphazela njani usapho lwam nabanye abantu.*	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None
Section 3 Item 1	It is hard to feed my child because it takes a long time to prepare liquids and foods the "right" way *Kunzima ukutyisa umntwana wam ngoba kuthatha ixesha elide ukumlungiselela izinto eziselwayo nokutya kakuhle.*	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None
Section 3 Iten 2	It is hard to feed my child because I don't know how to prepare liquids and foods. *Kunzima ukutyisa umntwana wam ngoba andikwazi ukuba kulungiselelwa okanye kwenziwa kanjani ukutya nezinto eziselwayo.*	Three (60%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None
Section 3 Item 3	It is hard to feed my child because others give my child liquids or foods that are not allowed. *Kunzima ukutyisa umntwana wam ngoba abanye abantu banika umntwana wam izinto eziselwayo okanye ukutya okungavumelekanga*	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None
Section 3 Item 4	It is hard to feed my child because I don't know how long these problems will last. *Kunzima ukutyisa umntwana wam ngoba andiyazi zizohlala ixesha elingakanani ezingxaki.*	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None
Section 3 Item 5	It is hard to feed my child because family members or professionals have different opinions about taking care of my child's feeding/swallowing problems. *Kunzima ukutyisa umntwana wam ngoba amalungu osapho lwam, oogqirha nabanye abantu banemviwo ezingafaniyo ngokukhathalela ingxaki zomntwana wam zokutya okanye ezokuginya.*	Four (80%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	Banemviwo – was reportedly not very clear	Banemviwo was changed to banezimvo
Section 3 Item 6	It is hard to feed my child because I do not get enough information about how to get my child to eat and drink like other children. *Kunzima ukutyisa umntwana wam ngoba andifumani nkcukacha zaneleyo ukuze umntwana wam akwazi ukutya okanye asele njengabanye abantwana.*	Three (60%) of the caregiver participants thought this item was important/appropriate given their knowledge and experience with FSD and its impact on them and their families.	None	None

Table 10 indicates the percentage of agreement of all the caregiver participants – English, Afrikaans and isiXhosa speaking (n=15) – regarding the cultural and linguistic appropriateness of the FS-IS items in relation to the importance of the items, and whether they felt these statements were clear and appropriate for their preferred language, and South African families. It provides a representation of the responses to those items related to daily activities, worrying and feeding difficulties.

TABLE 10: PERCENTAGE OF CAREGIVER RESPONSES (N=15) TO ITEMS RELATED TO DAILY ACTIVITIES, WORRYING, AND FEEDING DIFFICULTIES AND THEIR CULTURAL AND LINGUISTIC APPROPRIATENESS FOR ENGLISH, AFRIKAANS AND ISIXHOSA SPEAKING CAREGIVERS OF CHILDREN WITH FSD.

		Percentage (%) of total participants (n=15)		
	Items on FS-IS	Important/appropriate given your knowledge and experience with FSD and its impact on you and your family.	Clear and appropriate for speakers of your preferred language (i.e., is spelling, word-choice and grammar understandable?)	Clear and appropriate for South African families (i.e., will this question relate to the experiences and everyday reality of South African families?)
DAILY ACTIVITIES	It is hard for me to do my job, go to school, or work around the house.	87	100	100
	It is hard for me to get help from others because they are scared to feed or take care of my child.	100	100	100
	It is hard for me to leave my child because I am scared to have other people feed or take care of my child.	100	100	100
	It is hard for my family to make plans or go out to eat.	80	100	100
	I am too tired to do the things I want or need to do.	87	100	100
ITEMS RELATED TO WORRYING	I worry about my child's general health.	100	100	100
	I worry that my child does not get enough to eat or drink.	100	100	100
	I worry about how others will react to my child's feeding/swallowing problems.	87	100	100
	I worry about how my child breathes when feeding and whether my child will choke.	93	100	100
	I worry that my child will never eat and drink like other children	93	100	100
	I worry about whether I am doing enough to help with my child's feeding /swallowing problems.	93	100	100
	I worry about how my child's feeding/swallowing problems affect others in my family.	80	100	100
ITEMS RELATED TO FEEDING DIFFICULTIES	It is hard to feed my child because it takes a long time to prepare liquids and foods the "right" way.	87	100	100
	It is hard to feed my child because I don't know how to prepare liquids and foods.	67	100	100
	It is hard to feed my child because others give my child liquids or foods that are not allowed.	80	100	100
	It is hard to feed my child because I don't know how long these problems will last.	80	100	100
	It is hard to feed my child because family members or professionals have different opinions about taking care of my child's feeding/swallowing problems.	87	100	100
	It is hard to feed my child because I do not get enough information about how to get my child to eat and drink like other children.	87	100	100

Suggestions and recommendations were considered if more than 70% of the participants indicated that an item should be changed or omitted. Items with 70% agreement were deemed acceptable and were retained. The majority (more than 70%) of the caregiver participants indicated they felt each item was important, clear and appropriate for speakers of their language as well as South African families and all items were thus retained. However, fewer than 70% of the participants felt that the item: **It is hard to feed my child because I don't know how to prepare liquids and foods** was appropriate given their knowledge of FSD and the impact of this on their families. Sixty-seven percent (n=10) of the participants felt that this item was suitable and that the item should be retained. The item was considered for amendment as it did not meet the 70% agreement criteria. The statement and responses were analysed and then amended to state, **It is hard to feed my child because I don't know how to prepare liquids and food the "right way"**. The amendment was made to ensure clarity as experts felt the original item could increase caregiver anxiety and there was a concern related to the potential anxiety raised by the expert. The research team thus discussed the amendment, and the adaptation was included for the pilot study.

5.3 Pilot use of FS-IS: description of the experiences of caregivers of children with FSD, related to stress and coping using the adapted FS-IS.

A total of 32 of caregiver participants were interviewed at RCWMCH (n=25; 78%) and TBH (n=7; 22%) in the Western Cape. The participants included parents as primary caregivers (n=28; 88%), grandparents (n=2; 6%), as well as foster parents (n=2; 6%). Thirty-one of the 32 participants were female with 14 English speaking, 9 isiXhosa and 9 Afrikaans speaking. The caregivers were the primary caregivers of children with a variety of FSD including non-oral feeding, oral feeds with specific modifications and picky or selective eaters. The pilot study was initiated once the recommendations were taken into consideration and changes made to the respective items in the FS-IS. The caregiver participants were interviewed using the adapted FS-IS. Results are presented as a mean score on the FS-IS, and illustrative quotes from caregiver participants are provided in relation to each subsection.

Table 11 indicates that most caregivers reported increased stress related to worrying about their child with FSD with the mean for the subsection at 2.97. The range for each subsection is 1-5. Caregiver participants were noted to have less stress related to their child's feeding difficulties than the other subsections, with the mean of caregiver responses at 1.98. Overall caregiver participants' HRQoL was noted to be impacted by their child's FSD with the mean of all components of the FS-IS at 2.54.

TABLE 11: MEANS (SD) OF CAREGIVER HRQOL IN EACH SUBSECTION OF FS-IS (N=32)

TRANSLATED AND VALIDATED FS-IS SUBSECTIONS (RANGE)	CAREGIVERS OF CHILDREN WITH FSD MEAN (SD)
DAILY ACTIVITIES (1-5)	2.68 (0.97)
WORRY (1-5)	2.97 (0.98)
FEEDING DIFFICULTIES (1-5)	1.98 (1.00)
TOTAL (1-5)	2.54 (0.69)

Table 12 summarises the number of caregiver participants who scored in the various ranges on the FS-IS. In the pilot study, higher scores were associated with reduced HRQoL (Lefton-Greif et al., 2014). The scores of the 32 caregiver participants were divided into 3 separate groups (termed 'good', 'medium', and 'reduced') to indicate their HRQoL. Only 19% (n=6) of caregiver participants average scores fell within the good (1-1.99) range with 31% (n=10) of participants scoring high on the FS-IS indicating reduced HRQoL.

TABLE 12: SUMMARY OF CAREGIVER HRQOL SCORES IN PILOT STUDY (N=32)

RANGE OF AVERAGE OVERALL SCORE OF CAREGIVER HRQOL	NUMBER OF CAREGIVER PARTICIPANTS	PERCENTAGE OF CAREGIVER PARTICIPANTS
GOOD (1-1,99)	6	19%
MEDIUM (2-2,99)	16	50%
REDUCED (3-3,99)	10	31%

The caregiver participants were interviewed using the adapted FS-IS and the results for the different subsections are presented in figures 1-3. Daily activities that caregiver participants found most difficult included getting help from others (50%, n=16) and leaving their child in the care of others as they are scared to have others feed or take care of their child (62.5%, n=19). Caregiver participants provided a variety of reasons as to why they were hesitant to leave their child in the care of others:

> *People are scared, it's scary for me too, you need to give people time to learn.*
>
> *I don't leave my child in the care of other people. I am very scared to give my child to someone else. Because they won't know how to treat him the way I do.*

I'm scared to leave her because she is fed using a PEG, other people can't feed her. She is always with me wherever I go.

I'm scared to allow them to feed him since he has a PEG. If the PEG would be taken out, I would even take him to creche.

He stays with me, I leave him with his grandfather when I go to the shop. But I make sure I leave him full so that they don't feed him when I am not there, I make sure I am back before his next feed.

Doing their job and going out to eat did not seem to be impacted by children's FSD as 53% (n=17) and 65% (n=21) of caregivers felt they never and almost never had difficulty with these aspects, respectively. Sixty five percent (n=21) of caregiver participants reported that it was *never* or *almost never* hard for their family to make plans to go out to eat, although some participants commented on a few factors that concerned them: *It's difficult because I must look after him all the time.* Another participant stated that going out to eat, frequently caused people to stare.

Yes, it is. Because If I want to go to Macdonald's or something it's like I'm embarrassed because the food needs to be mashed in a certain way so the people, they look at you funny. So we don't really, or I buy take-aways and then we go home and then I'll do it the right way.

Very difficult. We don't even go out to eat really.

Another caregiver participant stated:

We always take something along for him. We can't travel with him.

I also do not want them to have to feed in the public toilet for her. Then they say they will feed her inside the pram, and then we close the hood, throw the blanket over and then we feed her.- Translated from Afrikaans

A number of participants (n=10, 31%) reported they are *very often* or *almost always* too tired to do the things they want or need to do.

I really get tired. While another reported*, I get tired because I'm always interested to do something, but I can't do it because I don't have time.* One mother thought the item was humourful and stated*, "I'm just laughing because that's a funny one. I stay tired",* which was emphasized by a foster mom of three toddlers aged 3*, I'm constantly tired, I'm always tired*.

However, some participants stated they didn't get tired in their responsibilities as caregivers and commented; *I don't get tired, I do everything I wake up and prepare everything*. -Translated from isiXhosa.

Almost half (41%, n=13) of the caregiver participants find it hard to do their job, go to school, or work around the house. One father raised his concerns.

> *I want to work overtime tomorrow, but I can't. There's just my family that can look after her and the lady next door, but they haven't answered me yet. Because I am behind at work, I forgot I had an appointment today, because I am supposed to work until Monday*- Translated from Afrikaans

Another caregiver expressed her gratefulness for being able to continue working and afford a nanny to help care for their children who is also able to accompany the child with FSD to school, and is aware of the difficulties of other caregivers of children with FSD:

> *I've got nothing to complain about because we are, we can have a nanny to look after her I can keep on working because we've got care for her. But a friend of mine's little girl, we met her here, she can't work because (child) got a trache and a PEG and all of that and the effect of that on the family it can be disastrous.*

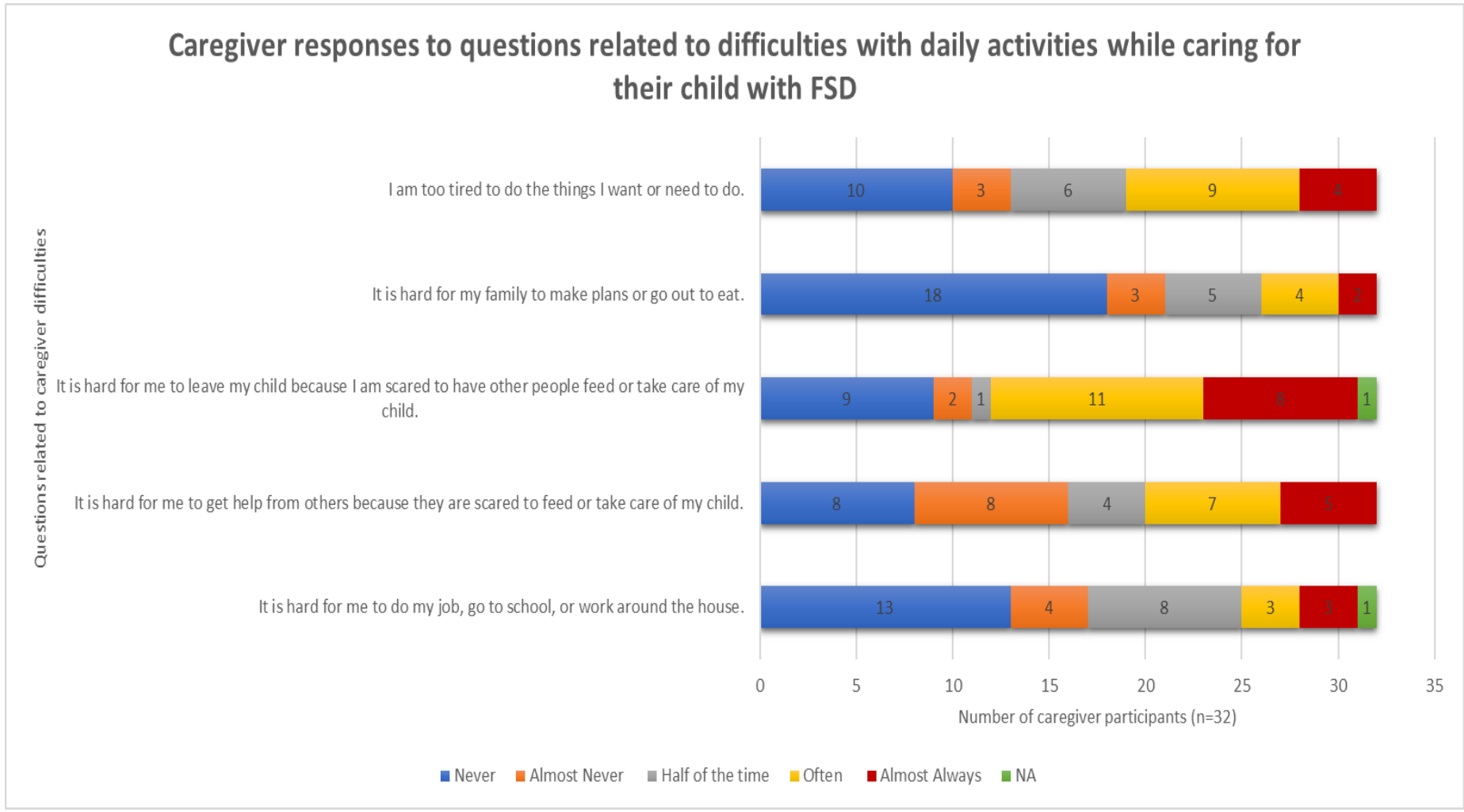

FIGURE 1: CAREGIVER PARTICIPANT PERCEPTION OF FSD MANAGEMENT ON THEIR DAILY ACTIVITIES (N=32)

Figure 2 below shows the responses of the participants for the items related to worrying about their child's FSD. The main concerns caregiver participants noted included their child's general health and whether they were doing enough to help with their child's FSD. A large proportion – 84% (n=27) - of the participants indicated that they *very often* or *almost always* worry about their child's general health; one caregiver commented on her concerns regarding the effects of the child's nutrition, or lack of adequate nutrition, has on his health:

> *Yes, sometimes I am worried about his eating, because sometimes he doesn't really want to eat. Then I am worried*
>
> *I'm often worried because we do not know what to expect.*

Eight caregiver participants (25%) reported they worried how their child breathes when feeding and whether their child will choke as a result of their FSD.

> *Sometimes I think she's going to choke if she eats her food.*
>
> *It used to be difficult before, it was difficult to breathe and to eat but now he is fine."-* Translated from isiXhosa.

Fifty percent reported they are *almost always or very often* concerned as to whether they are doing enough to help with their child's FSD. One mother was concerned as to whether the struggle she endured was enough and if there was more, she could still do for her child.

> *Yes, I am because I am always worried, have I struggled enough? I give her oral stim, so should I continue? Is three times a day not too little? Should I do it more frequently? And so forth.*

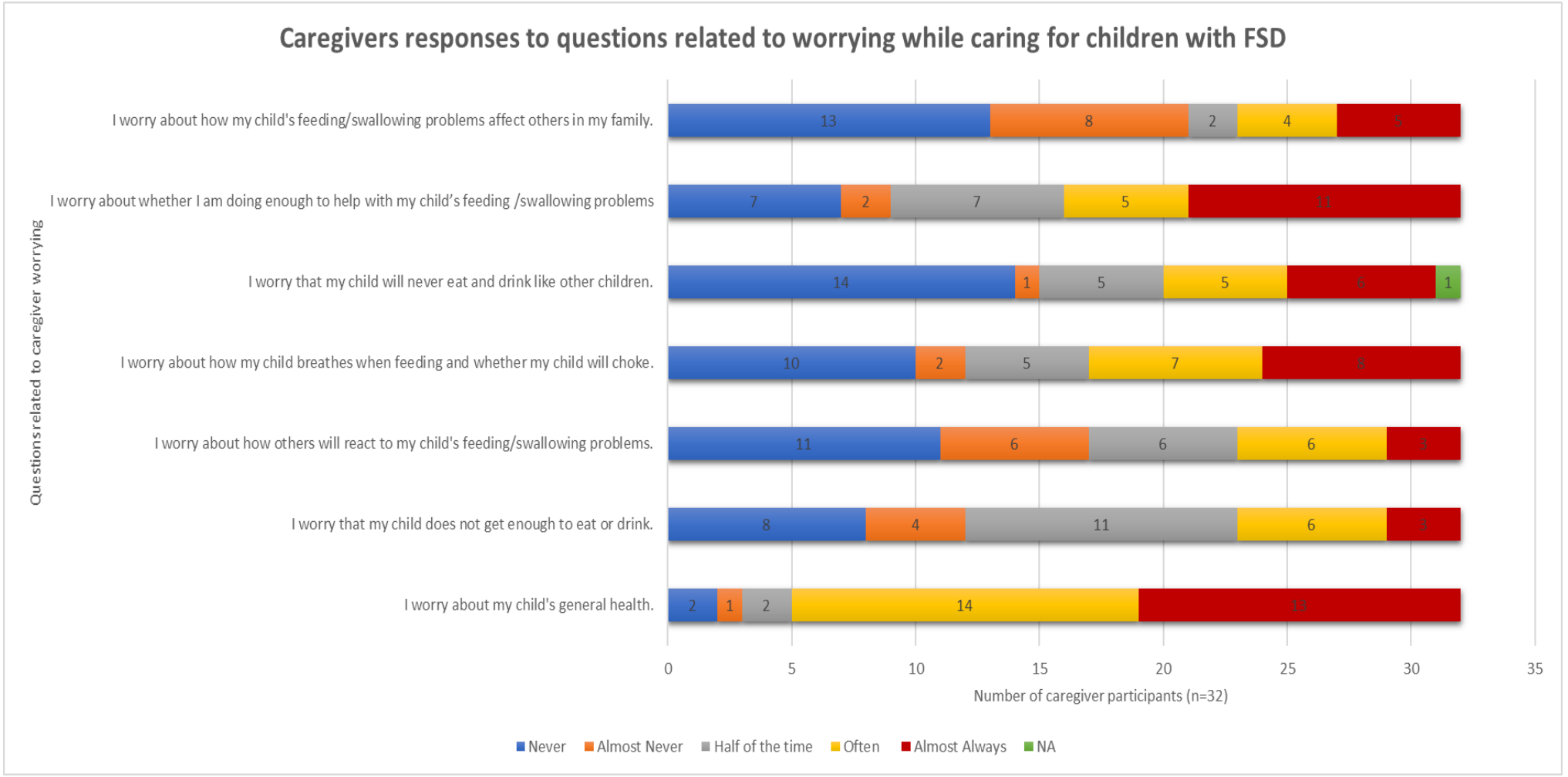

FIGURE 2: CAREGIVER PARTICIPANT PERCEPTION OF FSD MANAGEMENT AND WORRYING (N=32)

Figure 3 collates the responses from caregiver participants related to problems they may have while feeding their child with FSD. The majority of the participants indicated that they do not have difficulty feeding their child with FSD. These caregiver participants also indicated that they are used to the preparation of their child's food and report they receive adequate and sufficient information from health care professionals.

The majority, 87.5% (n=28), of the participants stated they *never* find it hard to feed their child because it takes a long time to prepare liquids or foods the right way while a significant portion, 81% of the participants, also reported they *never* and *almost never* find it hard to feed their child because they are not sure how to prepare liquids or foods the right way with one caregiver participant stating:

> *Learnt all the tricks.*

Furthermore, 72% (n=23) of the participants, reported that they *never* find that feeding their child is difficult due to differing opinions from professionals and/or family members on how to feed their child. Although caregivers did not feel they had difficulty feeding their child because of conflicting advice from professionals, two parents provided examples of how, while they respected the professional's advice, they have also tried things on their own.

> *Look, like (ST) says, she's not ready for porridge yet, but I'm going to try something on my own. I'm going to see if she's with me… in two weeks. Look, she can not eat today, but in two weeks I'm going to watch. Does she not want to eat little bit of porridge? Does she not want to swallow? There are many challenges with (child). As she asks me if I give water to (child), I have been giving (name of child) water through her mouth for a long time. She says now today, I can start now. I've already done that. See? I'm already giving that little bit of water. - I do my things so quietly".* - Translated from Afrikaans

> *Sometimes - I've had to compromise a lot between what my family said, what I felt, what my child wanted and what the professionals were advising. - And at times there was things that I did that I was told by the professionals not to do, but it didn't harm my child. - So when she started wanting to drink water, she wasn't supposed to be drinking water, but I started her on that because she wanted water. Um the same with the yoghurt. But I feel like the professionals need to kind of take into consideration, the mother and the child also because it's a big picture, it's got all three of us in there. And I think that with progress, if you include all three you'll get much more progress faster."*

Two caregivers made additional comments related to additional, informal support they felt would be beneficial for themselves and fellow caregivers of children with FSD and stated:

> *Since this child is in this situation, we have accepted it now, but it used stress me out a lot. It still stresses me a lot. I think talking with other parents in a similar situation in a support group it would be very helpful. Now I am scared to have another child because I don't know what will happen.* - Translated from isiXhosa

But if there is a support system in place somewhere. See my family is committed to wanting to help me but like me say, I believe there can be more help, besides the hospital and the attendees and that.– Translated from Afrikaans

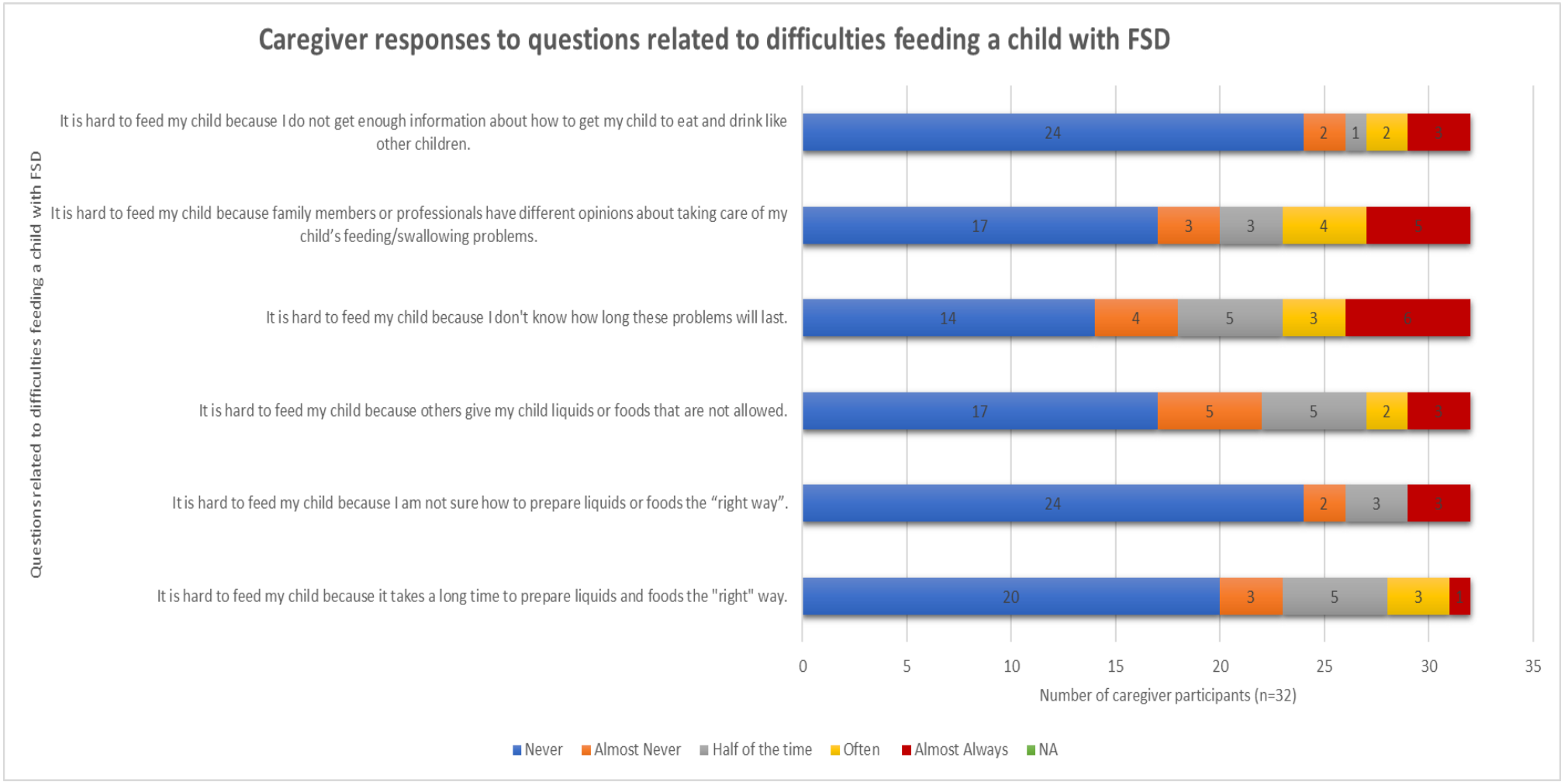

FIGURE 3: CAREGIVER PARTICIPANT PERCEPTION OF FEEDING THEIR CHILD WITH FSD (N=32)

The pilot study provided insight into the main concerns' caregiver participants experience in caring for their children with FSD in the South African context. The majority of caregiver participants reported concerns related to their child's general health, whether they were doing enough to help with their child's FSD, and reportedly felt it was hard to leave their child in the care of others.

5.4 Inter-item consistency and inter-rater reliability of the FS-IS

Cronbach's Alpha of 0.827 was obtained for item-total correlation, indicating an excellent level of inter-item consistency. Approximately 19% (6; n=32) of the questionnaires conducted were tested for inter-rater reliability and a 100% agreement was obtained between the two raters.

Intra-rater reliability was determined through the researcher randomly selecting 5% of the sample and readministering the FS-IS, blinded to the previous results. Intra-rater reliability was obtained with 100% agreement.

6 Discussion

Working as an SLT in a multilingual, multicultural and under-resourced environment such as South Africa, challenges arise that impact the care health professionals are able to provide to their patients including those with FSD (Bornman et al., 2010) and their caregivers. Some of these challenges include –but are not limited to– the variety of languages spoken which, in many cases, are not the first language of the health care professional. A barrier is often formed when health professionals are unable to communicate effectively with patients, even more so when the health care professional endeavours to provide care that is in-depth, and they do not have the resources to ask more appropriate or specific items to explore concerns of caregivers of the children in their care. Furthermore, cultural barriers may result in limited insight into the appropriate cultural and contextual care SLTs are able to provide. These barriers to care may prove to be inconsequential to those health care professionals unaware of the challenges caregivers of children with FSD face daily.

The needs of caregivers of children with FSD are complex and the burden of care can easily consume caregivers. Caring for a child with FSD is a challenge for caregivers as there is an increased burden related to the care they are required to provide for their child. Challenges include health concerns, nutritional status, psychological, emotional, behavioural, social, and environmental factors that contribute to continued caregiver burden, which further increases caregiver stress and consequently affects their HRQoL. These challenges can be complex for caregivers and create a great deal of stress which may affect adherence to care, household finances and the health of these caregivers. The health of caregivers of children with medical or chronic conditions such as FSD is an aspect that is commonly neglected when treating children with FSD. The FS-IS provides SLTs with a measure to evaluate HRQoL of caregivers. The cross-culturally adapted and translated versions developed as part of this study can be used in South Africa, and the concerns of caregivers can be identified and addressed by the treating health professional who is able to converse in the caregiver's language or with the assistance of an interpreter.

The discussion is organised according to the aims and objectives of the study. The limitations of the study will be discussed, as well as the clinical and research implications of the results. The results of the pilot study indicate that the validation and cross-cultural adaptation of the FS-IS for the South African context was successful and the adapted tool is suitable for use in the South African context. The pilot study described the effects of an increased burden of care on the HRQoL of caregivers caring for children with FSD.

6.1 Cross cultural-adaptation and validation of the FS-IS

Experts in the field of FSD in South Africa deemed the FS-IS appropriate for use in their context. Expert opinion feedback, as used in the current study, is an appropriate method for determining the content validity of a measure (Gosselin et al., 2014; Hyrkäs et al., 2003). The experts were able to provide judgements as to whether the FS-IS is able to measure its intended construct (Tuthill et al., 2014) in the South African context. The methodology used to obtain the content validity of the FS-IS was similar to the multi-step approach used by Tuthill et al. (2014) in which original tools were given to experts in their respective fields to determine whether items in the tools were appropriate for the South African context prior to translation into the official languages used.

The FS-IS has been validated in the Turkish language by Arslan et al. (2018) and it was therefore expected that the tool could be adapted for the South African context. As Turkey, like South Africa, is a lower middle-income country it was expected that the reliability and validity of the FS-IS would be similar. Furthermore, all the items on the Turkish version of the FS-IS, completed by Arslan et al. (2018) in which an expert committee reviewed the forward and back translations, remained the same as the original version of the FS-IS. Unlike the Turkish study, the current study also used caregiver participants in addition to an expert panel review to determine the cultural and linguistic appropriateness of the FS-IS in the South African context. Similarly, while determining the content validity of the FS-IS for the South African context, none of the items on the FS-IS were highlighted as irrelevant for the South African context by experts in the field of FSD or caregivers of children with FSD, with no omissions or redundancies identified.

Several of the experts' comments focused on the appropriacy of certain items for families accessing the public healthcare sector of South Africa. In South Africa, the two-tiered healthcare system consists of public and private healthcare. Most of the experts provided care in the public sector and felt there may be a large divide in the concerns caregivers may experience in lower income settings in comparison to those in the higher income settings such as those accessing private healthcare. Those accessing private healthcare are typically wealthier. The items highlighted by experts as potentially irrelevant included, **It is hard for my family to make plans or go out to eat** and **It is hard to feed my child because it takes a long time to prepare liquids and foods the "right way".** The experts felt that both items may not be relevant for South African families accessing the public health sector due to limited income and a lack of resources for these families.

With the assumption that these caregivers automatically fall within a certain income bracket the experts felt that caregivers accessing public healthcare services would not prioritize going out to eat. There are many aspects that play a part in accessing health care, and financial affordability is clearly

extremely important. However, assuming that all those accessing care in the public sector are less fortunate or poverty stricken may not be accurate. Chronic health conditions frequently require specialist care and therefore require recurrent medical check-ups and therapy sessions (Bandstra et al., 2011; Lutz, 2012) which may exceed the allocated allowance medical aids provide for families. These families may subsequently revert to public healthcare to continue the much-needed management for their child with a chronic condition, such as FSD. The public health care system is therefore often accessed by those who cannot afford medical aid or their medical aid funds have been diminished.

While it may be true that there are families accessing public health services who have limited resources and cannot afford the same luxuries as those in the private health sector, this should also not lead one to assumptions about the perceived importance of family outings. There may be those accessing public healthcare that value family excursions and going out to eat to places that are affordable or for special occasions, such as children's birthdays. Furthermore, going out to eat may not be limited to fine dining for all families, which discredits the assumption that going out to eat includes restaurant amenities that include tabletop dining. Limiting the meaning of **It is hard for my family to go out to eat** to restaurant dining is inappropriate and could be interpreted as patronising as it imposes a bias from the health professional that eating out is expensive and a rare luxury for all those accessing public healthcare and that it is restricted to restaurant dining. Going out to eat can be interpreted differently and could include fast food, a lunch or dinner at a family member's home, an outdoor event such as a braai or backyard birthday party or even weddings. It is seemingly prejudicial for healthcare professionals to presume that anyone accessing the public healthcare automatically excludes them from accessing food that is not home cooked, including fast food.

Experts also noted that those accessing public healthcare would probably not have access to blenders to prepare foods, which seems to limit food preparation for children with FSD to requiring a blender. Food preparation extends beyond blending to a pureed consistency and can include a variety of modifications including thickening of liquids to avoid aspiration of thin liquids, or mixing of powdered milk for gastrostomy feeding, increased textures or finger foods to improve the oral phase of the child or encourage feeding progression and further development. It is therefore important not to assume that these items are not appropriate for all caregivers accessing the state healthcare system. In addition, if a blender is the only consideration that professionals deem valuable in the preparation of foods for a child with FSD, it may be of concern if these professionals feel that this item was not relevant. Without a blender, the preparation time for pureed food may be increased for caregivers as they may be required to boil and mash the home cooked food to the desired

consistency which would be more time consuming and possibly stressful – thus increasing the relevance of the statement.

Similarly, it cannot be assumed that caregivers of children with FSD cannot afford to budget for the necessary utensils or equipment they require to ensure their child orally consumes the appropriate consistency, such as a blender. Priorities and responsibilities of caregivers of children with FSD may be different to those caregivers of children with other chronic conditions as well as those caregivers with typically developing children (Lutz, 2012). One should think laterally and not make assumptions about those accessing public healthcare or that preparation of food 'the right way' means using equipment such as blenders. It would be beneficial for health care professionals to recognize that there are a variety of ways in which a task can be done to yield the same result, encouraging cultural humility which promotes the development of an increased critical mindfulness of issues related to diversity (HPCSA, 2019). Despite their concerns the expert consensus was that those items should remain as they may be appropriate for some caregivers.

In addition to this, caregiver participants did not express the same concern regarding the item **It is hard for my family to go out to eat,** with 100% (n=15) of the caregiver participants reporting they felt the item was appropriate given their knowledge of FSD. This emphasizes that the preconceived ideas of what professionals deem important for caregivers of children with FSD are not necessarily consistent with those of caregivers themselves. Therefore, including the caregiver participants in cross-cultural and validation studies, such as this, is advantageous as it provides a contextually relevant interpretation of the tool and allows for a greater degree of accuracy in the content of items that caregivers identify as relevant.

Caregivers of children with FSD took part in the cross-cultural validation of the FS-IS through providing feedback on the English, Afrikaans and isiXhosa versions. The questionnaire used with the caregiver participants focused on the understanding of terms and items used in the translated and adapted versions of the FS-IS, the linguistic appropriateness, and whether caregiver participants considered the content of the items were appropriate for caregivers of children with FSD, and whether they would suggest any additions or omissions. The feedback from the caregiver participants was noted and changes to items on the FS-IS were made based on their feedback.

One expert stated that the statement **It is hard to feed my child because it takes a long time to prepare liquids and foods the "right" way** implied that there is a right way to prepare food for a child with FSD and suggested that the very next item in the original FS-IS could be omitted to reduced potential caregiver anxiety. This concern was only raised by one expert and thus did not meet the requirements for modification in the first phase of the study. The expert provided good

insight, as in phase 3 of the study this item was again flagged as one of interest and some dissent. While caregiver participants felt that all items were relevant and appropriate for caregivers of children with FSD, only 67% (n=10) felt that this item was important/appropriate based on their experience with FSD. Thus, a relatively high proportion of the caregiver participants indicated that the item should be reviewed and amended. While it is unclear why the caregiver participants felt this item was not relevant or appropriate it could possibly be due to the item potentially being vague. Caregivers may have felt that the item refers to general food preparation at home.

Ultimately, the item **It is hard to feed my child because it takes a long time to prepare liquids and foods the "right" way** was changed after phase 3, due to fewer than 70% of the caregiver participants stipulating that they felt that the item should be retained or remain unchanged. The item was amended to state: **It is hard to feed my child because I don't know how to prepare liquids and food the right way.** It appeared in the pilot study in this format so that the item could be clarified for caregiver participants. Changing the item may provide caregivers and caregiver participants with a clarification that the item refers to the preparation of food for their child with FSD.

The item **It is hard for my family to go out to eat** which had been raised by experts as potentially irrelevant or inappropriate for caregivers accessing the public health services was not raised by the caregivers. This indicated that caregiver participants felt this item was appropriate and relevant for fellow caregivers of children with FSD. This contrasting finding emphasises the role of "the single story" in literature and research, where the dominant story told (e.g., about being poor and not able to enjoy restaurants or special meals) becomes the single story which highlights the differences in people. However, stories empower and humanise those voices that go unheard while "the single story" is being told (Adichie, 2009). Utilising the opinions and experience of caregiver participants in the cultural and linguistic appropriateness component of cross-cultural adaptation and validation of the FS-IS allows for caregivers to create their unique narrative. Consequently, including caregiver participants in the creation, adaptation, and validation of a tool such as the FS-IS, was important, as professionals may not consider all aspects that are important to families.

There may be cultural components around mealtimes and eating that may vary between cultures but the challenges related to FSD seem to be universal (Mais et al., 2015). Cultural differences such as how meals are eaten (at the table or on the floor) or whether (and what) utensils are used are often components that define cultural differences surrounding mealtimes and food items (Hegde, Nair, Chandran, & Irshad, 2018). Despite these differences caregivers may feel as though the aspects surrounding FSD affect them equally or that the challenges they face during mealtimes are similar

despite their cultural differences. Furthermore, the items on the FS-IS are not culturally specific and do not mention utensils. Consequently, caregivers have the freedom to interpret items differently based on their own culture, context, and experience. In addition, it is also possible that, as the items chosen for the FS-IS were taken from caregiver reports in the original study, these items are more accurate and thus more relatable to caregivers of varying cultures, allowing them to be more appropriate for caregivers despite cultural differences.

The caregiver participants identified one word in isiXhosa that was incorrectly translated but they were able to understand the item with an explanation provided by the research assistant. The discrepancy was identified in the isiXhosa translated version of the item **It is hard to feed my child because family members or professionals have different opinions about taking care of my child's feeding/swallowing problems**. The original isiXhosa translated version translated to: **It is difficult to feed my baby because my family members, doctors and other people have different exams to take care of my child's eating or swallowing problems**. Therefore, *banemviwo* meaning t*hey have an exam* was reportedly not appropriate and was thus changed to *banezimvo,* meaning *they have ideas* for the adapted version which was used in the pilot study phase. Similar adaptations were seen in the studies completed by Smit et al. (2006), Morris et al. (2012), Tuthill et al. (2014) and Bresick et al. (2015) who followed the process of cross-cultural adaptation of various instruments for the South African context and made the necessary adjustments to adapt their tools where necessary for contextual and cultural relevance. For example, Smit et al. (2006) discussed concerns with formal and more conversational isiXhosa in their study notwithstanding the assurances that the language chosen should be more representative of the community – and thus informal as they consist of a mixture of dialects and other African languages. As there is no immediate past tense in isiXhosa, terms were discussed to ensure the most accurate message was conveyed to those participating. The translation of tools into a different language can be complicated by differences in dialect that impact on the translation process, and these translations should therefore focus on a broad audience (Pascoe & McLeod, 2016). For example, isiXhosa has many different varieties that are spoken in South Africa. These varieties depend on the geographical region, family history and language exposure and education of speakers. The amaXhosa are the second largest cultural group in South Africa, speaking isiXhosa which forms part of the Nguni group of languages. isiXhosa has several dialects including Mpondo, Xesibe, Bomwana, Gaika, Gcaleka, Thembu, Mpondomise, and Ndlambe with Ngqika named as the standard variety (Maqam, 2015). Some translators use the standard version of a language, but these 'standards' have often been arbitrarily chosen and are therefore not acceptable or easily understood by all language users. A good principle to use when translating is to use a variety that will be understood by the greatest possible number of people, and

the back translation method when translating from one language to another is beneficial in ensuring that the best possible translation is established (Colina, Marrone, Ingram, & Sánchez, 2017). In the current study, forward and back translation was used after experts reviewed the original FS-IS, and the translated versions of the FS-IS were cross-culturally and linguistically validated by caregivers of children with FSD who are native speakers of each of the languages. While there was only one term identified by caregivers as unclear in the isiXhosa version of the FS-IS, the FS-IS was cross-culturally validated and adapted in the Western Cape and thus, the dialects used may not be identical to that used by isiXhosa speakers in other provinces of South Africa.

The same holds true for Afrikaans spoken in different parts of South Africa with different dialects such as Kaaps (Cape Afrikaans), Orange River Afrikaans and East Cape Afrikaans (du Plessis & Grant, 2019). Due to the variety of dialects, there may be terms used in one dialect that may be different to another and this should be taken into consideration when considering the use of the adapted FS-IS for the South African context. The current version of the FS-IS was adapted in the Western Cape which should be noted when using the tool in other contexts as dialect can impact on the understanding of those participating (Isaacs, Roman, Savahl, & Sui, 2018).

In addition to the variety of dialects, there is often a lack of equivalence across the languages involved in the translation process. For example, the Afrikaans word “kort” when translated into English, depending on the context, can mean “short”, “brief”, “lack” or “shorten”. Due to the noun class system of African languages, agreement concords and morphosyntactic structure in translated items need to contain a noun class and subject concord as discussed in the study by Kunene Nicolas and Ahmed (2016). For example, “Show me running” when translated into isiZulu would be translated into “ngikhombise ogjimayo” back translating to, “Show me the person that is running”. In the current study one expert was concerned about the item **I worry about how my child breathes when feeding and whether my child will choke.** The translation of the word “choke” was potentially problematic as they were unsure if the meaning would change on translation and if the word “cough” would be substituted with another. Concerns from the expert were insightful and showed cognisance of the lack of equivalence in the translation process and the inconsistencies across different languages and cultures. However, no concerns were noted in the forward and back translation into Afrikaans or isiXhosa, with no concerns noted in phase 3 of the study in which caregivers reported on the cultural and linguistic appropriateness of the FS-IS in their respective languages. The context of the sentence may have increased comprehensibility of the statement posed to the caregiver participants as well as the caregivers’ personal experience of having a child with FSD. It is recommended to use the guidelines by Beaton et al. (2000) as the translation and cross-cultural adaptation process of tools into target languages is complex and requires analysis

prior to the administration of a pilot study to ensure the most appropriate translations and adaptations are used to ensure comprehension in the target audience.

Despite cultural and contextual differences, some items were noted by caregiver participants across the different languages to be inappropriate and although these items were retained in the adapted version (as the number of caregiver participants who highlighted concerns did not reach the cut off criteria of 70%), it is relevant to comment and highlight the concerns to provide additional insight into caregiver burden, concerns, and values. For example, some caregiver participants felt the item: **It is hard for my family to make plans or go out to eat,** was irrelevant as they felt strongly that caregivers should place the needs of their child above their own. Another felt that the item should only be asked to those who do not spend most of their time with their child. In addition to caregivers, experts had felt this item might not be relevant or appropriate due to economic reasons, but the caregivers who raised concerns about this particular item did so because they felt that caregivers should always put their child, and their child's caregiving needs, first.

This strong sense of parental duty was also noted in the responses of some caregivers to the items related to the caregiver **tiredness, how others will react to the child's FSD**, **and how the FSD may affects others in the family**. Caregivers caring for a child with a chronic medical condition such as FSD may experience a different "culture of parenting" to those with typically developing children. Caregivers of children with FSD frequently place the needs of their child above their own and may also feel a deep sense of responsibility towards their child as they may be the only caregiver who is able to care for their child adequately. This "culture of parenting a child with a chronic medical condition" may not be restricted to language, dialect, or ethnic origin, but extends to the burden of care primary caregivers experience in caring for their child. These caregivers may increase their own responsibilities as they may feel that if they complain about not being able to attend social events, go out to eat or feel tired, they would have failed in their duty as a primary caregiver (Murphy et al., 2007). It would be of great benefit to explore the culture of parenting a child with a medical condition as this may highlight the similarities across differing languages and cultures as families and caregivers of children with medical conditions have many common experiences as they care for their children (Baumbusch, Mayer, & Sloan-Yip, 2018).

In addition to these, the original item, **It is hard to feed my child because I don't know how to prepare liquids and foods** a participant stated that the healthcare team teaches caregivers in this regard. Another caregiver felt the following item was irrelevant, **It is hard to feed my child because family members or professionals have different opinions about taking care of my child's feeding/swallowing problems,** as they felt that professionals should be listened to. These caregiver

participants show confidence in their MDT and felt comfortable in the care they were receiving. This indicates the importance of a good MDT, in which the caregiver is a role player. Caregivers should be included in the care and trained to ensure they can prepare liquids and foods correctly, so they are subsequently confident in preparing these for their child with FSD. Caregiver satisfaction with their MDT impacts on their HRQoL. This can be identified using the FS-IS and should be addressed. Caregivers appreciate it when their feelings are heard and they are involved and valued in the care their child receives (Cowpe et al., 2014; Lutz, 2012). To manage varying opinions and to ensure the entire MDT (including caregivers) are 'on the same page,' caregivers' opinions must be taken into consideration when planning management. Furthermore, caregivers appreciate training and professionals who provide clear and consistent information. This may encourage caregivers to execute the appropriate management in the home environment (Dodrill, 2014), inform their MDT of changes and difficulties that may occur while working as a team towards a single goal for the benefit of their child with FSD.

The adapted and translated FS-IS was considered contextually, culturally and linguistically appropriate for use within the South African context. Expert participants found the tool to be contextually appropriate for the South African context with no items highlighted that required changes. Caregiver participants found the items to be suitable for their respective languages, indicating an adequately translated, adapted, and validated version of the FS-IS, apart from one amendment of the word, **banemviwo** which was changed to **banezimvo** in the isiXhosa version of the FS-IS.

6.2 Reliability and Validity of the FS-IS

Internal reliability, intra-rater reliability and inter-rater reliability were determined for the adapted FS-IS in the SA context. A Cronbach's alpha of 0.827 was established for internal reliability of the cross-culturally adapted and validated version of the FS-IS in South Africa, indicating excellent internal reliability as values above 0.80 are considered excellent (Grady, Cummings, & Hulley, 2013). The internal reliability of the FS-IS in the original validation study by Lefton-Greif et al. (2014) was good, with a Cronbach's alpha above 0.7.

Inter-rater reliability evaluates whether data collected by two separate raters agree with each other (Fink, 2008; Leedy & Ormrod, 2005; Tredoux & Durrheim, 2002). The inter-rater reliability in the current study was established with 100% agreement with 19% of the sample when a research assistant completed the FS-IS using audio recordings, blinded to the original results. This indicates that the FS-IS has a high usability among different raters and will produce similar results among

different raters. Therefore, the FS-IS can be administered by other health care professionals and yield accurate results.

Intra-rater reliability evaluates how well the data captured could be reproduced when the researcher repeated the process (Leedy & Ormrod, 2005; Tredoux & Durrheim, 2002). Inter-rater reliability was established with 5% of the sample and compared with the original data set, 100% agreement was established (Gomm, 2008; Jackson, 2015). This indicates that the researcher was able to complete the FS-IS in the same manner in which the FS-IS was administered in the pilot study. This is a good indication for future research, indicating that the administration of this tool was sound and can be duplicated for use in other similar studies.

The validity and reliability of the FS-IS was established for the South African context indicating that the FS-IS is a reliable and valid tool that can be used to determine the HRQoL of caregivers of children with FSD in this context. The validation and reliability of the FS-IS contributes to the field of FSD in South Africa encouraging SLTs to use the FS-IS to improve their care and identify those caregivers that require additional support as they care for their child with FSD.

6.3 Pilot use of the adapted and validated FS-IS in the South African Context

The cross-culturally adapted and validated versions of the FS-IS in English, Afrikaans and isiXhosa were used in the pilot study with 32 caregivers to describe caregiver participant concerns related to caring for a child with FSD. Children with FSD are frequently medically complex and their care has an impact on the HRQoL of their caregivers. Information obtained from a contextually relevant tool, such as the adapted FS-IS, would therefore be beneficial in assisting South African healthcare professionals to identify stressors in caregivers required to care for their child with FSD.

The scores ranged from 1 to 5 with lower scores indicating better QoL as caregivers would have responded to most items with *never*. Higher scores indicated that caregivers answered most of the items with *almost always.* Caregivers scoring between 3-3.99 indicate that most of their responses were *half of the time* or *often* – and could indicate that their HRQoL is moderately affected by their child's FSD. Thirty one percent (n=10) of participants scored between 3-3.99 on the adapted FS-IS, indicating a reduction in their HRQoL as a result of the care they are required to provide for their child with FSD. Most of these participants included English (n=4) and Afrikaans (n=4) participants with few isiXhosa (n=2) indicating that participants' HRQoL can be affected despite cultural differences. Less than 20% of caregiver participants (19%, n=6) scored low on the adapted version of the FS-IS indicating their HRQoL was not significantly affected by the care they were required to

provide for their child with FSD. Reasons for the reduced caregiver HRQoL can be identified on the FS-IS as higher scores indicate a reduced HRQoL. Reasons for the impact on caregivers' HRQoL are discussed below.

The majority of caregiver participants reported worrying about their child's general health, with 84% (n=27) sharing this sentiment. It is common for caregivers of children with chronic conditions – including FSD – to be concerned regarding their child's physical health (Besser, 2018; Howe et al., 2014), and this may be further exacerbated by medical complications associated with FSD (Anderson et al., 2001; McDougall et al., 2009; Wu et al., 2012). The constant concern for their child's health increases the caregivers' stress which results in an increased burden of care and stress (Batchelor, 2007; Franklin & Rodger, 2003; Lefton-Greif et al., 2014; Mahant et al., 2011; Simione et al., 2020; Winston et al., 2010). Increased levels of stress and burden of care have been linked to reduced HRQoL of caregivers (Iconomou, 2001). This was found to be consistent with previous studies, such as the one conducted by Tregay et al. (2017) in which it was found that caregivers experienced high levels of stress due to the health concerns they have regarding their child and their constant fear about their child's survival. Supporting the notion that constant worry and concern increases caregiver burden, increasing caregiver stress which results in a reduced HRQoL, a large proportion of caregivers participating in the pilot study expressed concerns regarding their child's health.

Health professionals may be accustomed to discussing medical conditions or complications as they are concepts spoken about daily, however, caregivers may be addressing these concerns for the first time and medical terminology in conjunction with any complications that may occur as a result of their child's condition can be overwhelming and stressful. Many caregiver participants stated they had difficulties in the initial stages of caring for their child with FSD suggesting that those initial stages are crucial for professionals to assist caregivers in managing their child and their FSD as well as manage the stress they experience while caring for their child, particularly after the initial diagnosis.

The stress experienced by these caregivers may result in reduced comprehension of the medical condition of their child, furthermore, these caregivers may not recall all the information provided to them by their health care professional (Engel et al., 2009). Empathy should be practiced by health care professionals (Sabzevari & Nematollahi, 2016) to ensure caregivers are sufficiently educated and confident in the care they are required to provide for their child. It would be recommended that health professionals provide additional, regular feedback and therapy sessions to assist with comprehension and retention of information, as effective communication is essential to ensure the engagement of families (James, Ziviani, King, & Boyd, 2016). Continued caregiver education,

physical handouts and follow up appointments to discuss the diagnosis in person or telephonically can be beneficial to assist in this regard. Furthermore, caregivers may appreciate opportunities in which they can discuss their concerns regarding their child's health with their child's health professional as they are familiar with their child and their medical condition. Health care professionals should be encouraged to provide formal and informal support to these caregivers, particularly in the initial stages of treatment. Learning to care for a child with a chronic condition impacts on caregiver HRQoL (Lutz, 2012) and they would thus benefit from formal and informal support (Azios et al., 2016; Erasmus et al., 2012).

In addition to the concerns regarding their child's general health, caregivers are faced with feelings of fear related to their child's survival. These may include concerns of the safety of oral intake due to aspiration and choking risks (Batchelor, 2007; Franklin & Rodger, 2003; Mahant et al., 2011; Marques & Sá, 2016; Rybak, 2015; Winston et al., 2010). Twenty-five percent (n=8) of caregiver participants stated that they worried about how their child breathes when feeding and whether their child will choke as a result of their FSD, as penetration of a bolus into the airway may result in coughing, choking or aspiration (Mahant et al., 2011; Rybak, 2015).

Coughing, choking or aspiration episodes can be stressful for any caregiver but are understandably increasingly stressful for caregivers of children with FSD as these episodes may be more frequent for their children. The negative effects of aspiration on a child's health and the consequences of choking can typically cause an increase in stress for caregivers as these may have lifelong effects on the child, such as damage to developing lungs and further increasing the risk of the child contracting recurrent LRTIs and hospitalisation (Anderson et al., 2001; Besser, 2018; Tutor & Gosa, 2012; Wu et al., 2012). With this in mind, caregivers of children with FSD would probably be familiar with the repercussions following aspiration or choking episodes as they may have previously led to hospitalisations, which may already be a frequent occurrence in the lives of children with FSD. In addition to caregiver experiences, health professionals may have trained caregivers to observe and be aware of the more subtle signs of aspiration and this may cause caregivers additional stress as their knowledge of the potential impact of aspiration on their child can cause them to feel overwhelmed.

This stress these caregivers experience when feeding their child with FSD may cause them to be extra cautious and fear other people feeding their child when they are not present, or even fear progressing their child in the feeding plan as they feel the current plan is the safest. However, delaying progression can impact negatively on the child's feeding development. It would therefore be recommended that caregivers of children with FSD receive continual education surrounding the safety of their child's oral feeding to ensure caregivers are comfortable, confident and competent in

the home environment when providing the management recommended by their SLT. Healthcare professionals should also explore dysphagia support groups to encourage parent-to-parent interaction and allow for the expression of frustration and stress related to caring for a child with FSD, as it is evident that the HRQoL of caregivers is affected. In a qualitative study by Howells, Cornwell, Ward, and Kuipers (2021) some caregivers reported benefits of support groups for FSD including; social interaction and the sharing of ideas between caregivers.

Although some caregivers expressed concern surrounding their child coughing or choking during feeding times, 75% (n=24) of the caregiver participants did not, which may be due to different reasons, which include their child being tube fed or the caregivers being used to or comfortable with the feeding management. For some, the tube is the only method of feeding their child and these caregivers may feel stress related to the tube itself; management of the tube, site and feeds, as well as the possibility of the tube dislodging as this is the only manner in which their child can receive nutrition (Burdall et al., 2017). Caregivers may consequently be hesitant to allow others to care for their child and feed their child as they are solely trained in the event something goes amiss.

It is also possible that many of the caregivers participating in the pilot study had grown accustomed to their child's FSD and were no longer constantly concerned about aspiration and choking as they may have been in the initial stages of the diagnosis. This fits with Pinquart (2018) who mentions that lower levels of parenting stress is expected in those caregivers who have been living with a child with a chronic condition over a longer duration. While the caregivers in the present study are currently receiving treatment for their child's FSD, it is possible that their reduced concern is related to the established safe manner of oral feeding reducing the risk of choking or aspiration during feeds (Benfer et al., 2015). In addition to this, caregivers may feel confident in their ability to feed their child with the guidance they have received from their SLT. Thus, indicating that good education and training of caregivers may have a tremendous impact on the HRQoL of the caregivers, with many caregiver participants indicating their contentment with the care they received from their health care professional.

Half (n=16) of the caregiver participants worried about whether they were doing enough to help with their child's FSD. Many caregivers create associations between feelings of success with feelings of competency. This association may result in caregivers blaming themselves for their child's inability to meet their nutritional requirements through oral feeding (Andrew et al., 2012; Andrew & Sullivan, 2010; Batchelor, 2007; Besser, 2018; Cowpe et al., 2014; Craig, 2013). These feelings of inadequacy are common for caregivers of children with chronic conditions (Tregay et al., 2017). However, such

feelings may result in an increase in caregiver anxiety and feelings of stress, and add to the emotional burden resulting in reduced HRQoL (Lowes et al., 2016).

Caregivers would benefit from continued education surrounding their child's medical condition and reinforcement that they are providing the correct, adequate and appropriate care for their child with the guidance of their MDT. They should be reminded that they, as caregivers, are vital in the management of their child's FSD (Rogers, 2004). Furthermore, caregivers, as part of the MDT should be part of the decision making process to avoid feelings of being unheard or undervalued as a key member of the MDT (Cowpe et al., 2014). Creating a healthy, open and honest communication channel between caregiver and their child's MDT alleviates the additional stress and allows for understanding, value and support to be key components of the management of a child with FSD. This will allow further investment from caregivers as they see their child's MDT invested in the care of their child, updating management plans and goals based on their child's progress.

In the event that caregivers are emotionally consumed in blaming themselves, it would be beneficial to ensure they are treated appropriately by a mental health professional, especially if their HRQoL is being affected significantly. The emotional impact of caring for a child with FSD should not be underestimated due to the negative effects on the HRQoL of caregivers (Lima et al., 2016) and these should be identified by health care professionals to ensure caregivers are provided with or referred to the appropriate professional for additional support. Support in the forms of services, education, information and training as well as informal support has the potential to reduce stress and improve QoL and subsequent HRQoL in caregivers of children with FSD (Charpentier et al., 2020; Swift & Scholten, 2010). It may also be beneficial for an SLT to assess whether caregivers' HRQoL is improving over time due to the additional support provided after the initial completion of the FS-IS.

Half (n=16, 50%) of the caregiver participants found it **hard to get help from others** while more than half (n=19; 62.5%) reported that it is **difficult to leave their child with someone else**. Caregiver participants stated the causes of these difficulties included the fear others have in caring for a child with FSD, and the lack of trust they themselves had in others to assist with the complex needs of their child's FSD as reported by Winston et al. (2010) which makes it more challenging to find carers or babysitters for their child (Mahant et al., 2011). Therefore, caregiver participants reportedly arranged chores and errands around their child's feeding schedule, such as their shopping trips, to ensure they were home on time for mealtimes.

Caregivers may be solely trained in feeding and preparing meals for their child and subsequent stress related to caring for their child's meticulous needs may cause caregivers to be hesitant when sharing the burden of care. A caregiver participant reported family members and babysitters require

training and time to learn how to care for their child with FSD. Caregivers need training to insert and reinsert NGT and gastrostomy tubes therefore, caregiver participants were concerned about leaving their child receiving tube feeds in the care of others with the fear of these needing replacement or management when they are not present (Burdall et al., 2017). This concurs with the research of Winston et al. (2010) in which caregivers reported that leaving their child in the care of others was difficult as they may not be equipped to attend to their feeding needs. Difficulties leaving home and finding suitable babysitters or carers was a problem (Mahant et al., 2011). Caregivers may therefore feel safer to maintain the role of sole caregiver instead of handing over the care to others. This hesitance may result in caregivers having reduced opportunities to leave home, work or tend to other chores or social events, subsequently resulting in increased burden of care and reduced HRQoL.

Secondary caregiver training should be encouraged to assist with alleviating the burden of care on the primary caregiver (Zuurmond et al., 2019). Secondary caregiver training could take on the form of the primary caregiver training a secondary caregiver under the supervision of the health professional to ensure proper training is being conducted. Secondary caregiver training would alleviate the sole burden of care from the primary caregiver and allow the primary caregiver adequate time for work, chores and other personal activities. Having a secondary caregiver that the primary caregiver trusts will ease their burden as they may feel as though they are able to share in the care of their child. Caregivers may be able to take turns attending appointments and reduce the number of times a single caregiver needs to take off work to attend appointments, this could improve the financial burden experienced as they have a greater chance of maintaining a stable job to ensure sufficient income into the household. Furthermore, those caregivers who miss medical appointments because of work will have someone they trust attend the medical or therapy appointments with their child with FSD thus allowing for these children to attend more frequent therapy sessions and allow opportunities for improvement and progress with more regular sessions attended. The shared load will allow for a balanced life which will hopefully reduce stress and subsequently improve HRQoL of the caregivers of children with FSD. Improving caregiver HRQoL impacts on the care children with FSD receive. Lastly, health care professionals should be open to assisting with secondary caregiver training for those caregivers who feel it may be useful. Caregivers may feel further supported by the care they receive from their health care provider and appreciate their thoughtfulness.

Almost half of the caregiver participants (41%, n=13) reported feelings of tiredness associated with the care for their children with FSD. The burden of caring for a child with a disability impacts on the health of caregivers as there is an increased physical demand required to care for their child

(Cousino & Hazen, 2013; Lima et al., 2016). Follent et al. (2017) reported that many mothers found caring for a child with FSD to be exhausting, and caregiver participants in the pilot study also reported exhaustion due to caring for their child with FSD. It was expected that more caregivers would express feelings of exhaustion due to the increased caregiving demands. While a few caregivers acknowledged the effects of the burden of care there are others who may not feel it is a priority in relation to their child's needs (Murphy et al., 2007). Caregiver participants may have become accustomed to the care needed for their child with FSD and neglect to care for themselves. Literature suggests that caregivers may neglect themselves and their own well-being in an effort to prioritise the care for their child and the needs of their child, and therefore neglect to report these feelings (Raatz et al., 2020; Simione et al., 2020). This could subsequently result in the dismissal of any feeling of tiredness as caregiver participants may feel as though the acknowledgement of their feelings of tiredness, diminishes or reduces their value or ability as caregivers.

Caregiver participants may feel that reporting tiredness is a sign of complaining about their responsibilities to their child with FSD. They may feel that being tired and acknowledging their tiredness is a sign that they are not adequate parents or doing enough for their child, which would thus result in caregiver participants stating that they "never" feel tired when they in fact do. Caregivers may feel a sense of duty to their child and thus place their child's needs above theirs, their *child comes first*. In addition to the sense of duty caregivers may feel an irrevocable sense of value, which is not disregarded, in the care they provide for their child with FSD, but may feel that others, similarly, should share the same perceptions and values.

The lack or reduced amount of help that these caregiver participants have access to can be an additional stressor in the care of their child with FSD as they are the sole caregiver ensuring their child's specific needs are met. This may compound the reasons for caregivers' unwillingness to admit their exhaustion. Admitting exhaustion may cause caregivers additional emotional stress as they may feel helpless in their ability to care for their child with FSD. Insecurities and feelings of self-doubt may result in a reduced emotional QoL in caregivers of children with FSD (Lowes et al., 2016).

Despite the 'single story' of caregivers receiving public health care being unable to afford to go out to eat, it is fascinating to note that more than half of the participants reported difficulty going out to eat. Sixty-five percent (n=20) of caregiver participants reported that it was **hard for their family to make plans to go out to eat**. Some of the reasons included the frequent occurrence of people staring and the need to ensure the correct consistency of the food their child can manage – all of which can be embarrassing for some caregiver participants. Some caregiver participants reported they hide their child in their pram and under a blanket during feeds when in public due to the stigma

surrounding their child's tube feed – a common theme noted by Mahant et al. (2011). The reasons for these difficulties vary between caregiver participants. While there are those who withstand the stares, there are others who limit the number of times they go out to eat to avoid uncomfortable glances when they are with their child. This avoidance creates additional stress and isolation as caregivers avoid other social events that require their child to eat in front of others and structure their lives around their child's feeding schedule (Balling & McCubbin, 2001; Batchelor, 2007; Craig, 2013; Hewetson & Singh, 2009; Mahant et al., 2011).

The impact of stigma and stress may result in a negative impact of social isolation on caregivers and family HRQoL, a common theme in the literature (Lutz, 2012; Mahant et al., 2011). In the event they are to attend a social gathering without children, leaving a child with FSD in the care of a babysitter or another carer who is not trained in caring for the child, adds stress to the caregivers and may subsequently reduce their HRQoL as they avoid social functions to reduce the anxiety they may experience when they are required to leave their child. The stress these caregivers may experience may result in the social event being stressful instead of a positive social experience. Caregivers can be encouraged to prepare meals for their child ahead of time to allow for easy feeding by the babysitter when they are not present. In addition, SLTs can offer secondary caregiver training to assist with the alleviation of stress when caregivers do leave their child to attend social gatherings alone.

The mealtime experience for families with children with FSD may be lost due to the stress associated with possible aspiration, choking, feeding specifications or messy eating. There may be increased feelings of stress experienced in public spaces whether it be a birthday party or restaurant. Health care professionals can encourage these families to enjoy family outings that do not involve meals, in a different environment to encourage positive social experiences as a family.

Caregiver participants reported a desire for additional support to assist them in the care they provide for their child with FSD. Addressing caregiver support needs assists in the reduction of caregiver stress (Garro et al., 2005). In addition caregiver satisfaction with the care they receive from health care professionals assists caregivers in their ability to cope with their stress (Franklin & Rodger, 2003). In the pilot study caregiver participants mentioned support groups as a form of informal support they would have appreciated as they cared for their child with FSD. The same sentiment was noted in the literature with support groups being identified as helpful and empowering (Cowpe et al., 2014) and health care professionals should be encouraging to caregivers and provide them with resources to access the appropriate support groups (Hsiao, 2018) which reduces stress and increase HRQoL. An example of a successful support group is the Toy Library at

RCWMCH that gathers once a month for caregivers of children with Down Syndrome where they have the opportunity to share experiences and provide, informal, parent-to-parent support. Support groups can start on social media sites such as Facebook or WhatsApp with caregivers helping each other over a secure platform in which they feel encouraged and supported by others who have similar experiences to theirs. However, bringing children along could be distracting for caregivers as they will be required to care for their child while still being present at the support group. Caregivers may therefore appreciate support groups that accommodate children so that they will not need to find alternative carers or babysitters at home which may incur additional costs.

In response to the item: **It is hard to feed my child because family members or professionals have different opinions about taking care of my child's feeding/swallowing problems** caregivers noted the importance of listening to the health care professionals, and while they did not feel they experienced difficulties in feeding their child because of differing opinions, there were those caregivers who, respectfully tried things on their own using their discretion. While the risk of coughing, choking and aspiration may be stressful for caregivers, it can be a source of stress for health care professionals as well, due to the adverse health effects of aspiration on a child. This stress may cause professionals to be cautious and at times, over cautious, to ensure adequate safety of any oral intake of children with FSD. An overcautious, stringent therapist may cause caregivers to be dishonest regarding the feeding management in the home environment and result in caregivers progressing their children without guidance, further increasing their risk of choking, coughing and aspiration as seen in the pilot study. An open-door policy may be valuable for all involved, to encourage honesty from all parties, and it would be of great benefit to include the caregiver as part of the MDT to ensure that holistic and appropriate care is provided for the child with FSD.

Financial strain also impacts caregiver stress. There is a relationship between income, caregiver responsibility and distress. For example, Molzon et al. (2018) found that all families were impacted financially, but those in the lower income bracket were more affected than those in higher income groups. One of the caregiver participants highlighted this, as the support she was able to afford was different to that of a mother and friend she met at the hospital who had subsequently given up her job to care for her child with FSD. The stark divide between incomes was noted by this caregiver who compared the stress that she and her friend experienced. She felt that her double income household was privileged enough to afford a carer who was able to accompany their child with FSD to school daily and her family did not experience a loss of income compared to the caregiver in the lower income bracket. While some caregivers may be better off financially these additional costs could still

cause stress as there is still an increase in the household expenses and may place additional pressure on working parents. Attending numerous hospital appointments and frequent hospitalisations may result in caregivers choosing to stay at home to care for their child or not being able to retain their employment because of frequently missing work (Connor et al., 2010). This potential loss of income together with the considerable health costs associated with caring for a child with FSD (Connor et al., 2010; Eunson, 2015; Howe et al., 2014; Sloper & Turner, 1992; Winston et al., 2010) may cause additional stress on the caregivers subsequently affecting their HRQoL.

Children with FSD are usually medically complex which impacts on the physical, psychological and emotional wellbeing of their caregivers (Hatzmann et al., 2009; Lefton-Greif et al., 2014; Pedersen et al., 2004; Raina et al., 2004). As noted in the pilot study, caregivers assume the role of the sole caregiver when caring for their child with FSD (Azios et al., 2016). Furthermore, feelings of guilt, inadequacy and failure were common among the caregivers participating in the study. These feelings have the potential to increase as caregivers experience the impact of the burden of care on their physical, psychological and emotional well-being, which may be overwhelming for some and subsequently increase caregiver stress, reducing their HRQoL. The data suggest that the HRQoL of parents and caregivers is a vital aspect to consider in patient care as it affects the care that caregivers provide for their child with FSD. The identification of caregiver stressors and management of these through support assists in the improvement of their HRQoL (Swift & Scholten, 2010).

The FS-IS that was adapted and validated for the SA context was helpful in identifying caregiver HRQoL and their awareness (or lack thereof) of the effects of caring for a child with FSD. This version of the FS-IS for the South African context provides SLTs in this context with the opportunity to identify and address the health needs of caregivers of children with FSD. It was seen to be beneficial in identifying the need for additional support for caregivers as well as improvements in the management of caregivers as part of the MDT to ensure optimal health outcomes for children with FSD. In addition, the FS-IS can be used with a caregiver at different stages in the care of their child, including to assess their initial HRQoL as they adjust to their child's diagnosis and coping in the home environment. In the US the FS-IS filled a gap in the literature and now assists in the identification and tracking of the needs of caregivers of children with FSD (Lefton-Greif et al., 2014).

In line with the hypothesis that caregiver HRQoL is affected by the stress related to the care they are required to provide for their child with FSD, the adapted and validated version of the FS-IS assists in the identification of the stress parents and caregivers experience and its subsequent effect on their HRQoL. The cross-cultural adaptation and validation of the FS-IS will provide SLTs with insight into

the additional care caregivers and their children require to ensure optimal and holistic health. The responses of the parents and caregivers in the pilot study relating to Daily activities, Worry and Feeding Difficulties, subscales of the FS-IS, were similar to that obtained in the original study completed by Lefton-Greif et al. (2014), both with good internal reliability. Therefore, as stress affects the HRQoL of caregivers it is important to identify caregiver support needs as part of the comprehensive care we provide for children with FSD and the cross-culturally adapted and validated version of the FS-IS is an appropriate way to do this.

The continuous care caregivers are required to provide for their child with FSD notably affected them. A variety of concerns were highlighted in the pilot study including concerns around the general health of their child, concerns surrounding whether their child will choke during meals, lack of additional carers and not being able to go out to eat. All these factors result in social isolation, increased stress and reduced HRQoL. These caregivers may feel so burdened in caring for their child that they do not comprehend how engulfed their lives are in the care of their child with FSD. Furthermore, caregivers are noted to distrust the ability of another person to care for their child due to their difficulty leaving their child with FSD in the care of an individual that is not adequately trained in the provision of the care their child needs (Winston et al., 2010).

It is mutually beneficial for SLTs to use the FS-IS to determine which areas caregivers require assistance to ensure improved HRQoL as they care for their child with FSD. Comprehensive management can be done with the help of the FS-IS as caregivers may not be aware of the effect the burden of caring for their child with FSD has on their HRQoL. Caregivers will benefit from support which could be provided in various forms including formal and informal support to ensure a good HRQoL.

7 Limitations and recommendations for future research

A limitation identified in the first phase of the study was the sample size of expert SLTs (n=5) participating in the study. Although more SLTs were contacted, only five responded and agreed to participate. It would, therefore, be beneficial to recruit more than five expert participants as five to ten experts are recommended to assure good content validity (Hyrkäs et al., 2003).

A limitation identified in phase 2 of the study was that none of the translators used in the translation process, for their respective languages, consulted with each other to discuss any of the discrepancies, such as that identified in the isiXhosa version of the FS-IS, that arose in phase 3 of the study. These discrepancies were discussed with the researchers and the translator and research assistant but not by the forward and back translators. It would be beneficial to ensure accuracy of changes if first language speakers of the respective languages can discuss and agree on the best amendment, especially if the amendment is for a language that is not the first language of one of the researchers (as it was in this case).

While the sample size of the pilot study was sufficient for the validation of the FS-IS and showed similar results to other studies of validation of the FS-IS, it cannot be generalised beyond the specific context. However, the work described here could be used as a starting point for future studies that would involve the use of the FS-IS in the South African context. Future research should therefore consider using the FS-IS with a larger sample and in a longitudinal study to track and compare the HRQoL of caregivers of children with FSD over time. Longitudinal studies would be beneficial for future research to determine the progression of caregiver HRQoL over time and the subsequent effects of continued management of children with FSD and the impact improving the care has on caregivers' HRQoL.

Additional information surrounding the diagnoses of the children involved, date of initiation of FSD management as well as socioeconomic information, including caregiver employment, would be useful for future studies in determining additional factors that could be associated with the HRQoL of caregivers of children with FSD. The participants consisted of biological parents, grandmothers and foster parents that were deemed the primary caregiver of the child with FSD. The type, range and severity of FSD varied, however all were included with some children requiring gastrostomy feeds, NGT feeds and oral feeds with consistency limitations due to aspiration risks. However, caregivers of children in long-term placement facilities were not included in the study.

Furthermore, comparison studies could be conducted to compare the HRQoL of children with FSD who are diagnosed with other chronic conditions in comparison to those without. Further research

would be beneficial in determining the perceived stress caregivers experience as they care for their child with FSD as well as their perceived HRQoL.

Although the FS-IS was used as a determiner of the HRQoL of caregivers of children with FSD, the overall HRQoL score should be interpreted by the professional involved. There are no baseline OR ceiling scores that professionals can use to determine whether caregivers required additional psychological review to assist them in coping with their child's FSD, the treating health professional is to determine this at their own discretion.

Another limitation of this study is that the FS-IS was administered by SLTs and it can therefore not be assumed that the questionnaire can be used by other health care professionals, such as social workers, doctors, physiotherapists etc. and other professionals that are not directly involved in the intricacies of FSD management. Both inter- and intra-rater reliability was established by SLTs. This in part is due to the knowledge SLTs have surrounding FSD and the potential impact of this on caregivers as they care for their child with FSD. It would therefore be recommended that inter and intra-rater reliability be established by other professionals as this will ensure that the usability of the FS-IS in the SA context can be used by other professionals and not only SLTs, ensuring that the HRQoL of caregivers of children with FSD, is not overlooked by other professionals involved in the care of these children, for example by dieticians.

The study was conducted in the Western Cape and the FS-IS adapted for this population and dialect of English, isiXhosa and Afrikaans, all of which are limitations to the generalisability of the use of the FS-IS in other contexts of South Africa due to varying dialects. With 11 official languages in South Africa and immense diversity, it would be beneficial to validate the FS-IS for other languages spoken.

Access to MDT management of children with FSD in rural settings is a known difficulty of caregivers in the South African context. Furthermore, this study was conducted at two tertiary hospitals in the Western Cape both of which have established SLT services running. Many children with FSD live in rural areas and subsequently travel to cities for health care. Therefore, studies that investigate the caregiver burden and HRQoL of caregivers of children with FSD, in different contexts would be beneficial to the knowledge base of appropriate and effective care for these caregivers and their children.

In addition to the recommendations, future research should focus on expanding the usability of the FS-IS for other communities in South Africa, including those families in rural settings and at primary healthcare facilities where there is limited access to healthcare and where the initial point of contact is usually their local clinic. Further research conducted in various settings in South Africa is needed to

improve the robustness of the FS-IS. To achieve this, it is recommended that the FS-IS be translated into other South African languages so they can be used in a broader range of settings. For example, similar to the study conducted by Bresick et al. (2015), the FS-IS included only the public sector and not the private sector. It is therefore recommended that the FS-IS be validated for use within the private sector of South Africa as well.

Therefore, it is recommended that future research uses a larger sample size that has a substantial representation of caregivers who have children with recently diagnosed FSD as well as those who have adapted and adjusted their lives around their child's FSD. This could indicate whether HRQoL improves as caregivers adapt to caring for their child with FSD, or whether they have reached some form of overcompensation or perhaps denial about the effects of their child's FSD on their HRQoL. Furthermore, it is recommended that the FS-IS be administered using other health professionals involved in the treatment of children with FSD, as it has only been established with SLTs.

8 Conclusion

The current study has shown promising results for the use of the FS-IS as a tool to determine the HRQoL of caregivers of children attending tertiary FSD clinics in the Western Cape. The nature, range and severity of FSD these children may present with is complex and has the potential to impact on the HRQoL of their caregivers. The findings provide insight into the burden caregivers experience in caring for their child with FSD, as well as the need for a tool to measure their HRQoL in the South African context.

The FS-IS was cross-culturally adapted and validated into English, Afrikaans and isiXhosa for use in the South African context. Face and content validity were determined by expert participants, while the linguistic appropriateness of all three versions of the scale was refined through interviews with caregivers. The study has shown that the FS-IS has acceptable criterion validity and construct validity, along with acceptable inter and intra-rater reliability suggesting a new and important contribution to contextually relevant resources for South African healthcare providers and the families they serve.

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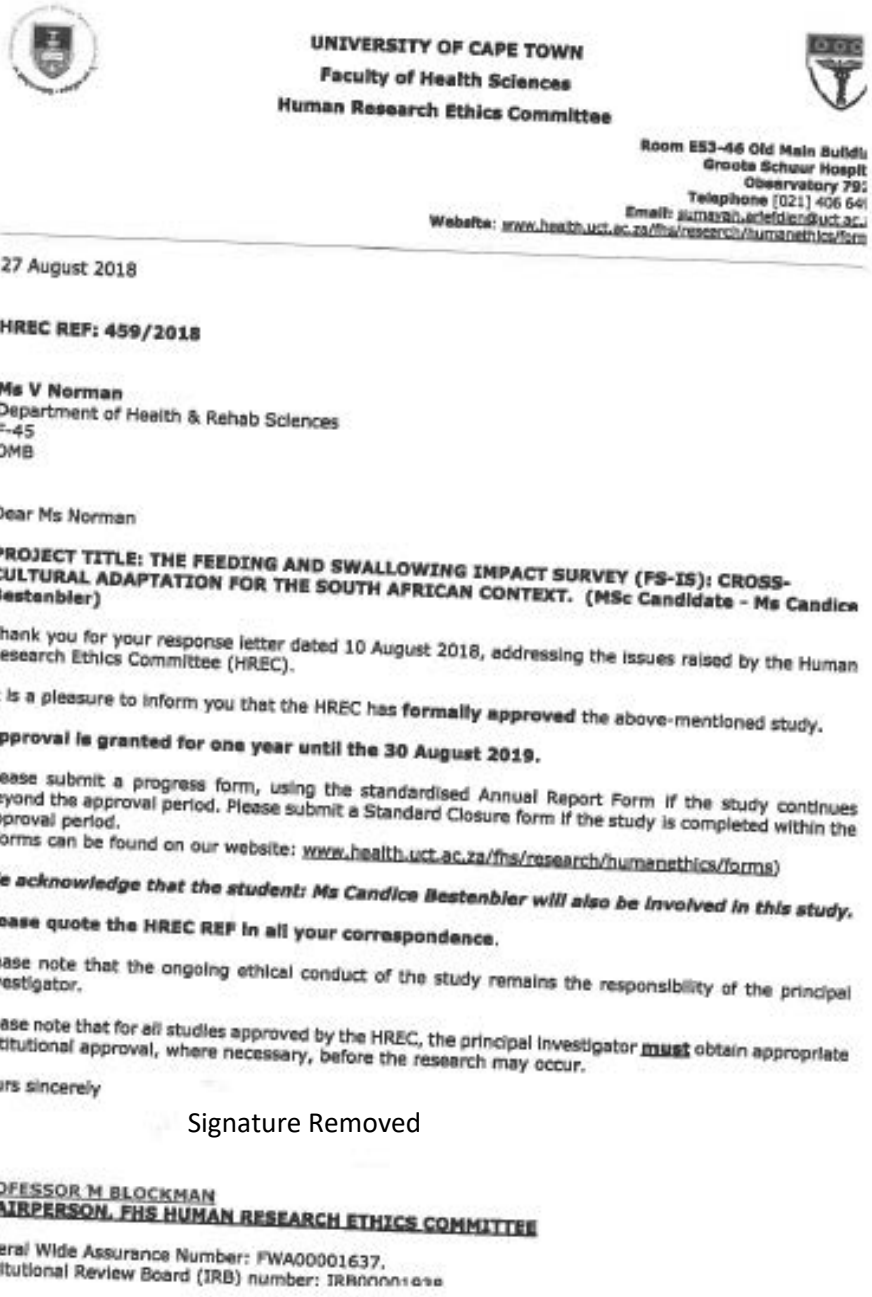
10 Appendices

10.1Appendix A: Ethics Approval Letter



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

Room E53-46 Old Main Buildi
Groote Schuur Hospit
Observatory 79
Telephone (021) 406 6
Email: sumaya
Website: www.health.uct.ac.za/fhs/research/humanethics/form

27 August 2018

HREC REF: 459/2018

Ms V Norman
Department of Health & Rehab Sciences
F-45
OMB

Dear Ms Norman

PROJECT TITLE: THE FEEDING AND SWALLOWING IMPACT SURVEY (FS-IS): CROSS-CULTURAL ADAPTATION FOR THE SOUTH AFRICAN CONTEXT. (MSc Candidate - Ms Candice Bestenbier)

Thank you for your response letter dated 10 August 2018, addressing the issues raised by the Human Research Ethics Committee (HREC).

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

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

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: Ms Candice Bestenbier will also be involved in this study.

Please quote the HREC REF in all your correspondence.

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

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

Yours sincerely

Signature Removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001696

10.2 Appendix B: Consent Form for the SLTs

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences

Department of Health and Rehabilitation Sciences
Divisions of Communication Sciences and Disorders,
Nursing and Midwifery, Occupational Therapy, Physiotherapy

Dear Participant

RE: The Feeding / Swallowing – Impact Survey: Cross-cultural adaptation for the South African context

My name is Candice Bestenbier. I am an MSc. Speech-Language Pathology student from the University of Cape Town. I am conducting a study focusing on the Feeding/Swallowing-Impact Survey (FS-IS, Lefton-Greif et al., 2014) and its use in South Africa. This study has been granted ethics approval from the University of Cape Town Faculty of Health Sciences' Human Research Ethics Committee (Protocol Number 459/2018).

The FS-IS is a tool to determine the health-related quality of life of parents and caregivers of children with dysphagia, developed and validated in the United States. The aim of this study is to adapt the FS-IS for a South African context, and pilot its use with parents of children with dysphagia. The tool is important because it aids SLTs in identifying those parents and caregivers whose health-related quality of life is affected as they care for their child with dysphagia.

You are invited to participate in this research study as you have been identified as an expert in the field of paediatric dysphagia in South Africa. You will be required to complete a short questionnaire regarding the FS-IS and its usability in the South African context and return it to me via email within one week. This questionnaire will take approximately 30 minutes to complete, including the review of the FS-IS. Your recommendations will be considered along with the feedback of other experts before the FS-IS is translated into Afrikaans and isiXhosa. Caregivers of children with dysphagia will then be consulted regarding the cultural and linguistic appropriateness of the translated versions. Finally, the revised and translated versions will be piloted with a group of caregivers of children with dysphagia.

If you are willing to participate, please complete the attached consent form and return it to me via email within one week of receipt, as indicated on the form. The FS-IS and Questionnaire for Experts will be forwarded to you for completion on receipt of the consent.

All identifying information will be kept confidential and not shared with anyone. You have the right to choose not to participate in the study, and you will be free to withdraw at any stage, without a given reason. You will be given a participant number; this number will have no information related to you. An electronic master list of participant names and participant number will be kept on a password protected drive. This document will be needed to assist with reliability checks. There is no risk related to your participation in this study. If you would like further information regarding the study or your participation, please do not hesitate to contact me (BSTCAN001@myuct.ac.za) and I will answer your questions.

If you have any queries, please contact me or my research supervisors.

Yours sincerely,

Candice Bestenbier
MSc. Speech-Language Pathology Student
Email: bstcan001@myuct.ac.za
Cell phone: 083 389 1627

Research Supervisors

Ms Vivienne Norman
Department of the Division of Communication Sciences and Disorders
Email: Vivienne.norman@uct.ac.za
Cellphone number: 083 414 7928

Associate Professor Michelle Pascoe
Head of Division of Communication Sciences and Disorders
Email: michelle.pascoe@uct.ac.za
Cellphone number: 083 379 8746

For any complaints or questions regarding your rights as a research participant or enquiries regarding the ethical approval of this study please contact:

Professor Marc Blockman
Chair of Human Research Ethics Committee
021 406 6492

The Feeding / Swallowing – Impact Survey: Cross-cultural adaptation for the South African context. Protocol Number 459/2018.

I, _____, consent to participate in the following research study.

I have read the information letter and had the opportunity to ask questions to the researcher. I understand that my participation in this study is voluntary and I am free to withdraw from the study at any time.

_____ _____

Signed Date

10.3 Appendix C: Questionnaire for Experts

RE: The Feeding / Swallowing – Impact Survey: Cross-cultural adaptation for the South African context

Questionnaire for experts

Instructions: Please review the attached Feeding and Swallowing Impact Survey, and complete the following questions. Please keep in mind that the Feeding and Swallowing Impact Survey is an instrument designed to measure and improve understanding of caregiver issues.

Please indicate with a √ if you feel that the item meets the criteria; and indicate with a **X** if you feel that it does not meet/agree with the criteria mentioned. Please complete this for each item of the questionnaire.

Once completed, return the completed *Questionnaire for Experts* to bstcan001@myuct.ac.za. Once your questionnaire has been received, your comments and suggestions will be reviewed, together with those of the other experts.

All identifying information will be kept confidential and not shared with anyone. You will be given a participant number; this number will have no information related to you. An electronic master list of participant names and participant number will be kept on a password protected drive. This document will be needed to assist with reliability checks. You have the right to choose not to participate in the study, and you will be free to withdraw at any stage, without a given reason If you would like further information regarding the study or your participation, please do not hesitate to contact me (BSTCAN001@myuct.ac.za) and I will answer your questions.

If you have any queries, please contact me or my research supervisors.

Yours sincerely,

Candice Bestenbier

MSc. Speech-Language Pathology Student

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For any complaints or questions regarding your rights as a research participant or enquiries regarding the ethical approval of this study please contact:

Professor Marc Blockman

Chair of Human Research Ethics Committee

021 406 6492

Thank you for your participation!

		Important/appropriate given our knowledge and experience with paediatric dysphagia and its impact on families	Clear and appropriate for speakers of South African English (i.e. is spelling, word-choice and grammar optimal for our local context?)	Clear and appropriate for South African families (i.e. will this question relate to the experiences and everyday reality of South African families?)
*In the past **ONE** month, as a result of your child's feeding/swallowing problems, how often have **you** had problems **carrying out your daily activities?***		√/**X**	√/**X**	√/**X**
1	It is hard for me to do my job, go to school, or work around the house.			
2	It is hard for me to get help from others because they are scared to feed or take care of my child.			
3	It is hard for me to leave my child because I am scared to have other people feed or take care of my child.			
4	It is hard for my family to make plans or go out to eat.			
5	I am too tired to do the things I want or need to do.			

		Important/appropriate given our knowledge and experience with paediatric dysphagia and its impact on families	Clear and appropriate for speakers of South African English (i.e. is spelling, word-choice and grammar optimal for our local context?)	Clear and appropriate for South African families (i.e. will this question relate to the experiences and everyday reality of South African families?)
*In the past **ONE** month, as a result of your child's feeding/swallowing problems, how often have **you** had problems with **worrying?***		√/**X**	√/**X**	√/**X**
1	I worry about my child's general health.			
2	I worry that my child does not get enough to eat or drink.			
3	I worry about how others will react to my child's feeding/swallowing problems.			
4	I worry about how my child breathes when feeding and whether my child will choke.			
5	I worry that my child will never eat and drink like other children.			
6	I worry about whether I am doing enough to help with my child's feeding /swallowing problems			
7	I worry about how my child's feeding/swallowing problems affect others in my family.			

		Important/appropriate given our knowledge and experience with paediatric dysphagia and its impact on families	Clear and appropriate for speakers of South African English (i.e. is spelling, word-choice and grammar optimal for our local context?)	Clear and appropriate for South African families (i.e. will this question relate to the experiences and everyday reality of South African families?)
*In the past **ONE** month, as a result of your child's feeding/swallowing problems, how often have **you** had problems **feeding your child?***		√/**X**	√/**X**	√/**X**
1	It is hard to feed my child because it takes a long time to prepare liquids and foods the "right" way.			
2	It is hard to feed my child because I don't know how to prepare liquids and foods.			
3	It is hard to feed my child because others give my child liquids or foods that are not allowed.			
4	It is hard to feed my child because I don't know how long these problems will last.			
5	It is hard to feed my child because family members or professionals have different opinions about taking care of my child's feeding/swallowing problems.			
6	It is hard to feed my child because I do not get enough information about how to get my child to eat and drink like other children.			

1. Can any of the items on the *Feeding and Swallowing Impact Survey* be omitted?

   □Yes

   □No

   If yes, state which items, and why they should be omitted.

_____

_____

_____

2. Do you think the *Feeding and Swallowing Impact Survey* would be an appropriate to be used in the context of South Africa?

   □ Yes

   □ No

   If no, state why.

   _____

   _____

   _____

3. Are there any items on this tool that are not appropriate for the parents/caregivers of the children you would typically see and treat?

   □ Yes

   □No

   If yes, state which items and why.

   _____

   _____

   _____

   Additional comments:

   _____

   _____

   _____

   _____

10.4 Appendix D: Feeding/Swallowing - Impact Survey (FS-IS)

(Used with permission from the Author)

Feeding / Swallowing - Impact Survey (FS-IS)

In the past **ONE** month, as a result of your child's feeding/swallowing problems, how often have **you** had problems **carrying out your daily activities?**		**Never**	**Almost Never**	**Half the Time**	**Very Often**	**Almost Always**	**NA**
1	It is hard for me to do my job, go to school, or work around the house.	1	2	3	4	5	6
2	It is hard for me to get help from others because they are scared to feed or take care of my child.	1	2	3	4	5	6
3	It is hard for me to leave my child because I am scared to have other people feed or take care of my child.	1	2	3	4	5	6
4	It is hard for my family to make plans or go out to eat.	1	2	3	4	5	6
5	I am too tired to do the things I want or need to do.	1	2	3	4	5	6

In the past **ONE** month, as a result of your child's feeding/swallowing problems, how often have **you** had problems with **worrying?**		**Never**	**Almost Never**	**Half the Time**	**Very Often**	**Almost Always**	**NA**
1	I worry about my child's general health.	1	2	3	4	5	6
2	I worry that my child does not get enough to eat or drink.	1	2	3	4	5	6
3	I worry about how others will react to my child's feeding/swallowing problems.	1	2	3	4	5	6
4	I worry about how my child breathes when feeding and whether my child will choke.	1	2	3	4	5	6
5	I worry that my child will never eat and drink like other children.	1	2	3	4	5	6
6	I worry about whether I am doing enough to help with my child's feeding /swallowing	1	2	3	4	5	6

	problems						
7	I worry about how my child's feeding/swallowing problems affect others in my family.	1	2	3	4	5	6

In the past **ONE** month, as a result of your child's feeding/swallowing problems, how often have **<u>you</u>** had problems **feeding your child?**		**Never**	**Almost Never**	**Half the Time**	**Very Often**	**Almost Always**	**NA**
1	It is hard to feed my child because it takes a long time to prepare liquids and foods the "right" way.	1	2	3	4	5	6
2	It is hard to feed my child because I don't know how to prepare liquids and foods.	1	2	3	4	5	6
3	It is hard to feed my child because others give my child liquids or foods that are not allowed.	1	2	3	4	5	6
4	It is hard to feed my child because I don't know how long these problems will last.	1	2	3	4	5	6
5	It is hard to feed my child because family members or professionals have different opinions about taking care of my child's feeding/swallowing problems.	1	2	3	4	5	6
6	It is hard to feed my child because I do not get enough information about how to get my child to eat and drink like other children.	1	2	3	4	5	6

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences

Department of Health and Rehabilitation Sciences
Divisions of Communication Sciences and Disorders,
Nursing and Midwifery, Occupational Therapy, Physiotherapy

10.5 Appendix E: Feedback from Caregivers - English

The Feeding / Swallowing – Impact Survey: Cross-cultural adaptation for the South African context

Questionnaire for parents and/caregivers

Instructions: The researcher will complete the questionnaire with you and ask you how well you understand each question. The researcher with then also ask if you have any suggestions of other questions that can be included or any questions that you feel can be left out.

		Important/appropriate given your knowledge and experience with feeding and swallowing difficulties/problems and its impact on you and your family	Clear and appropriate for speakers of your preferred language (i.e. is spelling, word-choice and grammar understandable?)	Clear and appropriate for South African families (i.e. will this question relate to the experiences and everyday reality of South African families?)
	*In the past **ONE** month, as a result of your child's feeding/swallowing problems, how often have **you** had problems **carrying out your daily activities?***	**√/X**	**√/X**	**√/X**
1	It is hard for me to do my job, go to school, or work around the house.			
2	It is hard for me to get help from others because they are scared to feed or take care of my child.			
3	It is hard for me to leave my child because I am scared to have other people feed or take care of my child.			
4	It is hard for my family to make plans or go out to eat.			
5	I am too tired to do the things I want or need to do.			

		Important/appropriate given your knowledge and experience with feeding and swallowing difficulties/problems and its impact on you and your family	Clear and appropriate for speakers of your preferred language (i.e. is spelling, word-choice and grammar understandable?)	Clear and appropriate for South African families (i.e. will this question relate to the experiences and everyday reality of South African families?)
*In the past **ONE** month, as a result of your child's feeding/swallowing problems, how often have **<u>you</u>** had problems with **worrying?***		**√/X**	**√/X**	**√/X**
1	I worry about my child's general health.			
2	I worry that my child does not get enough to eat or drink.			
3	I worry about how others will react to my child's feeding/swallowing problems.			
4	I worry about how my child breathes when feeding and whether my child will choke.			
5	I worry that my child will never eat and drink like other children.			
6	I worry about whether I am doing enough to help with my child's feeding /swallowing problems			
7	I worry about how my child's feeding/swallowing problems affect others in my family.			

		Important/appropriate given your knowledge and experience with feeding and swallowing difficulties/problems and its impact on you and your family	Clear and appropriate for speakers of your preferred language (i.e. is spelling, word-choice and grammar understandable?)	Clear and appropriate for South African families (i.e. will this question relate to the experiences and everyday reality of South African families?)
*In the past **ONE** month, as a result of your child's feeding/swallowing problems, how often have **<u>you</u>** had problems **feeding your child?***		**√/X**	**√/X**	**√/X**
1	It is hard to feed my child because it takes a long time to prepare liquids and foods the "right" way.			
2	It is hard to feed my child because I don't know how to prepare liquids and foods.			
3	It is hard to feed my child because others give my child liquids or foods that are not allowed.			
4	It is hard to feed my child because I don't know how long these problems will last.			
5	It is hard to feed my child because family members or professionals have different opinions about taking care of my child's feeding/swallowing problems.			
6	It is hard to feed my child because I do not get enough information about how to get my child to eat and drink like other children.			

1. Do you think this tool is relevant to you, as a parent/caregiver with a child with a feeding and swallowing difficulty?

   □ Yes
   □ No

   If no, please state why.

   _____
   _____
   _____

2. Can any of the items on the *Feeding and Swallowing Impact Survey* be removed?

   □Yes
   □No

   If yes, state which items, and why they should be removed.
   _____
   _____
   _____

3. Do you think the *Feeding and Swallowing Impact Survey* covers all the aspects **<u>you</u>** face/have difficulty with daily?

   □Yes
   □No

   If no, state aspects you feel should be included.
   _____
   _____
   _____

4. Do you understand all the terms used in the *Feeding and Swallowing Impact Survey*?

   □ Yes
   □ No

   If no, state which terms you have difficulty understanding.
   _____
   _____
   _____

5. Do you feel this tool will be useful to help other parents/caregivers who have children with feeding and swallowing difficulties?

   □Yes
   □No

   If no, please state why.
   _____
   _____
   _____

   Additional comments:
   _____ _____

Procedures Checklist Linguistic Appropriateness (Phase 3):

Date: _____

Participant Number: P3EXX

I _____ (The research assistant) have completed the research process as follows:

- ☐ I have introduced myself as well as the translator.
- ☐ I have provided the participant with the consent documents to peruse/I have read through the consent document with them
- ☐ I've answered any questions the participant may have with regards to the consent form
- ☐ I have ensured the participant has signed and dated the consent form
- ☐ I have provided the participant with a participant number
- ☐ I began audio recording the interview
- ☐ I've labelled the audio recording according to the participant number allocated on the consent form
- ☐ I have gone through each question on the questionnaire
- ☐ I have ensured that the participant understands each of the questions as well as the terminology used in each of the questions.
- ☐ I have allowed the participant to make suggestions surrounding the terminology and choice of words used, whether they would like anything to be omitted or added to the questionnaire.
- ☐ I've answered any questions the participant may have had during the interview process
- ☐ I have stopped the audio recording at the end of the interview.

_____ ----------

Research Assistant Translator

10.6 Appendix F: Feedback from Caregivers – Afrikaans

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences

Department of Health and Rehabilitation Sciences
Divisions of Communication Sciences and Disorders,
Nursing and Midwifery, Occupational Therapy, Physiotherapy

Die Voeding/Sluk-Impak Opname: Kruiskulturele aanpassing vir die Suid-Afrikaanse konteks

Vraelys vir ouers en/ voogde

Instruksies: Die navorser sal die vraelys met u voltooi en u vra hoe goed u elke vraag verstaan. Die navorser sal dan vra of u enige voorstelle of ander vrae wat dalk ingesluit kan word of vrae wat uitgelaat kan word.

		Belangrik/ gepas gebaseer op u kennis en ondervinding met voeding en sluk probleme en die impak op u en u gesin.	**Duidelik en toespaslik vir sprekers van u taal voord-keuse (bv. Spelling, word-keuse en verstaanbare grammatika).**	**Duidelik en toepaslik vir Suid-Afrikaanse gesinne (bv. Hou hierdie vraag verband met die ondervindinge en daaglikse realiteit van Suid-Afrikaanse gesinne?)**
*In die afgelope **EEN** maand, hoe gereeld het **U** probleme ondervind met **daaglikse take** asgevolg van U kind se eet/sluk probleme?*		**√/X**	**√/X**	**√/X**
1	Dit is moeilik vir my om my werk te doen, skool toe te gaan of huiswerk te doen.			
2	Dit is moeilik vir my om help van ander te ontvang omdat hulle bang is om my kind te voed of na my kind te kyk.			
3	Dit is moeilik vir my om my kind in ander se toesig te laat omdat ek vrees wanneer ander my kind moet voed en na my kind kyk.			
4	Dit is moeilik vir my gesin om planne te maak of om uit te eet.			

5	Ek is te moeg om die dinge te doen wat ek wil of moet doen.			

		Belangrik/ gepas gebaseer op u kennis en ondervinding met voeding en sluk probleme en die impak op u en u gesin.	**Duidelik en toespaslik vir sprekers van u taal voord-keuse (bv. Spelling, word-keuse en verstaanbare grammatika).**	**Duidelik en toepaslik vir Suid-Afrikaanse gesinne (bv. Hou hierdie vraag verband met die ondervindinge en daaglikse realiteit van Suid-Afrikaanse gesinne?)**
*In die afgelope **EEN** maand, hoe gereeld het U **bekommernisse** gehad asgevolg van U kind se eet/sluk probleme?*		**√/X**	**√/X**	**√/X**
1	Ek is bekommerd oor my kind se algemene gesondheid.			
2	Ek is bekommerd dat my kind nie genoeg kry om te eet of drink nie.			
3	Ek is bekommerd oor hoe ander sal reageer oor my kind se eet/sluk probleme.			
4	Ek is bekommerd oor hoe my kind asemhaal gedurende voeding en of my kind sal verstik.			
5	Ek is bekommerd dat my kind nooit soos ander kinders sal eet en drink nie.			
6	Ek is bekommerd of ek genoeg doen om my kind te help met hom/haar eet/sluk probleme.			
7	Ek is bekommerd oor hoe my kind se eet/sluk probleme ander in my gesin affekteer.			

		Belangrik/ gepas gebaseer op u kennis en ondervinding met voeding en sluk probleme en die impak op u en u gesin.	**Duidelik en toespaslik vir sprekers van u taal voord-keuse (bv. Spelling, word-keuse en verstaanbare grammatika).**	**Duidelik en toepaslik vir Suid-Afrikaanse gesinne (bv. Hou hierdie vraag verband met die ondervindinge en daaglikse realiteit van Suid-Afrikaanse gesinne?)**
*In die afgelope **EEN** maand, asgevolg van U kind se eet/sluk probleme,hoe gereeld het **U** probleme ondervind **gedurende voeding?***		**√/X**	**√/X**	**√/X**
1	Dit is moeilik om my kind te voed omdat dit 'n langtyd neem om die vloeistowwe en kos die "regte" manier voorteberei.			
2	Dit is moeilik om my kind te voed omdat ek nie weet hoe om die vloeistowwe en kos voorteberei nie.			
3	Dit is moeilik om my kind te voed omdat ander my kind vloeistowwe en kos gee wat nie toelaatbaar is nie.			
4	Dit is moeilik om my kind te voed omdat ek nie weet hoe lank hierdie probleme sal aanhou nie.			
5	Dit is moeilik om my kind te voed omdat familie en ander professionele verskillende opinies het oor my kind se eet/sluk probleme.			
6	Dit is moeilik om my kind te voed omdat ek nie genoeg inligting kry oor hoe ek my kind soos ander kinders kan voed nie.			

6. Dink u hierdie vraelys is relevant vir u as 'n ouer/voogd wat 'n kind met voeding en sluk probleme het?

   □ Ja
   □ Nee

   Indien nee, meld hoekom.

   _____
   _____
   _____

7. Kan enige van die items op die Voeding en Sluk Impak Opname verwyder word?

   □ Ja
   □ Nee

   Indien ja, meld aan watter items en waarom hulle verwyder moet word.

   _____
   _____
   _____

8. Dink u die *Voeding en Sluk Impak Opname* dek alle aspekte wat **U** op 'n daaglkse base deurmaak?

   □ Ja
   □ Nee

   Indien nee, meld aan watter aspekte ingesluit moet word.

   _____
   _____
   _____

9. Verstaan u al die terme wat in die *Voeding en Sluk Impak Opname* gebruik was*?*

   □ Ja
   □ Nee

   Indien nee, meld aan watter terme U nie verstaan het nie.

   _____
   _____
   _____

10. Dink u hierdie hulpmiddel sal ander ouers/ voogde help wie kinders met voeding en sluk probleme het?

    □ Ja
    □ Nee

    Indien nee, sê asseblief hoekom

    _____
    _____
    _____

    Addisonele kommentare:

    _____
    _____
    _____
    _____

Procedures Checklist Linguistic Appropriateness (Phase 3):

Date: _____

Participant Number: P3AXX

I _____ (The research assistant) have completed the research process as follows:

- ☐ I have introduced myself as well as the translator.
- ☐ I have provided the participant with the consent documents to peruse/I have read through the consent document with them
- ☐ I've answered any questions the participant may have with regards to the consent form
- ☐ I have ensured the participant has signed and dated the consent form
- ☐ I have provided the participant with a participant number
- ☐ I began audio recording the interview
- ☐ I've labelled the audio recording according to the participant number allocated on the consent form
- ☐ I have gone through each question on the questionnaire
- ☐ I have ensured that the participant understands each of the questions as well as the terminology used in each of the questions.
- ☐ I have allowed the participant to make suggestions surrounding the terminology and choice of words used, whether they would like anything to be omitted or added to the questionnaire.
- ☐ I've answered any questions the participant may have had during the interview process
- ☐ I have stopped the audio recording at the end of the interview.

_____ ----------

Research Assistant Translator

10.8 Appendix G: Feedback from Caregivers – isiXhosa

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences

Department of Health and Rehabilitation Sciences
Divisions of Communication Sciences and Disorders,
Nursing and Midwifery, Occupational Therapy, Physiotherapy

The Feeding / Swallowing – Impact Survey: Cross-cultural adaptation for the South African context

Questionnaire for parents and/caregivers

Instructions: The researcher will complete the questionnaire with you and ask you how well you understand each question. The researcher with then also ask if you have any suggestions of other questions that can be included or any questions that you feel can be left out.

		Ukubaluleka kolwazi namava akho malunga nengxaki zokutya kwakunye nokugwinya kunye nemiceli mingeni ethi ivele kwisapho lakho ngenxa yezingxaki	Ingaba icacile kwaye ibafanele abantu abathetha olulwimi ulithethayo (oku kukuthi upelo, ukhetho lwamagama kwakunyenegrama uyaziqonda na?)	Ingaba icacile kwaye ibafanele abemi beli loMzantsi Afrika (oku kukuthi Ngaba lo mbuzo uza kuhambelana namava kunye neentsuku zentsuku zeentsapho zaseMzantsi Afrika?)
Kulenyanga INYE idlulileyo, ngenxa yengxaki zomntwana wakho zokutya nokuginya , kukangaphi udibana nezingxaki XA USENZA IMISEBENZI YAKHO YEMIHLA NGEMIHLA?		**√/X**	**√/X**	**√/X**
1	Kunzima ukuba ndenze imisebenzi yam enjegokuya esikolweni okanye ukwenza umsebenzi endlini.			
2	Kunzima ukucela uncedo kwabanye abantu kuba besoyika ukutyisa okanye ukukhathalela umntwana wam.			
3	Kunzima ukushiya umntwana wam ngoba ndoyikisela abanye bantu bammtyise okanye bamkhathelele			
4	Kunzima ukuba mna nosapho lwam siphume siyotya kwezinye indawo okanye sizikhuphe			

5	Ndiyadinwa ukwenza izinto ekufuneka ndizenzile okanye endirhalela ukuzenza.			

		Ukubaluleka kolwazi namava akho malunga nengxaki zokutya kwakunye nokugwinya kunye nemiceli mingeni ethi ivele kwisapho lakho ngenxa yezingxaki	Ingaba icacile kwaye ibafanele abantu abathetha olulwimi ulithethayo (oku kukuthi upelo, ukhetho lwamagama kwakunyenegrama uyaziqonda na?)	Ingaba icacile kwaye ibafanele abemi beli loMzantsi Afrika (oku kukuthi Ngaba lo mbuzo uza kuhambelana namava kunye neentsuku zentsuku zeentsapho zaseMzantsi Afrika?)
Kulenyanga INYE idlulileyo, ngenxa yengxaki zomntwana wakho zokutya nokuginya , kungaphi ubanengxaki NGOKUBANENKXALABO ngomntwana?		**√/X**	**√/X**	**√/X**
1	Ndiyaxhalaba ngempilo yomntwana wam.			
2	Ndiyaxhalaba ukuba umntwana wam akafumani kutya okanye akaseli ngokwaneleyo?			
3	Ndiyaxhalaba ukuba abanye abantu bazoyibona njani ingxaki yomntwana wam yokutya okanye yokuginya.			
4	Ndiyaxhalaba ukuba umtwana wam uphefumla njani xa esitya nokuba umntwana wam akazukomiwa na.			
5	Ndiyaxhalaba ukuba umntwana wam akanoze aphinde akwazi ukutya nokusela njengabanye abantwana.			
6	Ndiyaxhalaba ukuba ndenza okwaneleyo na ukunceda kwingxaki zomtwana wam zokutya nokuginya.			
7	Ndiyaxhalaba ukuba ingxaki zomntwana wam zokutya nokuginya ziluchaphazela njani usapho lwam nabanye abantu.			

		Ukubaluleka kolwazi namava akho malunga nengxaki zokutya kwakunye nokugwinya kunye nemiceli mingeni ethi ivele kwisapho lakho ngenxa yezingxaki	Ingaba icacile kwaye ibafanele abantu abathetha olulwimi ulithethayo (oku kukuthi upelo, ukhetho lwamagama kwakunyenegrama uyaziqonda na?)	Ingaba icacile kwaye ibafanele abemi beli loMzantsi Afrika (oku kukuthi Ngaba lo mbuzo uza kuhambelana namava kunye neentsuku zentsuku zeentsapho zaseMzantsi Afrika?)
Kulenyanga INYE idlulileyo, ngenxa yengxaki zomntwana wakho zokutya nokuginya, kungangaphi UNENGXAKI ZOKUTYISA UMNTWANA WAKHO?		**√/X**	**√/X**	**√/X**
1	Kunzima ukutyisa umntwana wam ngoba kuthatha ixesha elide ukumlungiselela izinto eziselwayo nokutya kakuhle..			
2	Kunzima ukutyisa umntwana wam ngoba andikwazi ukuba kulungiselelwa okanye kwenziwa kanjani ukutya nezinto eziselwayo.			
3	Kunzima ukutyisa umntwana wam ngoba abanye abantu banika umntwana wam izinto eziselwayo okanye ukutya okungavumelekanga.			
4	Kunzima ukutyisa umntwana wam ngoba andiyazi zizohlala ixesha elingakanani ezingxaki.			
5	Kunzima ukutyisa umntwana wam ngoba amalungu osapho lwam, oogqirha nabanye abantu banemviwo ezingafaniyo ngokukhathalela ingxaki zomntwana wam zokutya okanye ezokuginya..			
6	Kunzima ukutyisa umntwana wam ngoba andifumani nkcukacha zaneleyo ukuze umntwana wam akwazi ukutya okanye asele njengabanye abantwana.			

1. Njengomzali okanye umongikazi womntwana onengxaki zokutya okanye ukuginya ingaba esisixhobo sifanelekile ngokubona kwakho.

   □ Ewe
   □ Hayi

Ukuba uthi hayi, chaza kutheni usitsho

_____
_____
_____
_____

2. Ingaba zikhona izinto ofuna zisuswe kwesisixhobo (Feeding and Swallowing Impact Survey).
   □ Ewe
   □ Hayi

   Ukuba uthi ewe, chaza ukuba zeziphi izinto ofuna zisuswe unike nesizathu.

   _____
   _____

3. Ingaba esisixhobo (Feeding and Swallowing Impact Survey) siyichapazela yonke imiba/ingxaki ojongana nazo imihla ngamihla.

   □ Ewe
   □ Hayi

   Ukuba uthi hayi, chaza imiba ekufanele ibandakanywe.

   _____
   _____
   _____

4. Ingaba uyaziqonda zonke izinto ezikwesisixhobo (Feeding and Swallowing Impact Survey)

   □ Ewe
   □ Hayi

   Ukuba uthi hayi, zeziphi izinto ongaziqondiyo.

   _____
   _____

5. Ucinga ukuba esisixhobo (Feeding and Swallowing Impact Survey) sizakubanceda abanye abazali abanabantwana abanengxaki zokutya nokuginya.

   □ Ewe
   □ Hayi

   Ukuba uthi hayi, nika isizathu.

   _____
   _____
   _____

Izimvo ezongeziweyo

Procedures Checklist Linguistic Appropriateness (Phase 3):

Date: _____

Participant Number: P3XXX

I _____ (The research assistant) have completed the research process as follows:

- ☐ I have introduced myself as well as the translator.
- ☐ I have provided the participant with the consent documents to peruse/I have read through the consent document with them
- ☐ I've answered any questions the participant may have with regards to the consent form
- ☐ I have ensured the participant has signed and dated the consent form
- ☐ I have provided the participant with a participant number
- ☐ I began audio recording the interview
- ☐ I've labelled the audio recording according to the participant number allocated on the consent form
- ☐ I have gone through each question on the questionnaire
- ☐ I have ensured that the participant understands each of the questions as well as the terminology used in each of the questions.
- ☐ I have allowed the participant to make suggestions surrounding the terminology and choice of words used, whether they would like anything to be omitted or added to the questionnaire.
- ☐ I've answered any questions the participant may have had during the interview process
- ☐ I have stopped the audio recording at the end of the interview.

_____ ----------

Research Assistant Translator

10.9 Appendix H: Permission Letter from Medical Superintendent at RCWMCH

DR AN PARBHOO
Manager: Medical Services
Red Cross War Memorial Children's Hospital
Email: Anita.Parbhoo@westerncape.gov.za
Tel: +27 21 658 5430 Fax: +27 21 658 5006/5166

01 November 2018

Ms C Bestenbier
Department of Health & Rehab Sciences

Dear Ms Bestenbier,

RESEARCH: RXH: RCC 157

PROJECT TITLE: The Feeding and Swallowing Impact Survey (FS-IS): Cross-cultural adaptation for the South African context.

It is a pleasure to inform you that approval is hereby granted to conduct above-mentioned study at Red Cross War Memorial Children's Hospital.

Yours sincerely,

Signature Removed

DR AN PARBHOO
MANAGER: MEDICAL SERVICES

10.10 Appendix I: Permission Letter from Medical Superintendent at TBH

Western Cape Government
Health

TYGERBERG HOSPITAL
REFERENCE:
Research Projects
ENQUIRIES: **Dr GG Marinus**
TELEPHONE:**021 938 5752**

Ethics Reference: 459/2018

TITLE: **THE FEEDING AND SWALLOWING IMPACT SURVEY (FS-IS): CROSS-CULTURAL ADAPTATION FOR THE SOUTH AFRICAN CONTEXT.)Msc Candidate – Ms Candice Bestenbier)**

Dear Ms V Norman

PERMISSION TO CONDUCT YOUR RESEARCH AT TYGERBERG HOSPITAL.

1. In accordance with the Provincial Research Policy and Tygerberg Hospital Notice No 40/2009, permission is hereby granted for you to conduct the above-mentioned research here at Tygerberg Hospital.

2. Researchers, in accessing Provincial health facilities, are expressing consent to provide the Department with an electronic copy of the final feedback within six months of completion of research. This can be submitted to the Provincial Research Co-Ordinator (Health.Research@westerncape.gov.za).

Signature Removed

DR GG MARINUS
MANAGER: MEDICAL SERVICES

Signature Removed

DR D ERASMUS
CHIEF EXECUTIVE OFFICER
Date: 19 November 2018

Administration Building, Francie van Zijl Avenue, Parow, 7500 Private Bag X3, Tygerberg, 7505
tel: +27 21 938-6267 fax: +27 21 938-4890 www.capegateway.gov.za

Ethics Reference: 459/2018

TITLE: **THE FEEDING AND SWALLOWING IMPACT SURVEY (FS-IS): CROSS-CULTURAL ADAPTATION FOR THE SOUTH AFRICAN CONTEXT.)Msc Candidate – Ms Candice Bestenbier)**

Signature Removed

BY _____
An authorized representative of Tygerberg Hospital

NAME Dr DS Erasmus

TITLE CEO

DATE 19 November 2018

10.11 Appendix J: Permission Letter from SLT Department at RCWMCH

To Ms Le Roux

RE: The Feeding / Swallowing – Impact Survey: Cross-cultural adaptation for the South African context

I am Candice Bestenbier; a MSc. Speech-Language Pathology student from the University of Cape Town. I am conducting a research study on health related quality of life of parents and caregiver of children with dysphagia, the Feeding/Swallowing Impact Survey (FS-IS)(Lefton-Greif et al., 2014). Our goal is to translate it into two different South African languages and test the usability of the scale in these languages. This work may contribute to making speech and language therapy services more relevant to speakers of all languages in South Africa.

I would like to request permission to recruit 2 groups of participants from Red Cross hospital/Tygerberg Hospital paediatric dysphagia clinics. The first group would include caregivers of children with dysphagia attending the feeding clinics at RCWMCH and TBH (n=15). I would administer two short questionnaires to the parents / guardians in their first language, this first groups will be required to complete the FS-IS and then state any changes or recommendations they feel would be needed to ensure adequate understanding. The second group would also include caregivers of children with dysphagia attending the feeding clinics at RCWMCH and TBH (n=30). The second group of participants will be required to complete the questionnaire in a pilot study. I would like to enquire to have the opportunity to talk with the parents / guardians bringing their children for dysphagia therapy, in a private space in the clinic. The completion of the questionnaire would take approximately 20 minutes of their time. We would like to know if parents/guardians understand the scale and, from the speech and language therapists themselves, whether useful data is obtained from the FS-IS.

The speech therapists on site will assist in the identification of any potential participants for the study, the researcher will then approach them to explain the study and invite them to participate.

The speech therapists will not be involved in the recruitment process, as to avoid any potential for roles to be blurred for the onsite SLT.

Steps involving the participants:

Informed written consent from the participants will be gained prior to their participation in the study. Participants will be free to not participate or to withdraw from the completion of the questionnaire at any time without giving a reason. All personal information gathered will remain confidential and will only be used for research purposes. All names and personal information will be kept confidential and the name of the hospitals will not be named without permission.

The researcher/research assistant will make an audio recording of the completion of the questionnaire, for research purposes. This is done so that the researcher can check that all the information collected is accurate, participant names will not be mentioned at all or linked to any recording made. Each participant will be given a participant number that will link the recording to the questionnaire. All research records will be kept safe, and only the researcher and her supervisors will have access to the records. When not in use, the hardcopies of the records will be secured in an access-controlled room.

If there are any concerns raised, regarding the caregiver's health related quality of life during the completion of the questionnaire, the researcher or the assistant will refer participants to the necessary professional for additional assistance. Risks could include feelings of emotional vulnerability in the sharing of experiences and stressors.

There are no immediate benefits for the caregivers of the children with dysphagia. There will be no costs incurred.

If there are any concerns raised during the completion of the questionnaire, the researcher or the assistant will refer participants to the necessary professional for additional assistance.

Yours Faithfully,

If you have any queries, please contact me or my research supervisors.

Yours sincerely,

Candice Bestenbier

MSc. Speech-Language Pathology Student

Email: bstcan001@myuct.ac.za

Cell phone: 083 389 1627

Research Supervisors

Ms Vivienne Norman
Department of the Division of Communication Sciences and Disorders
Email: Vivienne.norman@uct.ac.za
Cellphone number: 083 414 7928

Associate Professor. Michelle Pascoe
Head of Division of the Division of Communication Sciences and Disorders
Email: michelle.pascoe@uct.ac.za
Cellphone number: 083 379 8746

For any complaints or questions regarding your rights as a research participant or enquiries regarding the ethical approval of this study please contact:

Professor Marc Blockman
Chair of Human Research Ethics Committee
021 406 6492

To whom it may concern

The student speech and language therapist of the University of Cape Town has the permission of Red Cross Hospital Speech Therapy Department to seek participants for their research study at our unit.

Signed

Signature Removed

Date

10.12 Appendix K: Permission Letter from SLT Department at TBH

To Ms Randall

RE: The Feeding / Swallowing – Impact Survey: Cross-cultural adaptation for the South African context

I am Candice Bestenbier; a MSc. Speech-Language Pathology student from the University of Cape Town. I am conducting a research study on health related quality of life of parents and caregiver of children with dysphagia, the Feeding/Swallowing Impact Survey (FS-IS)(Lefton-Greif et al., 2014). Our goal is to translate it into two different South African languages and test the usability of the scale in these languages. This work may contribute to making speech and language therapy services more relevant to speakers of all languages in South Africa.

I would like to request permission to recruit 2 groups of participants from Red Cross hospital/Tygerberg Hospital paediatric dysphagia clinics. The first group would include caregivers of children with dysphagia attending the feeding clinics at RCWMCH and TBH (n=15). I would administer two short questionnaires to the parents / guardians in their first language, this first groups will be required to complete the FS-IS and then state any changes or recommendations they feel would be needed to ensure adequate understanding. The second group would also include caregivers of children with dysphagia attending the feeding clinics at RCWMCH and TBH (n=30). The second group of participants will be required to complete the questionnaire in a pilot study. I would like to enquire to have the opportunity to talk with the parents / guardians bringing their children for dysphagia therapy, in a private space in the clinic. The completion of the questionnaire would take approximately 20 minutes of their time. We would like to know if parents/guardians understand the scale and, from the speech and language therapists themselves, whether useful data is obtained from the FS-IS.

The speech therapists on site will assist in the identification of any potential participants for the study, the researcher will then approach them to explain the study and invite them to participate.

The speech therapists will not be involved in the recruitment process, as to avoid any potential for roles to be blurred for the onsite SLT.

Steps involving the participants:

Informed written consent from the participants will be gained prior to their participation in the study. Participants will be free to not participate or to withdraw from the completion of the questionnaire at any time without giving a reason. All personal information gathered will remain confidential and will only be used for research purposes. All names and personal information will be kept confidential and the name of the hospitals will not be named without permission.

The researcher/research assistant will make an audio recording of the completion of the questionnaire, for research purposes. This is done so that the researcher can check that all the information collected is accurate, participant names will not be mentioned at all or linked to any recording made. Each participant will be given a participant number that will link the recording to the questionnaire. All research records will be kept safe, and only the researcher and her supervisors will have access to the records. When not in use, the hardcopies of the records will be secured in an access-controlled room.

If there are any concerns raised, regarding the caregiver's health related quality of life during the completion of the questionnaire, the researcher or the assistant will refer participants to the necessary professional for additional assistance. Risks could include feelings of emotional vulnerability in the sharing of experiences and stressors.

There are no immediate benefits for the caregivers of the children with dysphagia. There will be no costs incurred.

If there are any concerns raised during the completion of the questionnaire, the researcher or the assistant will refer participants to the necessary professional for additional assistance.

Yours Faithfully,

If you have any queries, please contact me or my research supervisors.

Yours sincerely,

Candice Bestenbier

MSc. Speech-Language Pathology Student

Email: bstcan001@myuct.ac.za

Cell phone: 083 389 1627

Research Supervisors

Ms Vivienne Norman
Department of the Division of Communication Sciences and Disorders
Email: Vivienne.norman@uct.ac.za
Cellphone number: 083 414 7928

Associate Professor. Michelle Pascoe
Head of Division of the Division of Communication Sciences and Disorders
Email: michelle.pascoe@uct.ac.za
Cellphone number: 083 379 8746

For any complaints or questions regarding your rights as a research participant or enquiries regarding the ethical approval of this study please contact:

Professor Marc Blockman
Chair of Human Research Ethics Committee
021 406 6492

To whom it may concern

The student speech and language therapist of the University of Cape Town has the permission of Red Cross Hospital Speech Therapy Department to seek participants for their research study at our unit.

Signatures Removed

Signed

Date 12/12/2018.

ASD: SPEECH THERAPY & AUDIOLOGY (HOD)

CHIEF SPEECH THERAPIST

10.13 Appendix L: Consent Form for Caregivers Phase 3 – English

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences

Department of Health and Rehabilitation Sciences
Divisions of Communication Sciences and Disorders,
Nursing and Midwifery, Occupational Therapy, Physiotherapy

Dear parent / caregiver

RE: The Feeding / Swallowing – Impact Survey: Cross-cultural adaptation for the South African context

My name is Candice Bestenbier. I am a MSc. Speech-Language Pathology student from the University of Cape Town. I am conducting a study on the Feeding/Swallowing-Impact Survey (FS-IS, Lefton-Greif et al., 2014) and its use in South Africa. This study has been granted ethics approval from the University Of Cape Town Faculty Of Health Sciences' Human Research Ethics Committee (Protocol Number 459/2018).

What is the study about and why have you been invited?

The FS-IS is a tool that measures the health-related quality of life of parents and caregivers of children with feeding and swallowing problems and was developed and validated in the United States. The aim of this study is to make sure that speech therapists in South Africa can use this tool in English, Afrikaans and isiXhosa to assist them in finding out about the health-related quality of life of parents and caregivers of children with dysphagia, so that we can provide the best support for parents and caregivers. I therefore want to invite you, as a parent of a child with feeding and swallowing difficulties to take part in this study.

What will you need to do?

If you agree to take part in this study, the researcher (with the assistance of an interpreter if needed) will complete the tool with you, in your preferred language. The researcher will then complete the questionnaire with you and ask if any of the questions, terms or words that need to be explained, and if there are any items you would take out or add. The researcher will also ask you if you would suggest different words or questions.

This will take about 20 minutes and we will do this on the same day as your clinic appointment at the hospital. There is no payment for taking part in the study but there are also no costs for you.

There is a small risk that this may result in you feeling uncomfortable or upset by reflecting on how you feel. Should you become distressed during the completion of the questionnaire the researcher will refer you to the appropriate health care professional for further support.

The researcher will make an audio recording while completing the questionnaire so that we can go back and listen to the recording to check that your answers are written down correctly. Your name and personal details (Name and Surname) will be recorded on the consent form for documentation purposes. Your details will be kept private and will not be included on the questionnaire. Instead of your name, a number will be used on the form. All research records will be kept safe, and only the researcher and her supervisors will have access to the records. When not in use, the hardcopies of the records will be stored in an access-controlled room.

What do I do now?

If you are happy to take part in this study you need to sign the consent form before you can complete the questionnaire. It is your choice to say if you want to take part in the study and you are free to say no. If you do not choose to take part in the study you will not be affected negatively in any way, and the standard of care that you and your child receive will not be affected. Even if you do agree to take part in the study, you can choose to stop at any time without giving a reason.

The researcher will assist you in the completion of the questionnaire, and read each question to you, and record your answer on the questionnaire. There is no payment or reward for participating but by taking part in this research you will be helping us make a tool for South Africa that speech therapists can use to help support parents and caregivers of children with feeding and swallowing difficulties.

The results of this study will be published, and they will be made available to the hospital. However, your personal information will only be known by the researcher, the assistant as well as the research supervisors.

If you have any queries, please contact me or my research supervisors.

Yours sincerely,

Candice Bestenbier

MSc. Speech-Language Pathology Student

Email: bstcan001@myuct.ac.za

Cell phone: 083 389 1627

Research Supervisors

Ms Vivienne Norman

Division of Communication Sciences and Disorders

Email: Vivienne.norman@uct.ac.za

Cellphone number: 083 414 7928

Associate Professor Michelle Pascoe

Head of Division of the Division of Communication Sciences and Disorders

Email: michelle.pascoe@uct.ac.za

Cellphone number: 083 379 8746

For any complaints or questions regarding your rights as a research participant or enquiries regarding the ethical approval of this study please contact:

Professor Marc Blockman

Chair of Human Research Ethics Committee

021 406 6492

Title: The Feeding/Swallowing Impact Survey: Cross-cultural adaptation for the South African context

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Consent form (please tick)

- ☐ I consent to participate in the research.
- ☐ I have read the letter attached (or had it read to me) and had opportunity to ask questions.
- ☐ I understand that I am free to leave the study at any time.
- ☐ I give permission to be audio recorded for research purposes.

_____

Name and Surname

_____ _____

Signed Date

10.14 Appendix M: Consent Form for Caregivers Phase 3 – Afrikaans

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences

Department of Health and Rehabilitation Sciences
Divisions of Communication Sciences and Disorders,
Nursing and Midwifery, Occupational Therapy, Physiotherapy

Geagte ouer/ voogd

Met betrekking tot: Die Voeding/Sluk-Impak Opname: Kruiskulturele aanpassing vir die Suid-Afrikaanse konteks.

My naam is Candice Bestenbier. Ek is 'n MSc. Spraak-Taal Patologie student van die Universiteit van Kaapstad. Ek voer 'n studie uit oor die Voeding/Sluk- Impak Opname (FS-IS, Lefton-Greif et al., 2014) en die gebruik daarvan in Suid-Afrika. Hierdie studie het etiese goedkeuring ontvang van die Universteit van Kaapstad se Fakulteit van Gesondheidswetenskappe, Menslike Navorsings en Etiese Komitee (Protokol Nommer 459/2018).

Waaroor gaan hierdie studie en waarom is u genooi?

Die FS-IS is 'n hulpmiddel wat in die Vereenigde State ontwikkel en bekragtig is om die gesondheidsverwante kwalitet van lewe van ouers en voogde van kinders met voeding en sluk probleme te meet. Die doel van hierdie studie is om seker te maak dat die spraakterapeute in Suid-Afrika hierdie hulpmiddel in Engels, Afrikaans en isiXhosa kan gebruik om hul te help om uit te vind oor die gesondsheidsverwante kwaliteit van lewe van ouers en voogde van kinders met disfagie. Hierdie studie sal ons, as Spraakterapeute, dis help om die beste ondersteuning aan ouers en voogde te voorsien. Ek wil u dis, as 'n ouer van 'n kind met eet en sluk probleme, nooi om aan hierdie studie deelteneem.

Wat sal u moet doen?

As u instem om deelteneem aan hierdie studie, sal die navorser (met die hulp van 'n vertolker, indien nodig) die hulpmiddel met u voltooi, in die taal van u keuse. Die navorser sal dan die vraelys met u voltooi en vra of daar engie vrae is, terme of woorde is wat verduidelik moet word, of enige items is wat u wil byvoeg of wil verwyder. Die navorser wil sal ook vra of daar voorstelle is vir ander woorde of vrae.

Dit sal omtrent 20 minute neem en ons sal die vraelys op dieselfde dag as u kliniek afspraak by die hospitaal voltooi. Daar is geen betaling om deelteneem aan hierdie studie nie, maar daar is ook geen koste vir u nie

Daar is ‘n kans dat hierdie vraelys u dalk ongemaklik sal laat voel omdat u oor u gevoelens sal moet reflekteer. As u gedurende die voltooiing van die vraelys benoud raak sal die navorser u na die toepaslike gesondheidspersoneel verwys vir verder ondersteuning

Die navorser sal ‘n klankopname neem gedurende die voltooiing van die vraelys sodat ons later daarna kan luister om seker te maak dat u antwoorde korrek neergeskryf word. U naam en persoonlike besonderhedes (Naam en Van) sal op die toestemmingsvorm geskryf word vir dokumentasie doeleindes. U persoonlike besonderhede sal privaat gehou word en nie op die vraelys ingesluit word nie. Inplaas van u naam sal ‘n nommer op die vorm geskryf word. Al die navorsingsinligting (klankopname en voltooide vraelyse) sal veilig bewaar word, slegs die navorser en haar toesighouers sal toegang hê tot die navorsingsinligting. Wanneer nie ingebruik nie, sal die hardekopieë van die navorsingsinligting in ‘n toegangbeheerde kamer geplaas word.

Wat doen ek nou?

As u daarmee tevrede is om deelteneem aan hierdie studie sal u eers die toestemmingsvorm moet teken voor u die vraelys voltooi. Dit is u keuse om deel te neem in hierdie studie en u is vry om nee te sê. As u besluit om nie deelteneem aan hierdie studie nie, sal u in geen manier negatief geaffekteer word nie, en die standaar van sorg wat aan u en u kind ontvang sal ook nie geaffekteer word nie. Selfs as u besluit om deelteneem aan hierdie studie, kan u enige tyd besluit om te onttrek sonder om ‘n rede te verskaf.

Die navorser sal u help om die vraelys te voltooi en elke vraag aan u lees en u antwoord neer skryf. Daar is geen betaling of beloning vir u deelname aan hierdie studie nie, maar deurmiddel van u deelname sal u ons help om ‘n hulpmiddel te ontwikkel vir spraakterapeute in Suid-Afrika. Hierdie hulpmiddel sal dis gebruik word om ondersteuning to verleen aan ouers en voogde van kinders met voeding en sluk probleme.

Die resultate van hierdie studie sal gepubliseer word en sal aan die hospitaal beskikbaar gemaak word. Wees gerus dat u persoonlike besonderhede slegs aan die navorser, die assistent en navorsing toesighouers bekend sal wees.

As u enige vrae het kontak gerus vir my of my navorsing toesighouers.

U opregte,

Candice Bestenbier

MSc. Spraak-Taal Patologie Student

Epos: bstcan001@myuct.ac.za

Sellfoon Nommer: 083 389 1627

Navorsing toesighouers

Ms Vivienne Norman

Afdeling van Kommunikasiewetenskappe en Versteurings

Epos: Vivienne.norman@uct.ac.za

Selfoon Nommer: 083 414 7928

Geassosieerde Professor Michelle Pascoe

Hoof van Kommunikasiewetenskappe en Versteurings

Epos: michelle.pascoe@uct.ac.za

Selfoon Nommer: 083 379 8746

Vir enige klagtes of vrae oor u regte as navorsingsdeelnemer of navrae met betrekking tot die etiese goedkeuring van hierdie studie kontak gerus:

Professor Marc Blockman

Voorsitter van Menslike Navorsings en Etiese Komitee

021 406 6492

Titel: Die Voeding/Sluk-Impak Opname: Kruiskulturele aanpassing vir die Suid-Afrikaanse konteks.

Toestemmingsvorm (merk asseblief)

- ☐ Ek gee toestemming om deelteneem in hierdie navorsing.
- ☐ Ek het die aangehegte brief gelees (of dit was vir my gelees) en het die geleentheid gehad om vrae te vra.
- ☐ Ek verstaan ek is vry om die studie op enige oomlik te verlaat/ stop
- ☐ Ek gee toestemming vir ‘n klankopname vir navorsing doeleindes.

_____

Naam en Van

_____ _____

Handtekening Datum

10.15 Appendix N: Consent Form for Caregivers Phase 3 – isiXhosa

Mzali Obekekileyo

RE: The Feeding / Swallowing – Impact Survey: Cross-cultural adaptation for the South African context

Igama lam ndingu Candice Bestenbier. Ndingumfundi wemastazi kwiSpeech-Language Pathology ofunda kwiDyunivesithi yaseKapa (UCT). Ndenza uphando lwempembelelo ekondleni nasekuginyeni (FS-IS, Lefton-Greif et al., 2014) nendlela okwenziwa ngayo kweli lo Mzantsi Africa. Oluphando selufumene imigaqo yokuziphatha kwDyunivesithi yaseKapa Faculty of Health Sciences' Human Research Ethics Committee (Protocol Number 459/2018).

Uphando luqulathe ntoni kwaye kutheni umenyiwe?

i- FS-IS sisixhobo esisetyenziselwa ukumeta umgangatho onxulumene nempilo yabamzali okanye oomongikazi babantwana abanengxaki zokutya nokuginya, esisixhobo siphuhliswe kwaye sigqityeleliswe kwelase Melika. Injongo zoluphando kukuqinisekisa ukuba abantu bonyango lo kuthetha kweli loMzantsi Afrika bayakwazi ukusebenzisa esisixhobo ngesiNgesi ngesiBhulu nangesiXhosa ekuncedeni ukumeta umgangatho onxulumene nempilo yabamzali okanye oomongikazi babantwana abanengxaki zokutya nokuginya. Ukuze sizokwazi ukunika abazali nomongikazi eyonanxaso ibafaneleyo. Kungoko ndikucela njengomzali womntana enengxaki zokutya nokuginya ukuba uthabathe inxaxheba koluphando.

Kuzofuneka wenzentoni?

Ukuba uyavuma ukuthabatha inxaxheba koluphando, umphandi (kwakunye netoliki ukuba iyadingeka) bazakukuncedisa ekusebenziseni esisixhobo, ngolwimi olukhethwa nguwe. Umphandi uzokugcwalisa uluhlu lwemibuzo kunyenawe, ukuba unemibuzo ungabuza okanye xa unamagama ongawaqondiyo ofuna ingcaciso ungatsho okanye xa kunamaga athile ofuna asuswe okanye

ongezwe ungatsho. Umphandi uzokucela ingcebiso malunga namagama athile kunye nemibuzo ethile.

Oluphando luzokuthath imizuzu enga-20 kwaye izobe iqhubeka ngalomhla uneKlinikhi apayintimenti ngayo esibhedlele. Awufumani mbuyekezo ngokuthi uthabathe inxaxheba kwaye ukuthabatha inxaxheba kusimahla. Ingcuphekwana ekhoyo kukuba uzive ungonwabanga okanye uqumbe ngenxa yemibuzo ethi ivuse imvakalelo. Ukuba uthe wava ulunxinzelelo emphefumlweni xa ugcwalisa oluluhlu lwemibuzo umphandi uzakuthi akuthumele kumboneleli wezempilo ofanelekileyo ukuze ufumane inxaso efanelekileyo.

Umphandi uzokwenza ushicilelo lwamazwi xa ugcwalisa oluluhlu lwemibuzo ukuze sikwazi ukumamela impendulo zakho siyazi ukuba ziyahambelana neziuzibhalileyo. Igama nencukacha zakho zizokufumaneka kwifomu yesivumelwano ngesizathu sobigqina. Ezincukacha zizokugcinwa emfihlakalweni kwaye azidingeki kuluhlu lwemibuzo. Endaweni yegama lakho kuzokufakwa inani. Ezincukacha zizokugcunwa wndaweni ekhuselekileyo eyaziwa ngumphandi nompathi wakhe. Wonke lamaphepha azokuhlala kwindawo ekhuselekileya xa engasetyenziswa.

Yintoni endiyenzayo ngoku?

Ukuba uyavuma ukuthatha inxaxheba koluphando kufuneka utyikitye ifomu yesivumelwano phambi kokuba ugcwalise uluhlu lwemibuzo. Kuxhomekeke kuwe ukuba uyafuna na ukuthabatha inxaxheba koluphando, ukuba awufuni ungatsho uthi hayi. Ukuba uthe awavuma ukuthabatha inxaxheba akuzubakho miphumela mibi kwaye uzunga lwenkathalelo yakho neyomntwana wakho izizokuchaphazeleka. Umntwana wakho akasoze achaphazeleke konke konke. Ukuba uthe wavuma ukuthabatha inxaxheba unalo ilungelo lokuthi uyeke phakathi ungachazanga sizathu.

Umphandi uzakukuncedisa ekugcwaliseni uluhlu lwemibuzo kwaye uzakukufundela wena kuzokufuneka ubhale phantsi ipendulo zakho. Ngokuthabatha inxaxheba awuzokubhatalwa okanye ofumane amaqithi-qithi. Kodwa ngokuthi uthabathe inxaxheba uyakuba unceda thina ekuphuhlisen isixhobo salapha eMzantsi Afrika apho khona iSpeech therapist zingasisebenzisa ekuxhaseni impilo yabamzali okanye oomongikazi babantwana abanengxaki zokutya nokuginya.

Iziphumo zoluphano zizakupapashwa. Kwaye izokufumaneka ezibhedlele. Kunjalo icukacha zakho zizokugcinwa ngumphandi, isekela lakhe kwakunye nompathi wabo.

Ukuba unayo nayiphi na imibuzo qhagamshelana nam okanye umphathi wam.

Ozithobileyo,

Candice Bestenbier

MSc. Speech-Language Pathology Student

Email: bstcan001@myuct.ac.za

Cell phone: 083 389 1627

Umphathi Wephando

Ms Vivienne Norman

Division of Communication Sciences and Disorders

Email: Vivienne.norman@uct.ac.za

Cellphone number: 083 414 7928

Associate Professor Michelle Pascoe

Head of Division of the Division of Communication Sciences and Disorders

Email: michelle.pascoe@uct.ac.za

Cellphone number: 083 379 8746

Title: The Feeding/Swallowing Impact Survey: Cross-cultural adaptation for the South African context

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Ifomu yesivumelwano (ndicela ukhorekitshe)

- ☐ Ndiyavuma ukuthabatha inxaxheba koluphando.
- ☐ Ndiyifundile incwadi encanyathiselweyo (okanye ndiyifundelwe) kwaye ndiye ndalifumana ithuba likubuza imibuza.
- ☐ Ndiyayiqonda ukuba ndikhululekile ukuba ndingahamba nanini na ndifuna.
- ☐ Ndiyanikeza ngemvume yokuba ilizwi lam lishicilelwe ngenjongo zophando.

_____

Igama ne Fani

_____ _____

Ityikitywe Umhla

10.16 Appendix O: Adapted version of FS-IS - English

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences

Department of Health and Rehabilitation Sciences
Divisions of Communication Sciences and Disorders,
Nursing and Midwifery, Occupational Therapy, Physiotherapy

The Feeding / Swallowing – Impact Survey: Cross-cultural adaptation for the South African context

Questionnaire for parents and/caregivers

Instructions: The researcher will complete the questionnaire with you.

	In the past ONE month, as a result of your child's feeding/swallowing problems, how often have you had problems carrying out your daily activities?	**Never**	**Almost Never**	**Half the Time**	**Very Often**	**Almost Always**	**NA**
1	It is hard for me to do my job, go to school, or work around the house.	1	2	3	4	5	6
2	It is hard for me to get help from others because they are scared to feed or take care of my child.	1	2	3	4	5	6
3	It is hard for me to leave my child because I am scared to have other people feed or take care of my child.	1	2	3	4	5	6
4	It is hard for my family to make plans or go out to eat.	1	2	3	4	5	6
5	I am too tired to do the things I want or need to do.	1	2	3	4	5	6

	In the past ONE month, as a result of your child's feeding/swallowing problems, how often have <u>you</u> had problems with worrying?	**Never**	**Almost Never**	**Half the Time**	**Very Often**	**Almost Always**	**NA**
1	I worry about my child's general health.	1	2	3	4	5	6
2	I worry that my child does not get enough to eat or drink.	1	2	3	4	5	6
3	I worry about how others will react to my child's feeding/swallowing problems.	1	2	3	4	5	6
4	I worry about how my child breathes when feeding and whether my child will choke.	1	2	3	4	5	6
5	I worry that my child will never eat and drink like other children.	1	2	3	4	5	6
6	I worry about whether I am doing enough to help with my child's feeding /swallowing problems	1	2	3	4	5	6
7	I worry about how my child's feeding/swallowing problems affect others in my family.	1	2	3	4	5	6

In the past ONE month, as a result of your child's feeding/swallowing problems, how often have <u>you</u> had problems feeding your child?		**Never**	**Almost Never**	**Half the Time**	**Very Often**	**Almost Always**	**NA**
1	It is hard to feed my child because it takes a long time to prepare liquids and foods the "right" way.	1	2	3	4	5	6
2	It is hard to feed my child because I am not sure how to prepare liquids or foods the “right way”.	1	2	3	4	5	6
3	It is hard to feed my child because others give my child liquids or foods that are not allowed.	1	2	3	4	5	6
4	It is hard to feed my child because I don't know how long these problems will last.	1	2	3	4	5	6
5	It is hard to feed my child because family members or professionals have different opinions about taking care of my child’s feeding/swallowing problems.	1	2	3	4	5	6
6	It is hard to feed my child because I do not get enough information about how to get my child to eat and drink like other children.	1	2	3	4	5	6

Procedures Checklist Pilot Study:

Date: _____

Participant Number: _____

I _____ (the researcher) have completed the research process as follows:

- ☐ I have introduced myself as well as the translator.
- ☐ I have provided the participant with the consent documents to peruse/I have read through the consent document with them
- ☐ I've answered any questions the participant may have with regards to the consent form
- ☐ I have ensured the participant has signed and dated the consent form
- ☐ I have provided the participant with a participant number
- ☐ I began audio recording the interview
- ☐ I've labelled the audio recording according to the participant number allocated on the consent form
- ☐ I have gone through each question on the questionnaire
- ☐ I have ensured that the participant understands each of the questions as well as the terminology used in each of the questions.
- ☐ I have allowed the participant to provide reasons for their answers where necessary
- ☐ I've answered any questions the participant may have had during the interview process
- ☐ I have stopped the audio recording at the end of the interview.

_____ ----------

Candice Bestenbier
Researcher

Translator

10.17 Appendix P: Translated and Adapted version of FS-IS - Afrikaans

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences

Department of Health and Rehabilitation Sciences
Divisions of Communication Sciences and Disorders,
Nursing and Midwifery, Occupational Therapy, Physiotherapy

Die Voeding/Sluk-Impak Opname: Kruiskulturele aanpassing vir die Suid-Afrikaanse konteks

Vraelys vir ouers en/ voogde

Instruksies: Die navorser sal die vraelys met u voltooi.

	In die afgelope EEN maand, hoe gereeld het U probleme ondervind met daaglikse take asgevolg van U kind se eet/sluk probleme?	**Nooit**	**Amper Nooit**	**Halfte van die tyd**	**Dikwels**	**Amper Altyd**	**Nie van toepassing nie**
1	Dit is moeilik vir my om my werk te doen, skool toe te gaan of huiswerk te doen.	1	2	3	4	5	6
2	Dit is moeilik vir my om help van ander te ontvang omdat hulle bang is om my kind te voed of na my kind te kyk.	1	2	3	4	5	6
3	Dit is moeilik vir my om my kind in ander se toesig te laat omdat ek vrees wanneer ander my kind moet voed en na my kind kyk.	1	2	3	4	5	6
4	Dit is moeilik vir my gesin om planne te maak of om uit te eet.	1	2	3	4	5	6
5	Ek is te moeg om die dinge te doen wat ek wil of moet doen.	1	2	3	4	5	6

	In die afgelope EEN maand, hoe gereeld het <u>U</u> bekommernisse gehad asgevolg van U kind se eet/sluk probleme?	**Nooit**	**Amper Nooit**	**Halfte van die tyd**	**Dikwels**	**Amper Altyd**	**Nie van toepassing nie**
1	Ek is bekommerd oor my kind se algemene gesondheid.	1	2	3	4	5	6
2	Ek is bekommerd dat my kind nie genoeg kry om te eet of drink nie.	1	2	3	4	5	6
3	Ek is bekommerd oor hoe ander sal reageer oor my kind se eet/sluk probleme.	1	2	3	4	5	6
4	Ek is bekommerd oor hoe my kind asemhaal gedurende voeding en of my kind sal verstik.	1	2	3	4	5	6
5	Ek is bekommerd dat my kind nooit soos ander kinders sal eet en drink nie.	1	2	3	4	5	6
6	Ek is bekommerd of ek genoeg doen om my kind te help met hom/haar eet/sluk probleme.	1	2	3	4	5	6
7	Ek is bekommerd oor hoe my kind se eet/sluk probleme ander in my gesin affekteer.	1	2	3	4	5	6

In die afgelope EEN maand, asgevolg van U kind se eet/sluk probleme,hoe gereeld het <u>U</u> probleme ondervind gedurende	**Nooit**	**Amper Nooit**	**Halfte van die tyd**	**Dikwels**	**Amper Altyd**	**Nie van toepassing nie**

	voeding?						
1	Dit is moeilik om my kind te voed omdat dit ‘n langtyd neem om die vloeistowwe en kos die ”regte” manier voorteberei.	1	2	3	4	5	6
2	Dit is moeilik om my kind te voed omdat ek nie seker is hoe om die vloeistowwe of kos op die “regte manier" voorteberei nie.	1	2	3	4	5	6
3	Dit is moeilik om my kind te voed omdat ander my kind vloeistowwe en kos gee wat nie toelaatbaar is nie.	1	2	3	4	5	6
4	Dit is moeilik om my kind te voed omdat ek nie weet hoe lank hierdie probleme sal aanhou nie.	1	2	3	4	5	6
5	Dit is moeilik om my kind te voed omdat familie en ander professionele verskillende opinies het oor my kind se eet/sluk probleme.	1	2	3	4	5	6
6	Dit is moeilik om my kind te voed omdat ek nie genoeg inligting kry oor hoe ek my kind soos ander kinders kan voed nie.	1	2	3	4	5	6

Procedures Checklist Pilot Study:

Date: _____

Participant Number: _____

I _____ (the researcher) have completed the research process as follows:

- ☐ I have introduced myself as well as the translator.
- ☐ I have provided the participant with the consent documents to peruse/I have read through the consent document with them
- ☐ I've answered any questions the participant may have with regards to the consent form
- ☐ I have ensured the participant has signed and dated the consent form
- ☐ I have provided the participant with a participant number
- ☐ I began audio recording the interview
- ☐ I've labelled the audio recording according to the participant number allocated on the consent form
- ☐ I have gone through each question on the questionnaire
- ☐ I have ensured that the participant understands each of the questions as well as the terminology used in each of the questions.
- ☐ I have allowed the participant to provide reasons for their answers where necessary
- ☐ I've answered any questions the participant may have had during the interview process
- ☐ I have stopped the audio recording at the end of the interview.

_____ ----------

Candice Bestenbier
Researcher

Translator

10.18 Appendix Q: Translated and Adapted version of FS-IS - isiXhosa

The Feeding / Swallowing – Impact Survey: Cross-cultural adaptation for the South African context

Questionnaire for parents and/caregivers

Imiyalelo: Abaphandi bazakugcwalisa uluhlu lwemibizo kunye nawe, bakubuze ukuba unazo na iingcebiso na ngalemibizo okanye khona imibuzo oziva ngathi ingashiywa ngaphandle.

	Kulenyanga INYE idlulileyo, ngenxa yengxaki zomntwana wakho zokutya nokuginya , kukangaphi udibana nezingxaki XA USENZA IMISEBENZI YAKHO YEMIHLA NGEMIHLA?	**Zange**	**Phantse kungaze**	**isiqinga tha sexesha**	**Qho**	**Phantse rhoqo**	**NA**
1	Kunzima ukuba ndenze imisebenzi yam enjegokuya esikolweni okanye ukwenza umsebenzi endlini.	1	2	3	4	5	6
2	Kunzima ukucela uncedo kwabanye abantu kuba besoyika ukutyisa okanye ukukhathalela umntwana wam.	1	2	3	4	5	6
3	Kunzima ukushiya umntwana wam ngoba ndoyikisela abanye bantu bamtyise okanye bamkhathelele	1	2	3	4	5	6
4	Kunzima ukuba mna nosapho lwam siphume siyotya kwezinye indawo okanye sizikhuphe	1	2	3	4	5	6
5	Ndiyadinwa ukwenza izinto ekufuneka ndizenzile okanye endirhalela ukuzenza.	1	2	3	4	5	6

	Kulenyanga INYE idlulileyo, ngenxa yengxaki zomntwana wakho zokutya nokuginya , kungaphi ubanengxaki NGOKUBANENKXALABO ngomntwana?	**Zange**	**Phantse kungaze**	**isiqingathasexesha**	**Qho**	**Phantse rhoqo**	**NA**
1	Ndiyaxhalaba ngempilo yomntwana wam.	1	2	3	4	5	6
2	Ndiyaxhalaba ukuba umntwana wam akafumani kutya okanye akaseli ngokwaneleyo?	1	2	3	4	5	6
3	Ndiyaxhalaba ukuba abanye abantu bazoyibona njani ingxaki yomntwana wam yokutya okanye yokuginya.	1	2	3	4	5	6
4	Ndiyaxhalaba ukuba umtwana wam uphefumla njani xa esitya nokuba umntwana wam akazukomiwa na.	1	2	3	4	5	6
5	Ndiyaxhalaba ukuba umntwana wam akanoze aphinde akwazi ukutya nokusela njengabanye abantwana.	1	2	3	4	5	6
6	Ndiyaxhalaba ukuba ndenza okwaneleyo na ukunceda kwingxaki zomtwana wam zokutya nokuginya.	1	2	3	4	5	6
7	Ndiyaxhalaba ukuba ingxaki zomntwana wam zokutya nokuginya ziluchaphazela njani usapho lwam nabanye abantu.	1	2	3	4	5	6

	Kulenyanga INYE idlulileyo, ngenxa yengxaki zomntwana wakho zokutya nokuginya, kungangaphi UNENGXAKI ZOKUTYISA UMNTWANA WAKHO?	**Zange**	**Phantse kungaze**	**isiqingatha sexesha**	**Qho**	**Phantse rhoqo**	**NA**
1	Kunzima ukutyisa umntwana wam ngoba kuthatha ixesha elide ukumlungiselela izinto eziselwayo nokutya kakuhle..	1	2	3	4	5	6
2	Kunzima ukutyisa umntwana wam kuba andiqinisekanga ngenedlela yokumlungiselela into eselwayo okanye etyiwayo ngendlela elungileyo.	1	2	3	4	5	6
3	Kunzima ukutyisa umntwana wam ngoba abanye abantu banika umntwana wam izinto eziselwayo okanye ukutya okungavumelekanga.	1	2	3	4	5	6
4	Kunzima ukutyisa umntwana wam ngoba andiyazi zizohlala ixesha elingakanani ezingxaki.	1	2	3	4	5	6
5	Kunzima ukutyisa umntwana wam ngoba amalungu osapho lwam, oogqirha nabanye abantu banezimvo ezingafaniyo ngokukhathalela ingxaki zomntwana wam zokutya okanye ezokuginya..	1	2	3	4	5	6
6	Kunzima ukutyisa umntwana wam ngoba andifumani nkcukacha zaneleyo ukuze umntwana wam akwazi ukutya okanye asele njengabanye abantwana.	1	2	3	4	5	6

Procedures Checklist Pilot Study:

Date: _____

Participant Number: _____

I _____ (the researcher) have completed the research process as follows:

- ☐ I have introduced myself as well as the translator.
- ☐ I have provided the participant with the consent documents to peruse/I have read through the consent document with them
- ☐ I've answered any questions the participant may have with regards to the consent form
- ☐ I have ensured the participant has signed and dated the consent form
- ☐ I have provided the participant with a participant number
- ☐ I began audio recording the interview
- ☐ I've labelled the audio recording according to the participant number allocated on the consent form
- ☐ I have gone through each question on the questionnaire
- ☐ I have ensured that the participant understands each of the questions as well as the terminology used in each of the questions.
- ☐ I have allowed the participant to provide reasons for their answers where necessary
- ☐ I've answered any questions the participant may have had during the interview process
- ☐ I have stopped the audio recording at the end of the interview.

_____ ----------

Candice Bestenbier
Researcher

Translator

10.19 Appendix R: Consent for Caregiver Participants Phase 4 – English

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences

Department of Health and Rehabilitation Sciences
Divisions of Communication Sciences and Disorders,
Nursing and Midwifery, Occupational Therapy, Physiotherapy

Dear parent / caregiver

RE: The Feeding / Swallowing – Impact Survey: Cross-cultural adaptation for the South African context

My name is Candice Bestenbier. I am a MSc. Speech-Language Pathology student from the University of Cape Town. I am conducting a study focusing on the Feeding/Swallowing-Impact Survey (FS-IS, Lefton-Greif et al., 2014) and its use in South Africa. This study has been granted ethics approval from the University Of Cape Town Faculty Of Health Sciences' Human Research Ethics Committee (Protocol Number 459/2018).

What is the study about and why have you been invited?

The FS-IS is a tool that measures the health-related quality of life of parents and caregivers of children with feeding and swallowing problems and was developed and validated in the United States. The aim of this study is to make sure that speech therapists in South Africa can use this tool in English, Afrikaans and isiXhosa to assist them in finding out about the health-related quality of life of parents /caregivers of children with feeding and swallowing difficulties. The FS-IS has been translated and adapted for South Africa, and we would like to test its use. The FS-IS is aimed at finding out how caregivers of children with feeding and swallowing difficulties are affected. I also want to see if it is helpful in South Africa with parents of children who have feeding and swallowing difficulties. The tool is important because it helps SLTs in identifying, and providing the appropriate management or relevant referrals, for those parents and caregivers whose health-related quality of life is affected as they care for their child with feeding and swallowing difficulties. I therefore want to invite you, as a parent of a child with feeding and swallowing difficulties to take part in this study.

What will you need to do?

If you agree to take part in this study, one of the researchers (with the assistance of an interpreter if needed) will go through the questionnaire with you and complete the questionnaire in your preferred language (English, Afrikaans and isiXhosa).

This will take about 20 minutes to complete and we will do this on the same day as your clinic appointment at the hospital. There is no payment for taking part in the study but there are also no costs for you.

There is a small risk that this may result in you feeling uncomfortable or upset by reflecting on how you feel. Should you become distressed during the completion of the questionnaire the researcher will refer you to the appropriate health care professional for further support.

The researcher will make an audio recording while completing the questionnaire so that we can go back and listen to the recording to check that your answers are written down correctly. Your name and personal details (Name and Surname) will be recorded on the consent form for documentation purposes. Your details will be kept private and will not be included on the completion of the questionnaire form. Instead of your name, a number will be used on the form. All research records will be kept safe, and only the researcher and her supervisors will have access to the records. When not in use, the hardcopies of the records will be stored in an access-controlled room.

What do I do now?

If you are happy to take part in this study you need to sign the consent form before you can complete the questionnaire. It is your choice to say if you want to take part in the study and you are free to say no. If you do not choose to take part in the study you will not be affected negatively in any way, and the standard of care that you and your child receive will not be affected. Even if you do agree to take part in the study, you can choose to stop at any time without giving a reason.

The researcher will assist you in the completion of the questionnaire, and read each question to you, and record your answer on the questionnaire. There is no payment or reward for participating but by taking part in this research you will be helping us make a tool for South Africa that speech therapists can use to help support parents and caregivers of children with feeding and swallowing difficulties.

The results of this study will be published, and they will be made available to the hospital. However, your personal information will only be known by the researcher, the assistant as well as the research supervisors.

If you have any queries, please contact me or my research supervisors

Yours sincerely,

Candice Bestenbier

MSc. Speech-Language Pathology Student

Email: bstcan001@myuct.ac.za

Cell phone: 083 389 1627

Research Supervisors

Ms Vivienne Norman

Division of Communication Sciences and Disorders

Email: Vivienne.norman@uct.ac.za

Cellphone number: 083 414 7928

A/ Prof Michelle Pascoe

Division of Communication Sciences and Disorders

Email: michelle.pascoe@uct.ac.za

Cellphone number: 083 379 8746

For any complaints or questions regarding your rights as a research participant or enquiries regarding the ethical approval of this study please contact:

Professor Marc Blockman

Chair of Human Research Ethics Committee

021 406 6492

Title: The Feeding/Swallowing Impact Survey: Cross-cultural adaptation for the South African context

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Consent form (please tick)

- ☐ I consent to participate in the research.
- ☐ I have read the letter attached or had it read to me and had opportunity to ask questions.
- ☐ I understand that I am free to withdraw from the study at any time.
- ☐ Allow the research team to share information obtained with our current Speech-Language therapist
- ☐ I give permission to be audio recorded for research purposes.

_____

Name and Surname

_____ _____

Signed Date

10.20 Appendix S: Consent for Caregiver Participants Phase 4 – Afrikaans

Geagte ouer/ voogd

Met betrekking tot: Die Voeding/Sluk-Impak Opname: Kruiskulturele aanpassing vir die Suid-Afrikaanse konteks.

My naam is Candice Bestenbier. Ek is 'n MSc. Spraak-Taal Patologie student van die Universiteit van Kaapstad. Ek voer 'n studie uit oor die Voeding/Sluk- Impak Opname (FS-IS, Lefton-Greif et al., 2014) en die gebruik daarvan in Suid-Afrika. Hierdie studie het etiese goedkeuring ontvang van die Universteit van Kaapstad se Fakulteit van Gesondheidswetenskappe, Menslike Navorsings en Etiese Komitee (Protokol Nommer 459/2018).

Waaroor gaan hierdie studie en waarom is u genooi?

Die FS-IS is 'n hulpmiddel wat in die Vereenigde State ontwikkel en bekragtig is om die gesondheidsverwante kwalitet van lewe van ouers en voogde van kinders met voeding en sluk probleme te meet. Die doel van hierdie studie is om seker te maak dat die spraakterapeute in Suid-Afrika hierdie hulpmiddel in Engels, Afrikaans en isiXhosa kan gebruik om hul te help om uit te vind oor die gesondsheidsverwante kwaliteit van lewe van ouers en voogde van kinders met disfagie. Hierdie studie sal ons, as Spraakterapeute, dis help om die beste ondersteuning aan ouers en voogde te voorsien. Ek wil u dis, as 'n ouer van 'n kind met eet en sluk probleme, nooi om aan hierdie studie deelteneem.

Wat sal u moet doen?

As u instem om deelteneem aan hierdie studie, sal die navorser (met die hulp van 'n vertolker, indien nodig) die hulpmiddel met u voltooi, in die taal van u keuse.

Dit sal omtrent 20 minute neem en ons sal die vraelys op dieselfde dag as u kliniek afspraak by die hospitaal voltooi. Daar is geen betaling om deelteneem aan hierdie studie nie, maar daar is ook geen koste vir u nie

Daar is ‘n kans dat hierdie vraelys u dalk ongemaklik sal laat voel omdat u oor u gevoelens sal moet reflekteer. As u gedurende die voltooiing van die vraelys benoud raak sal die navorser u na die toepaslike gesondheidspersoneel verwys vir verder ondersteuning

Die navorser sal ‘n klankopname neem gedurende die voltooiing van die vraelys sodat ons later daarna kan luister om seker te maak dat u antwoorde korrek neergeskryf word. U naam en persoonlike besonderhedes (Naam en Van) sal op die toestemmingsvorm geskryf word vir dokumentasie doeleindes. U persoonlike besonderhede sal privaat gehou word en nie op die vraelys ingesluit word nie. Inplaas van u naam sal ‘n nommer op die vorm geskryf word. Al die navorsingsinligting (klankopname en voltooide vraelyse) sal veilig bewaar word, slegs die navorser en haar toesighouers sal toegang hê tot die navorsingsinligting. Wanneer nie ingebruik nie, sal die hardekopieë van die navorsingsinligting in ‘n toegangbeheerde kamer geplaas word.

Wat doen ek nou?

As u daarmee tevrede is om deelteneem aan hierdie studie sal u eers die toestemmingsvorm moet teken voor u die vraelys voltooi. Dit is u keuse om deel te neem in hierdie studie en u is vry om nee te sê. As u besluit om nie deelteneem aan hierdie studie nie, sal u in geen manier negatief geaffekteer word nie, en die standaar van sorg wat aan u en u kind ontvang sal ook nie geaffekteer word nie. Selfs as u besluit om deelteneem aan hierdie studie, kan u enige tyd besluit om te onttrek sonder om ‘n rede te verskaf.

Die navorser sal u help om die vraelys te voltooi en elke vraag aan u lees en u antwoord neer skryf. Daar is geen betaling of beloning vir u deelname aan hierdie studie nie, maar deurmiddel van u deelname sal u ons help om ‘n hulpmiddel te ontwikkel vir spraakterapeute in Suid-Afrika. Hierdie hulpmiddel sal dis gebruik word om ondersteuning to verleen aan ouers en voogde van kinders met voeding en sluk probleme.

Die resultate van hierdie studie sal gepubliseer word en sal aan die hospitaal beskikbaar gemaak word. Wees gerus dat u persoonlike besonderhede slegs aan die navorser, die assistent en navorsing toesighouers bekend sal wees.

As u enige vrae het kontak gerus vir my of my navorsing toesighouers.

U opregte,

Candice Bestenbier

MSc. Spraak-Taal Patologie Student

Epos: bstcan001@myuct.ac.za

Sellfoon Nommer: 083 389 1627

Navorsing toesighouers:

Ms Vivienne Norman

Division of Communication Sciences and Disorders

Epos: Vivienne.norman@uct.ac.za

Selfoon Nommer: 083 414 7928

Geassosieerde Professor Michelle Pascoe

Head of Division of the Division of Communication Sciences and Disorders

Epos: michelle.pascoe@uct.ac.za

Selfoon Nommer: 083 379 8746

Vir enige klagtes of vrae oor u regte as navorsingsdeelnemer of navrae met betrekking tot die etiese goedkeuring van hierdie studie kontak gerus:

Professor Marc Blockman

Chair of Human Research Ethics Committee

021 406 6492

Titel: Die Voeding/Sluk-Impak Opname: Kruiskulturele aanpassing vir die Suid-Afrikaanse konteks.

Toestemmingsvorm (merk asseblief)

- ☐ Ek gee toestemming om deelteneem in hierdie navorsing.
- ☐ Ek het die aangehegte brief gelees (of dit was vir my gelees) en het die geleentheid gehad om vrae te vra.
- ☐ Ek verstaan ek is vry om die studie op enige oomlik te verlaat/ stop
- ☐ Laat die navorsingspan toe om informasie te deel met die huidige spraaktherapuut.
- ☐ Ek gee toestemming vir ‘n klankopname vir navorsing doeleindes.

_____

Naam en Van

_____ _____

Handtekening Datum

10.21 Appendix T: Consent for Caregiver Participants Phase 4 – isiXhosa

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences

Department of Health and Rehabilitation Sciences
Divisions of Communication Sciences and Disorders,
Nursing and Midwifery, Occupational Therapy, Physiotherapy

Mzali Obekekileyo

RE: The Feeding / Swallowing – Impact Survey: Cross-cultural adaptation for the South African context

Igama lam ndingu Candice Bestenbier. Ndingumfundi wemastazi kwiSpeech-Language Pathology ofunda kwiDyunivesithi yaseKapa (UCT). Ndenza uphando lwempembelelo ekondleni nasekuginyeni (FS-IS, Lefton-Greif et al., 2014) nendlela okwenziwa ngayo kweli lo Mzantsi Africa. Oluphando selufumene imigaqo yokuziphatha kwDyunivesithi yaseKapa Faculty of Health Sciences' Human Research Ethics Committee (Protocol Number 459/2018).

Uphando luqulathe ntoni kwaye kutheni umenyiwe?

i- FS-IS sisixhobo esisetyenziselwa ukumeta umgangatho onxulumene nempilo yabamzali okanye oomongikazi babantwana abanengxaki zokutya nokuginya, esisixhobo siphuhliswe kwaye siqinisekiswe kwelase Melika. Injongo zoluphando kukuqinisekisa ukuba abantu bonyango lo kuthetha kweli loMzantsi Afrika bayakwazi ukusebenzisa esisixhobo ngesiNgesi ngesiBhulu nangesiXhosa ukubanceda ekufumaneni umgangatho onxulumene nempilo yabamzali okanye oomongikazi babantwana abanengxaki zokutya nokuginya. Ukuze sizokwazi ukunika abazali nomongikazi eyonanxaso ibafaneleyo. Kungoko ndikucela njengomzali womntana enengxaki zokutya nokuginya ukuba uthabathe inxaxheba koluphando.

Yintoni ekumele ndiyenze?

Ukuba uyavuma ukuthabatha inxaxheba koluphando, umphandi (kwakunye netoliki ukuba iyadingeka) bazakuncedisa ekusebenziseni esisixhobo, ngolwimi olukhethwe nguwe.

Oluphando luzokuthatha imizuzu enga-20 kwaye izobe iqhubeka ngalomhla onedinga ngawo esibhedlele. Awufumani mbuyekezo ngokuthi uthabathe inxaxheba kwaye akukho ndleko. Ingcuphekwana ekhoyo kukuba uzive ungonwabanga okanye ukhathazeke ngenxa yemibuzo ethi

ivuse imvakalelo. Ukuba uthe wava ulunxinzelelo emphefumlweni xa ugcwalisa oluluhlu lwemibuzo umphandi uzakuthi akuthumele kumboneleli wezempilo ofanelekileyo ukuze ufumane inxaso efanelekileyo.

Umphandi uzokwenza ushicilelo lwamazwi xa ugcwalisa oluluhlu lwemibuzo ukuze sikwazi ukumamela impendulo zakho siyazi ukuba ziyahambelana nezi uzibhalileyo. Igama neencukacha zakho zizokufumaneka kwifomu yesivumelwano ngesizathu sobigqina. Ezincukacha zizokugcinwa emfihlakalweni kwaye azidingeki kuluhlu lwemibuzo. Endaweni yegama lakho kuzokufakwa inani. Ezincukacha zizokugcunwa wndaweni ekhuselekileyo eyaziwa ngumphandi nompathi wakhe. Wonke lamaphepha azokuhlala kwindawo ekhuselekileya xa engasetyenziswa.

Yintoni endiyenzayo ngoku?Ukuba uyavuma ukuthatha inxaxheba koluphando kufuneka utyikitye ifomu yesivumelwano phambi kokuba ugcwalise uluhlu lwemibuzo. Kuxhomekeke kuwe ukuba uyafuna na ukuthabatha inxaxheba koluphando, ukuba awufuni ungatsho uthi hayi. Ukuba uthe awavuma ukuthabatha inxaxheba akuzubakho miphumela mibi kwaye izinga lwenkathalelo yakho neyomntwana wakho izizokuchaphazeleka. Umntwana wakho akasoze achaphazeleke konke konke. Ukuba uthe wavuma ukuthabatha inxaxheba unalo ilungelo lokuthi uyeke phakathi ungachazanga sizathu.

Umphandi uzakuncedisa ekugcwaliseni uluhlu lwemibuzo kwaye uzakufundela wena kuzokufuneka ubhale phantsi ipendulo zakho. Ngokuthabatha inxaxheba awuzokubhatalwa okanye ofumane amaqithi-qithi. Kodwa ngokuthi uthabathe inxaxheba uyakuba unceda thina ekuphuhlisen isixhobo salapha eMzantsi Afrika apho khona iSpeech therapist zingasisebenzisa ekuxhaseni impilo yabamzali okanye oomongikazi babantwana abanengxaki zokutya nokuginya.

Iziphumo zoluphano zizakupapashwa. Kwaye izokufumaneka ezibhedlele. Kunjalo icukacha zakho zizokugcinwa ngumphandi, isekela lakhe kwakunye nompathi wabo.

Ukuba unayo nayiphi na imibuzo qhagamshelana nam okanye umphathi wam.

Ozithobileyo,

Candice Bestenbier
MSc. Speech-Language Pathology Student
Email: bstcan001@myuct.ac.za
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Umphathi Wephando
Ms Vivienne Norman

Division of Communication Sciences and Disorders

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Associate Professor Michelle Pascoe

Head of Division of the Division of Communication Sciences and Disorders

Email: michelle.pascoe@uct.ac.za

Cellphone number: 083 379 8746

Title: The Feeding/Swallowing Impact Survey: Cross-cultural adaptation for the South African context

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Ifomu yesivumelwano (ndicela ukhorekitshe)

- ☐ Ndiyavuma ukuthabatha inxaxheba koluphando.
- ☐ Ndiyifundile incwadi encanyathiselweyo (okanye ndiyifundelwe) kwaye ndiye ndalifumana ithuba likubuza imibuza.
- ☐ Ndiyayiqonda ukuba ndikhululekile ukuba ndingahamba nanini na ndifuna.
- ☐ Ndivumela abaphandi ukuba babelane ngolwazi olufunyenweyo neegcali zethu se Speech/Language Therapist.
- ☐ Ndiyanikeza ngemvume yokuba ilizwi lam lishicilelwe ngenjongo zophando.

_____

Igama ne Fani

_____ _____

Ityikitywe Umhla