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Caregivers' Experiences of Gastrostomy feeds: A Speech-Language Therapist's Role

A Dissertation in Fulfilment of the Requirements of Masters in Speech Pathology
Presented to

The Department of Speech Pathology and Audiology
School of Human and Community Development
Faculty of Humanities
University of Witswatersrand

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January 2022

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Abstract

Introduction: The insertion of a gastrostomy tube through the abdomen into the stomach is a common procedure for children with dysphagia or nutritional complications. This can be an emotionally laden decision for the caregivers of children requiring gastrostomy tubes. The caregiver's decision-making process, and the emotional effects thereof, have not been well explored. Ongoing support from a multidisciplinary team (MDT) is essential in order to assist and guide the caregiver through the difficult decision-making and transition phase. The Speech-Language Therapist (SLT) plays a vital role as part of the MDT. This study aimed to describe the caregivers' experiences of the decision-making process within the South African context when they consider a gastrostomy tube for their child. The study included investigating the SLT's role as perceived by the caregiver and the professional.

Methodology: This qualitative study was done using online questionnaires for thirteen caregivers of children with gastrostomy tubes in South Africa (SA), as well as for the twenty-three SLTs working in this setting. A follow-up focus group discussion was done with two willing caregivers. Participants were obtained using snowball sampling. All of the data was analyzed using a Reflexive Thematic Analysis approach following the six steps as set out by Braun and Clarke.

Results and discussion: The results show that the caregiver's decision to obtain and make use of a gastrostomy tube for the child under their care is a complex and emotionally laden one. A caregiver's experience can be altered by the information they obtain, or the information available to the caregiver, as well as their specific support needs and requirements. The themes that have emerged included the impact on the family system, the support system, and societal issues. It is further evident that SLTs could play a greater role in the decision-making process as well as in the subsequent support services to be provided to the caregiver. In the South African context, a lack of resources appears to further complicate the care and support provided. The education and training provided to caregivers may therefore be limited and the importance of education and training may be overlooked.

Conclusion: It is essential that healthcare providers are cognisant of how emotions and attitudes affect the family's overall experience of a gastrostomy tube. Support and counselling are therefore an essential part of the process.

Implication: The results from this study were used to assist in creating a protocol. The protocol could assist SLTs in educating and guiding caregivers through their decision-making processes when considering a potential gastrostomy tube. Further research would be required to assess the effectiveness of this protocol.

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List of Abbreviations

Acquired immunodeficiency syndrome	AIDS
Human immunodeficiency virus	HIV
Multidisciplinary Team	MDT
National Health Insurance	NHI
Percutaneous endoscopic gastrostomy	PEG
Speech-Language Therapist	SLT
South Africa	SA
Transdisciplinary Team	TDT
Tuberculosis	TB

Chapter 1: Introduction

Gastrostomy tubes allow for adequate nutrition by the means of nutritionally balanced and calculated formula being transported to the stomach without obstruction or dysfunction (Kazmierski, et al., 2013). It is a common procedure for children with dysphagia or nutritional complications which may exist due to neurological impairments and cardiac, or gastrointestinal, deficits (Norman et al., 2011). Many factors should be explored by a multidisciplinary team (MDT) in collaboration with the caregiver in order to inform and assist the family with the complex decision (Sullivan, 2013).

The decision-making process surrounding gastrostomy tubes in the paediatric population is particularly burdensome (Neille & Selikson, 2021). Little research exists which explores the nature of the 'emotionally-laden' decision for the caregiver who is responsible for making a life-altering decision on behalf of their child (Martínez-Costa et al., 2011). It is essential that there is support from an MDT to guide the caregiver through the decision-making process and to assist with the training thereafter (Sevilla et al., 2016). Without support it has been shown that caregivers adjust poorly to the required role and demonstrate increased signs of stress (Calderon et al., 2010).

The Speech-Language Therapist (SLT) plays a vital role in assessing and recommending a gastrostomy tube (South African Speech Language and Hearing Association [SASLHA], 2011). As part of their scope of practice, SLTs are involved in the education and counselling of the patient and their immediate support or family structures (Health Professions Council of South Africa [HPCSA], 2017). This is therefore an essential component of the management of dysphagia (Lubinski et al., 2007). The resolution and treatment required for a gastrostomy tube is multifaceted

and therefore, a collaborative effort is critical (Adams & Elias, 2014; SASLHA, 2011). In underserved countries, or countries where health services are under resourced and understaffed, it will be more difficult to achieve this objective (Bhengu & Maphumulo, 2019).

South African health services are under-resourced and in addition there are challenges that arise due to population diversity and unique socio-economic circumstances (Ned et al., 2017). Within this context, there is no clear protocol on the educational processes for caregivers seeking gastrostomy tubes for their children. It was, therefore, hypothesised that treatment and counselling varies and that caregivers' support needs may not be accurately anticipated or understood.

South Africa (SA) has unique circumstances which need to be explored in order to ensure improved support and education for caregivers facing these decisions (Kenny, 2015). With limited resources and cultural diversity; treatment priorities may need to be adjusted (Bhengu & Maphumulo; 2019). This study, therefore, aimed to describe caregivers' experiences of SLT support when considering gastrostomy feeds for their children. This was done by using a qualitative method to uncover the experiences from the perspective of caregivers, as well of that of SLTs that work with this cohort. Themes in the findings were identified to find shared feelings and potential fallouts in the services currently provided. This will be explored by looking at the education process within the private and public sectors to ensure a boarder perspective.

Chapter 2: Literature review

This chapter will start by discussing the South African context within the healthcare system. It describes the need for, and application of, gastrostomy tubes in the paediatric population, with an in-depth assessment of caregivers' perspectives and the impact on the decision-making and future management. Next, the role of the MDT, and more specifically that of the SLT, will also be discussed. Lastly, the *Organisational Framework for Caregiver Interventions* will be explored as a theoretical framework for understanding the elements that should be considered when looking at the caregiver and care recipient's needs (Van Houtven, et al., 2011). This assists the researcher in identifying factors that should be considered in assisting caregivers with their decision-making needs.

2.1. The Healthcare System and Speech-Language Therapist's Role in South Africa:

2.1.1. South Africa's past:

Bhengu and Maphumulo (2019) discusses the impacts of the Apartheid regime on SA's healthcare system. As well as altering the social structure of SA, the restrictive political structure resulted in a weighted distribution of resources (Bhengu & Maphumulo; 2019). Therefore, in a low-to-middle income country such as SA, the lack of resources puts the healthcare system under strain (Coutts, 2019). Poor service provision can often be a drawback when selecting the appropriate intervention for a patient (Kenny, 2015).

South African healthcare workers must consider many additional factors when providing appropriate care for the population. This includes SA's history of racial

segregation which resulted in unique obstacles; including a history of poor resource distribution, resulting in difficulty in providing the best quality care to patients (Lateef, 2011). In addition, SA's eleven official languages can result in communication and compliance difficulties between patients and healthcare workers, which can further impact on the treatment that is provided (Seedat, 2013). Owing to the cultural diversity there is a broad range of belief systems, as well as differing western and traditional beliefs. As a result, caregivers require information that is sympathetic and responsive to their specific needs (Vawda, 2017).

In post-Apartheid SA a large discrepancy is noted between the private and public sectors, where almost half of financial and human resources go to the private sector to service a small segment of the population (Coovadia et al., 2009). Although literature may be dated, these challenges still have an impact on the current healthcare sector. SA still strives towards a transformative policy which will encourage equality (Ned et al., 2017). It is expected that development will occur, resources will improve and service delivery will be more equally distributed when the National Health Insurance (NHI) comes into operation (Bhengu & Maphumulo; 2019). If poorly implemented, this system could result in further obstacles for the healthcare system in terms of patients access to services as well as the level of care provided (Ned et al., 2017). Therefore, it is essential to take note of SA's complex population and the heavily burdened health sector when planning service provision to the population.

In this context, healthcare workers in SA must ensure that patient and caregiver education is adjusted to provide for specific circumstances when dealing with

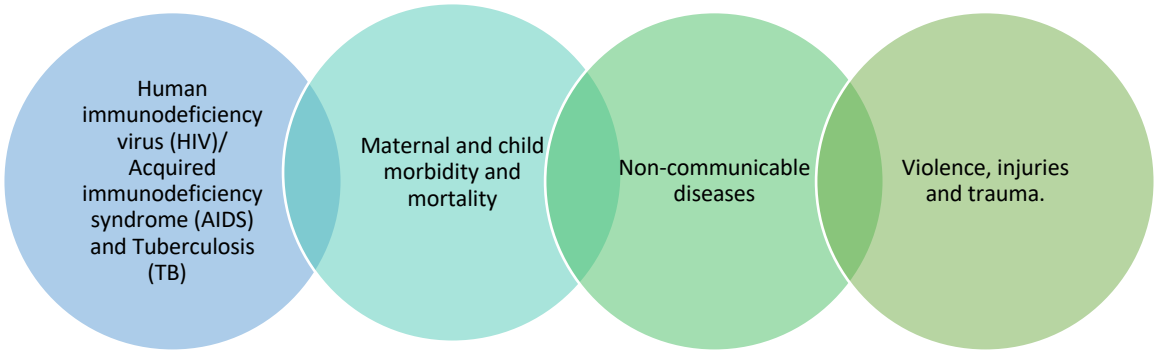
gastrostomy tube insertion. This will ensure the patient's care is adjusted to be most beneficial within their specific context.

2.1.2. The Quadruple Burden:

SA's healthcare system faces a '*quadruple burden'* (Hunter et al., 2017). In addition to the previously mentioned complexities, South Africans face the additional underlying healthcare issues described in Figure 1 below. The figure depicts how healthcare workers care for patients with complex family structures, and those who suffer from the co-morbidities and trauma, which adds an additional pressure on an under-resourced healthcare system (Hunter et al., 2017; Kenny, 2015). Families with a higher level of burden may be less receptive to change or to new information. If caregivers face any of these areas of challenge it may impact on their ability to provide care, as well as affecting their access to services, and therefore impact on the training and education they may receive (Zikhathile & Atagana, 2018). This places additional challenges on a family system. SLTs must therefore navigate adapting the treatment they provide so as to respond to a family's specific circumstances, social context and emotional needs.

Figure 1

The Quadruple Burden faced by the SA Healthcare System



Note. Adjusted from 'Case mix of patients managed in the resuscitation area of a district-level public hospital in Cape Town,' by L .Hunter, S. Lahri, and D. van Hoving, 2017, *African Journal Of Emergency Medicine*, *7*(1), 19-23. https://doi.org/0.1016/j.afjem.2017.01.001

The COVID-19 pandemic, which emerged in SA at the beginning of 2020, may add further strain to SA's already burdened healthcare system. Gale et al., (2020) described this as a '*public health crisis*' causing illness and further resource limitations. This could impact on the SLT's role in treatment and education, however it is currently unclear what the resultant consequences will be (Coutts, 2020). SLTs have already noted a shift in their treatment goals, reduced session lengths, and difficulty with ongoing care or outpatient services (Adams et al., 2021). In addition, Anderson and Lee-Davey (2020) have identified reduced visiting hours in paediatric settings, which could have a further ongoing impact in the interaction between SLT and caregiver, and in the interaction between caregiver and patient. This could affect caregiver bonding and inclusion, the quality of the treatment and education provided, as well as placing a burden on the South African SLT. When providing education on more complex

areas, such as decision-making concerning gastrostomy tubes, SLTs should make use of gradual information sessions for caregivers in order that they may receive and process the relevant information, and therefore session plans may need to be adapted as required (Lee & Corden, 2019).

2.1.3. The burden on SA's Speech-Language Therapists:

SLTs play a major role in identifying safe and appropriate feeding methods, as well as educating families if enteral feeding is necessary (SASLHA, 2011). With high delivery demands and a lack of resources, SLTs need support through appropriate systems and guidance protocols to ensure that the healthcare needs of their patients are met. The SLT and STA (Speech-Language Therapist and Audiologist) to patient ratio is 1: 21,500 (Health Professions Council of South Africa [HPCSA], 2020). Only a small percentage of these SLTs are assumed to be working with the paediatric population with dysphagia. Feeding is a delicate, yet essential, caregiving task, and therefore sensitive and individualised support must be provided. A lack of trained and passionate SLTs in this field may affect the service delivery and advocacy for their role.

2.2. Paediatric feeding:

A safe and efficient swallow involves the complex integration of four phases with well-coordinated movements (Murry & Carrau, 2012). As children grow and develop structurally and functionally they face new feeding milestones, making this population sector particularly vulnerable to feeding difficulties as they grow (Southall & Martin, 2011).

Table 1

Developmental stages of feeding

Age (months):	Feeding stage	Food tolerated
0 – 4/6	Nipple feeding (breast or bottle). Suckle.	Milk
6–9 (transition feeding)	Transition feeding: vertical munching Suckle becomes a sucking pattern Starts finger feeding	Soft dissolvable food
9–12	Chewing includes rotary jaw action Cup drinking.	Solid dissolvable
12–18	Self-feeding with facilitation: grasps spoon with whole hand	
18–24	Swallowing with lip closure Up–down tongue movements precise	
24–36	Total self-feeding Chewing with lips closed and circulatory jaw rotations.	Solids

Note. Adapted from 'Swallowing and feeding in infants and young children' by J. Arvedson, 2016,*GI Motility Online*. https://doi.org/10.1038/gimo17

Early identification of the occurrence of complications in swallowing or nutritional intake is essential in order to prevent secondary complications (Pike et al., 2016). This can include failure to thrive (FTT) due to poor intake, resulting in children not meeting their required growth standards (Arvedson & Brodsky, 2002). This could have major effects on a child's development.

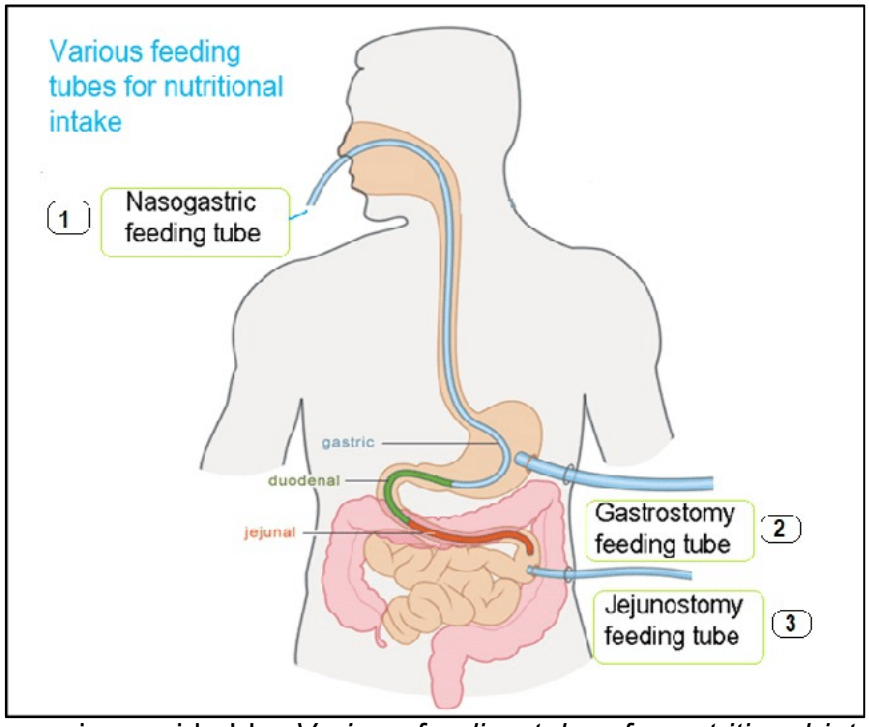
In SA, the children who required gastrostomy tubes are seen to present with multiple diagnoses meaning that feeding solutions for patients and caregivers should be individualised (Norman et al., 2011). Team members must decide on the best solution after viewing the child and the family circumstances holistically (Southall & Martin, 2011). Enteral feeding may be selected if oral feeding is no longer an option (SASLHA, 2011). Enteral feeding allows nutrition to be transported via a tube to the stomach (Green et al., 2019). An example of enteral feeding is a gastrostomy tube. Sevilla & McElhanon (2016) discussed that to transition to enteral feeds should include the choice of enteral access, the education of the caregiver, and ongoing multidisciplinary support.

2.3. Defining gastrostomy tubes

A gastrostomy tube is used as a long-term feeding solution for patients who are unable to feed orally safely and efficiently (Arvedson & Brodsky, 2002). Gastrostomy tubes are a form of enteral feeding which are used for long-term feeding support for a care recipient (Green et al., 2019). The tube is placed directly through the skin and into the stomach, making it less likely to be dislodged and less visible (Murry & Carrau, 2012). Since the 1980's percutaneous endoscopic gastrostomies (PEGs) have been used as the most common method of gastrostomy, although in more complex cases jejunal feeding tubes are inserted into the intestine rather than the stomach (Burdall et al., 2017).

Figure 2

Image showing points of insertion for various feeding tubes



Note. This image is provided by *Various feeding tubes for nutritional intake*[Image]. Yerrabolu in 2012. By S. Yerrabolu (https://www.researchgate.net/publication/258693646_Consideration_of_alternative_designs_for_a_Percutaneous_Endoscopic_Gastrostomy_feeding_tube)

Gastrostomy feeding may be recommended for children who display with an unsafe swallow or who suffer from a poor nutritional status (Martínez-Costa et al., 2011). Gastrostomy tubes are most often found in populations with neurological and nutritional impairments (Pars & Soyer, 2019). Most children who require gastrostomy feeds present with multiple diagnoses as seen in Table 2 (Norman et al., 2011).

Table 2

Indications and underlying diseases in paediatric patients requiring a PEG tube

Indications	Underlying disease
Inability to swallow	Neurological disorders (more than 50% of patients), multiple congenital malformations, oropharyngeal dysmotility, epidermolysis bullosa and others.
Inadequate caloric intake	Cystic fibrosis, congenital heart disease, chronic respiratory failure, chemotherapy in oncology and others.
Special feeding requirements	Unpalatable formula in multiple food allergies, unpalatable formula or reliable gastric access in metabolic diseases and unpalatable medications in renal failure.
Continuous enteral feeding	Short bowel syndrome and malabsorption.

Note. Adapted from 'Review article: percutaneous endoscopic gastrostomy in infants and children,' by T. Frohlich, M. Richter, R. Carbon, B. Barth, and H. Kohler, 2010, *Alimentary Pharmacology & Therapeutics*, *31*(8), 788- 801. https://doi.org/10.1111/j.1365-2036.2010.04246.x

Appropriate nutrition is essential in these population groups for children's brain, cardiac and respiratory functions, as well as further impacting on their immune ability and social participation (Figueroa at al., 2017). In SA, it is clear that there is an increased number of PEGs that are being inserted due to increasing availability and awareness of resources (van der Merwe et al., 2003).

2.3.1. Factors when considering Gastrostomy tubes:

2.3.1.1.Benefits:

The insertion of gastrostomy tubes are a long-term feeding solution that result in the survival of patients with feeding problems of a range of severities (Kazmierski al et., 2013). They simulate the natural feeding process, which is why they are the most commonly used form of enteral feeding (Gottrand & Sullivan, 2010). Gastrostomy tubes are known to improve growth rates, reduce infections and decrease healthcare costs post-insertion (Martínez-Costa et al., 2011). Therefore, as indicated by Khalil et al., (2016), gastrostomy tubes can potentially reduce parental anxiety and the burden of care.

2.3.1.2. Complications:

Possible complications which may occur cannot be ignored. The impact may result in additional costs and further complications for an already burdened healthcare system (Rosenberger et al., 2011).

Complications which may occur are:

- Blockages
- Infections
- Over granulation (an excess of tissue build up around the insertion site) (Martínez-Costa et al., 2013).

(Pars and Soyer, 2019).

More major complications which could be fatal include:

- Haemorrhage
- Perforation (common in paediatric cases) (Wong & Chung, 2021)
- Buried bumper syndrome (excessive tension between the bumpers causes erosion of the PEG into the gastric wall).

(Rahnemai-Azar, 2014).

Acknowledging possible contra-indications such as these, it is important for healthcare professionals to address these issues with caregivers in order for them to make informed decisions concerning the use of gastrostomy tubes (SASLHA, 2011). Complications such as these can result in increased hospitalisations (Ali et al., 2019). A supportive team can also assist in better follow up and reduce likelihood of these complications occurring or complicating.

2.3.2 Support Needs

Appropriate support systems are essential for referral and management when situations such as these arise. Psychological support is, therefore, also an essential resource for families who may feel over-burdened (Pedrón-Giner et al., 2013).

The decision to use a gastrostomy tube is multifaceted and therefore should be carefully considered by all team members. A study set in Taiwan discussed how the decision for gastrostomy tubes may differ according to a country's cultural perspective, resources and customs (Yeh et al., 2013). SA embraces a wide variation in the care provided as it contains a combination of '*developed and developing health systems'* (Raban et al., 2013). This can influence the variability of care and support that is received by patients owing to reduced access to professionals, resources and specialised feeds required for gastrostomy tubes. In addition, SA is made up of diverse cultural backgrounds and a variety of languages, making it a prerequisite to adapt treatment to suit the family's needs a prerequisite (Ned et al., 2017).

Input from an MDT is, therefore, essential in order to create a support system for the family and the caregiver. The importance of MDTs will be discussed in detail later in

this chapter. Although gastrostomy tubes are proven to be a life-altering change for families, a study found that a lack of information and emotional support can also affect caregivers' decision-making processes when making these changes due to the complexities involved, indicating that support may be required throughout the process and not only in initial decision-making phase (Yeh et al., 2013).

2.4. Caregivers: Decision-making and Third-Party Disability

2.4.1. Decision-making and the caregiver:

It is essential that caregivers are involved at an early stage of the decision-making process for gastrostomy feeds (Frohlich et al., 2010). The caregiver's decision is multifaceted, with medical, financial, emotional and cultural elements to consider (Adams & Elias, 2014; Serjeant & Tighe, 2021). These will differ within each family system.

Qualitative studies have begun investigating caregivers' experiences of gastrostomy feeding. However many of these studies are focused on the caregivers of patients in the adult populations (Green et al., 2019; Yeh et al., 2013). When looking at the caregiver's support needs, European studies showed that caregivers and patients were pleased to be less dependent on hospital care, but experienced a perceived lack of support post gastrostomy insertion (Green et al. 2019; Martínez-Costa et al., 2011). Studies also appeared to be focused on the process post-gastrostomy insertion on adult patients; showing that caregivers often felt there was minimal routine management for minor complications and follow-up interventions (Green et al., 2019). Caregivers should have a support system or a path for follow-up support post-discharge, as this is essential for a smooth transition to the home environment

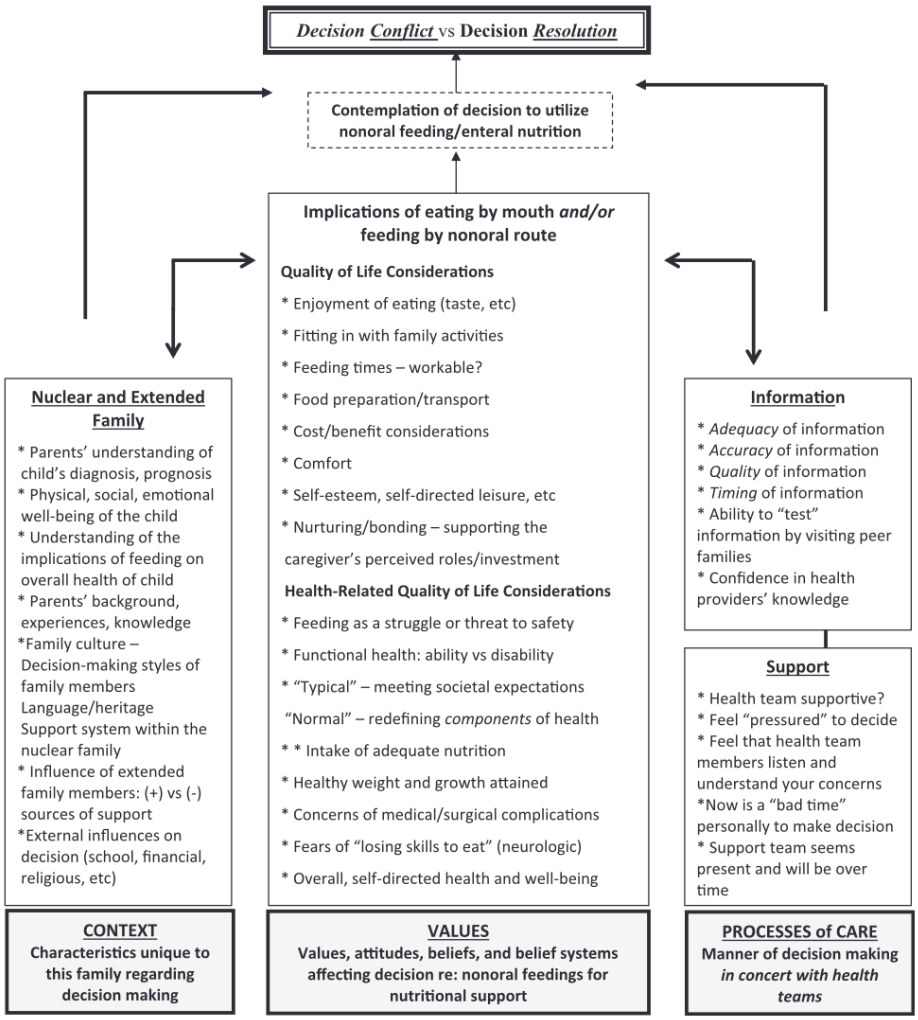
(Serjeant & Tighe, 2021; Sezer et al., 2019). More focus may be required for the design of a post-insertion support protocol prior to the initial surgery.

Caregivers of children have different experiences. They are required to make emotionally-demanding decisions for the children in their care, who are often unable to express their feelings (Martínez-Costa et al., 2011). The complexities of these decisions may make caregivers concerned about increasing the permanence of the disability and cause them to experience feelings of guilt (Petersen et al., 2007). In SA, contextual and cultural difference could further impact on the decision-making phase (Neille & Selikson, 2021). In certain environments caregivers may have less exposure to and cultural beliefs may result in later support seeking behaviours (Watermeyer & Penn, 2018).

Making the decision for gastrostomy feeds is complex and burdensome. In a study by Yeh et al. (2013); it was reported that caregivers felt that they would have made the decision for a gastrostomy tube sooner had they had known the positive impact that it would have on their lives. There was a perceived need for better support from the healthcare system in the decision-making process (Yeh et al., 2013). Figure 3, depicts a designed and adapted model which considers how a family's context, values and process of care all impact on the family's decision resolution when selecting enteral feeding solutions (Adams & Elias, 2014).

Figure 3

Figure indicating decision resolution vs decision conflict



Note. This model was produced by Adams and Elias in 2014, summarising decision resolution vs decision conflict. From 'Nonoral Feeding for Children and Youth With Developmental or Acquired Disabilities,' by R. Adams, and E. Elias, 2014, *Pediatrics*, *134*(6), 1745-1762. https://doi.org/10.1542/peds.2014-2829

This model emphasises the importance of investigating the 'process of care' (Adams & Elias, 2014). Literature shows that this transition phase has many benefits however,

some researchers believe that it can increase the burden on caregivers. This further emphasises their need to be informed and feel supported (Adams & Elias, 2014; Pars & Soyer, 2019). Adams & Elias (2014) identified the family's context and values as two of the important elements to consider. The impact of this decision can have a significant effect on the family structure as it could potentially reduce the burden of care that is endured. In the SA context this would be more complex given the many non-conventional family structures (Sooryamoorthy & Makhoba, 2016). A more user-friendly model may be required to consider the medical and emotional shortcomings and possible solutions when assisting caregivers through this decision-making phase.

2.4.2. Third-Party Disability:

Many studies emphasised the caregiver's need for emotional support due to the high levels of burden that they face, as well as pressure to acquire nursing and care skills (Pedrón-Giner et al., 2013). Research has begun to explore the concept of third-party disability (which refers to the caregiver's impairment in functioning when caring for an individual with a disability) (Nund et al., 2015). This trend in qualitative research is important as emotional and psychological impacts on the caregiver can have a great impact on the medical condition or the quality of care provided (Pars & Soyer, 2019).

Caregivers face increased pressure when caring for a person who is highly dependent on them (Van Houtven et al., 2011). Those who are predisposed to anxiety have a higher likelihood of experiencing this when caring for their minor child (Pars & Soyer, 2019). This high pressure on family members can increase the burden of care and can have financial, domestic and social impacts. This may further affect their work opportunities, sleep quality, as well as potentially cause marital difficulties (Pedrón-

Giner et al., 2013). A study which focused on the effects of gastrostomy feeds on mealtimes noted a strain on routine family time, post-insertion (Russell et al., 2017). This resulted in the family attempting to problem-solve and adapt to the changes in the family pattern. A study in SA, by Coutts & Solomon (2020), discussed that even adapting an adult patient's diet due to feeding difficulties placed an additional burden on the caregivers, and that this should be acknowledged as part of the treatment plan and process. There may be even greater demands on the caregivers of children and this should be explored within the South African context.

It is important that SLTs begin to acknowledge the impact a gastrostomy tube can have on the caregivers' daily lives in their functioning, activities and participation (Nund et al., 2015). It has been found that as the caregivers feel more secure in the knowledge and skills they possess, so the perceived burden of the care reduces (Pars & Soyer, 2019). This further emphasises that continuous support is required to assist parents throughout the process, including in decision-making, education and in monitoring for potential complications (Sharp et al., 2017). This requires the support from an MDT to appropriately guide caregivers from various perspectives throughout their treatment plans (Ayoob & Barresi, 2007).

Although a big life adaption is necessary, gastrostomy tubes show many benefits for the child, and also for the family system (Khalil et al., 2016). The family's transition will not be as effective without buy-in from the support system, therapy and psychological support with the adjustment to the gastrostomy tube (Russell et al., 2017). Therefore, it is essential to identify the caregiver's educational needs so they can make informed decisions and feel empowered in their caring abilities. Counselling may be further

required to permit caregivers and the patient to adapt to the gastrostomy tube given the restricted visiting hours due to the COVID-19 pandemic. These various challenges require a team of dedicated members, and must include members of the family system (Heuschkel et al., 2015).

With current literature focusing on caregivers of adult patients (Coutts & Solomon, 2020; Nund et al., 2015) in developed settings (Pedrón-Giner et al., 2013; Russell et al., 2017) there appears to be a gap in research considering the paediatric setting and when looking at settings with limited resources. Further investigations are required to examine how collaborative teams can assist in reducing the caregiver's burden when caring for a child with a gastrostomy tube.

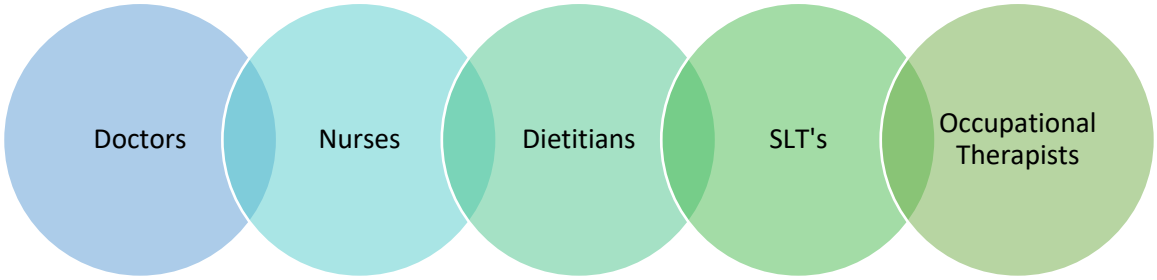
2.5. MDT and the role of the SLT:

2.5.1. The MDT approach:

A MDT is required to make appropriate recommendations and educate the family throughout the process (Burdall et al., 2017). An MDT is a partnership between healthcare professionals, from different disciplines, who collaboratively develop a common treatment plan with experiences drawn from their unique perspectives (Taberna et al., 2020). Benefits of an MDT include efficient, high quality care, improved team co-ordination, and advocacy for the care recipient as well as the team caregiver (Paganoni et al., 2017) This is essential in order to improve the global care of the patient (Licitra et al., 2016).

Figure 4

Team members involved in the decision-making process according to literature



Note. Depiction of the caregivers according to literature (Green et al, 2010, Russell et al., 2017; Sevilla & McElhanon, 2016)

The core team members to support the caregiver and the child include specialised doctors, nurses and allied members, including SLTs and dietitians. Participation from caregivers is essential for success (Sevilla & McElhanon, 2016). These team members play a large role in not only managing patients and caregivers, but also providing appropriate information to them. The amount and the detail of the educational support from team members may differ between countries according to available resources and the practice patterns that are imposed (Green et al., 2019). With time, research may also expose whether the COVID-19 pandemic has impacted on this.

2.5.2. The SLT's role:

SLTs play an important part in assessing, educating and managing populations with feeding and swallowing disorders (Ayoob & Barresi, 2007; SASLHA, 2011). This includes evaluating a child's oral-motor skills, the safety of their swallow, and the

impact of their feeding on the family environment (Adams & Elias, 2014). It is of concern that certain literature, such as Green et al, (2010), makes no mention of the involvement of the SLT in the team. This could have an impact on the appropriate referrals and therefore affect the decision-making process and the education and support provided to caregivers.

SA is an unique environment with varied cultural beliefs, socio-economic imbalances, and limited resources (Singh et al. 2015). It is essential that SLTs recognise the differences in the regional approach and adapt local training accordingly in order to cater to local patients' needs (Singh et al., 2015). A recent study highlighted that South African junior SLTs felt insufficiently equipped to deal with dysphagia management in the adult population (Coutts, 2019). Singh, et al. (2015) found a particular lack in the coverage of the assessment and management of paediatric dysphagia in South African undergraduate university courses. This may affect the intervention and education that families receive in both adult and paediatric settings.

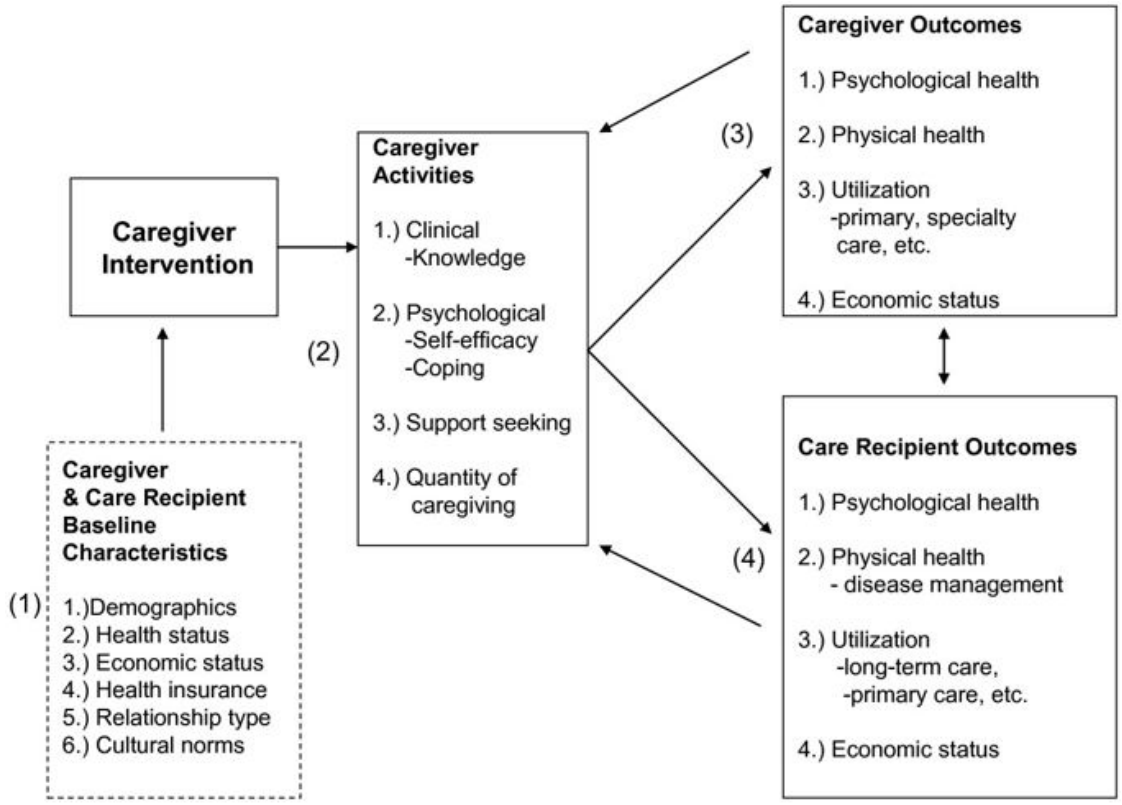
As a result, better training, and support for SLTs should be advocated for. It further emphasises that a collaborative partnership among all team members is essential (Seedat, 2013). This study is, therefore, important in order to identify what information is required for caregivers considering gastrostomy tubes for their children and how the SLT can facilitate a part of that process.

2.6. Organisational Framework for Caregiver Interventions (theoretical framework)

Van Houtven et al., (2011) compiled an organisational framework of the components to be highlighted when observing caregiver interventions, as seen in Figure 5. The purpose was to compare caregivers' intervention's rather than to guide the intervention which took place (Van Houtven, et al., 2011). This framework was therefore selected as allows one to monitor a caregivers context, their abilities and the impact it has on their lives. This still allows us to ensure that one is taking note of key elements:

Figure 5:

The Organisational Framework for Caregiver Interventions



Note. This model was produced by Van Houtven et al., 2011, diepicting an organisation framework for caregiver interventions. From 'An organizing framework for informal caregiver interventions: detailing caregiving activities and caregiver and care recipient outcomes to optimize evaluation efforts,' by C. Van Houtven, C. Voils and M. Weinberger, 2011, *BMC Geriatrics*, *11*(1). https://doi.org/10.1186/1471-2318-11-77

The framework first dissects the *Caregiver and Care Recipient Baseline Characteristics* as this affects the intervention plans and the care required (Van Houtven, et al., 2011). The caregiver's knowledge, as well as the care recipient's resource needs and the severity of their illness, can all be factors to be considered when a team is educating a caregiver (Pedrón-Giner et al., 2013).

The second component of the framework involves *Caregiving Activities,* which begins by assessing the caregiver's knowledge, as well as their psychological and support seeking skills (Van Houtven et al., 2011). The last element assesses the quality of caregiving or 'objective burden' by looking at the effectiveness of the caregiver's activities (Van Houtven et al., 2011).

The third component examines *the Caregiver Outcomes* by evaluating the positive and negative outcomes of caregiver interventions (Van Houtven et al., 2011). Many caregivers strongly promote the positive effects of gaining skills and a new role as described by Green et al., (2019), with caregivers who feel confident in administering gastrostomy feeds, responding positively. However, there is also increased anxiety and stress experienced by caregivers who may feel an increased burden of care (Pars & Soyer, 2019).

Lastly, the *Care Recipient Outcomes* looks at disease management skills (Van Houtven et al., 2011). This area focuses on the mental and physical health of a patient and how they may experience their situation, depending on their cognitive abilities.

The Organisational Framework for Caregiver Intervention does not directly assist in the caregivers decision-making process (Van Houtven, et al., 2011). However, it does help one to understand caregivers' experiences, and the areas where they may feel burdened, overwhelmed or uninformed, which may affect their decision-making process. It is essential that one understands the caregiver's needs in order that SLTs provide the best possible care and support, and so reduce their burden of care. This framework can be used for identifying the caregiver's burden and the impact that their knowledge and the support received has on the outcomes of the child and the caregiver. This framework was therefore be used in the study to assist in shaping the questionnaire, results and discussion to ensure that the caregivers' experiences remain the focus of the process throughout. Although this does not directly discuss the SLT's role it does allow the researcher to examine the caregivers needs to ensure professionals are providing the required support and assistance. Based on the above, this study therefore aims to explore caregivers' experiences when considering gastrostomy feeds for their child within in the SA context.

2.7. Rationale

South African caregivers need contextually appropriate information to make an informed decision when choosing tube feeding for the child in their care. Studies looking at gastrostomy feeds previously showed a greater medical focus (Gottrand & Sullivan, 2010, Khalil et al., 2016; Raban et al., 2013). Although this is important; it is essential that one begins to understand these processes from the role players' perspectives, including those of the caregivers and the healthcare workers. This will allow one to uncover practical, as well as emotional, shortcomings, and therefore consider the potential changes which may be made to the education process.

Studies are only now beginning to uncover the caregivers' stresses and burdens to ensure professionals are better equipped to assist this population (Pars & Soyer, 2019, Pedrón-Giner et al., 2013; Russell et al., 2017). New trends in qualitative research note third-party disability and caregiver burden in patients with dysphagia, however these are currently focused on the adult population (Nund et al., 2015; Pedrón-Giner et al.; 2013). Some research has begun to uncover on how caregivers beliefs and values could have an impact on families perceptions, however the research does not disuses clinical approaches (Coutts & Solomon, 2020; Neille & Selikson, 2021). This must be explored further within the South African context, with specific focus on the paediatric population.

SLTs need to identify whether caregivers feel well-supported and guided by the treating team, thus allowing them to feel confident when making decisions (SASLHA, 2011). It is necessary to examine the SLT''s actual role as part of the guidance and education process and the broader role they should play in an improved treatment protocol.

Chapter 3: Methodology

This chapter deals with the aims, objectives, and methodology of the study. The design is discussed together with the participants, data collection procedures, analysis and reliability and validity.

3.1. Aim of the Study

3.1.1. Research question:

What are the caregivers' and SLT's experiences during the decision-making process when considering gastrostomy feeds for their child within the SA context?

3.1.2. Aim

This study aims to explore:

1. the experiences of caregivers during the decision-making process when deciding to use gastrostomy feeds for the child in their care;
2. the role of the SLT in this decision-making process from the caregiver's perspective; and
3. the SLT's experiences in guiding caregivers though their decision-making processes.

3.1.3. Study Objectives

a) To describe caregivers' general needs in the decision-making process before their child's gastrostomy insertion.
b) To describe the support and information caregivers require from their SLTs during the decision-making process.

c) To describe SLT's experiences of the decision-making process when working with caregivers of children with gastrostomy tubes.

3.2 Research design

A qualitative method of research was selected using principles of an analytic phenomenological perspective. This allowed the researcher to identify shared feelings and experiences which are sustained by caregivers and SLT's in a common phenomenon (Creswell et al., 2007). This further allowed the researcher to develop insight into caregivers' and SLT's perspectives' while attempting to remove bias. The data was looked at thematically by finding common experiences from caregivers and SLTs (Miles et al., 2020).

3.3. Setting

This study was conducted online by contacting participants from across SA's private and public settings. This allowed for a broader perspective for themes identification across different contexts. Participants from all areas were included to get a general sample and a broad understanding of what knowledge should be provided to caregivers in SA.

Contact was limited owing to the COVID-19 pandemic. The use of online data instruments allowed for information from multiple sites to be obtained, and for diverse perspectives from a range of hospital contexts to be obtained. The contextual information can be seen under '*4.1 Participant Description*'. The SLTs were fairly equally distributed between the government (n=11/23) and private settings (n=9/23)

with the remaining participants from other settings such as schools where SLTs were involved in the treatment of paediatric dysphagia.

The setting was not directly identified for the caregiver participants. However, it is important to note that most of the caregivers were from Gauteng province. This could be due to accessibility of information and access to support groups being greater in this area, however this is discussed in detail in Chapter 4: '*Results'*.

3.4. Participants

3.4.1 Sample strategy

Participants of the caregiver questionnaire were identified through support groups on social media as well as those referred by their SLTs. Snowball sampling was then used to reach a greater number of geographically dispersed participants while preventing any form of stigma (Heckathorn, 2011). Snowball sampling allowed the researcher to obtain an in-depth perspective of the experiences of the specific population group (du Plooy-Cilliers et al., 2014). Questionnaires were distributed in social media platforms with a description of participants who would be appropriate as well as the purpose of the study. From the questionnaire, willing participants were invited to join the focus group discussion.

The same sampling techniques were used for the SLT questionnaires. They were identified using snowball sampling which allowed the researcher to reach other SLTs via social media, email and referrals from their colleagues.

The inclusion and exclusion criteria meant that some participants were not eligible to participate. Some caregivers completed the questionnaire despite the fact that their children did not fall within the indicated age range. Unfortunately, their responses were discounted. This is further described below.

3.4.2. Participant Selection Criteria and Rationale

Participants included SLTs working with paediatric dysphagia and caregivers of children with gastrostomy tubes. Participants were selected according to strict inclusion criteria, taking note of contact limitations for the COVID-19 pandemic.

3.4.3.1 Selection Criteria for Caregiver Participants

The main criteria for participants in this research included caregivers with children (2 - 6 years old) who required a gastrostomy tube for feeding. The inclusion criteria for the participants are presented in Table 3.

Table 3:

Selection criteria: Caregivers

Criteria	**Specifications**
Age	*Adults (Over 18 years old)*
Child's age	*2 - 6 years old*
Condition of child	*Child with an medical condition requiring a gastrostomy tube*
Location	*South African residence*
Resources	*Access to basic internet services*
Socio-economic status	*Any*
Race	*Any*
Gender	*Any*

Language	*Any (however must speak basic English)*

Hence in order to answer the research question participants needed to meet all of these criteria:

- Caregivers referred to parents or primary caregivers of the child who are responsible for making decisions on behalf of the child.
- Children of the age 2 - 6 years old:
    - This age range was selected as these children would fall within the same development stage related to their eating habits if they were oral feeders. The children would be independent feeders if they tolerated solid foods (Southall & Martin, 2011).
- Gastrostomy tube:
    - Participants were caregivers of children who use gastrostomy tubes as a part of their method for nutritional intake. Combination feeders who eat both orally and enterally were included.
    - The children must have had a tube for approximately 2 months to be included. The caregivers should feel comfortable with the device and the healing should have taken place. The child did not still need to have the tube as the caregiver would still have gone through the decision-making process. There was no implemented timeframe since the training had taken place as all caregivers would have undergone the decision-making process.
- The location was broadened to apply across SA to widen the range of participants, and to be able to make generalised trends.

- Although socio-economic status was not a direct restriction, it was essential that participants had access to basic services, as well as basic technology (cell phone/ laptop/ tablet). Owing to the COVID-19 pandemic restricted contact was essential to prevent any risk to participants.
- Gender and race of participants were not specified in the inclusion criteria as this would have no effect on their ability to answer the research questions.
- It was necessary for participants to have basic proficiency in the English language in order to answer questions.

Willing participants with internet access were given the option to join a focus group discussion. Consent was obtained before the group commenced, and participants were given the opportunity for decline to participate at any point.

3.4.3.2 Selection Criteria for SLT Participants

All willing registered SLTs were included in the study, together with community service SLTs, as they were part of the population who are involved in providing the education and treatment to these patients in certain facilities. The participants were South African SLTs in any sector where they were involved in the treatment of paediatric patients with dysphagia. The SLT's selection specifications to qualify for inclusion in the study can be seen in Table 4 below.

Table 4

Selection criteria: SLTs

Criteria	Specifications
Qualification	*Registered SLT including community service SLTs.*
Population	*SLTs that are involved in treating the paediatric dysphagia population.*
Location	*South Africa*
Work setting	*Public/private sector*

3.4.4 Sample size

Thirteen caregivers participated in the online questionnaire within the study. The focus was on parents, or the primary caregiver, of children with gastrostomy tubes between the ages of 2 to 6 years of age. Although the COVID-19 pandemic may in due course demonstrate a reduction in the gastrostomy surgeries, this did not impact on participant numbers. This is because the caregivers of children who already have gastrostomy tubes were the focus of the research. Owing to the specific participant group data collection continued until the data was saturated or no new data was obtained.

The follow-up focus group was based on participation willingness and consent. All of the participants who completed the questionnaire were invited to participate in the

focus group. Unfortunately, only the minimum of two participants were willing to participate in the discussion.

Twenty-three SLTs across SA participated in the online questionnaires due to the easy access and convenience. A full description of the participants will be discussed in detail in Chapter 4. *'Results'.*

3.5. Research instrument

Three separate data collection strategies were used to ensure a comprehensive examination of caregivers' experiences when they selected a gastrostomy tube for their child. The questionnaires were circulated and data collection occurred concurrently. A subsequent follow-up focus group took place with willing caregivers. This allowed the researcher to discuss topics based on the responses in the questionnaire that would allow deeper insights.

Firstly, a self-developed, online questionnaire was distributed to caregivers of children with gastrostomy feeds (see appendix A.1). Open-ended questions were used to add richness to the results (Marsden & Wright, 2010). A few closed-ended questions were used to add context to the participant population. Twenty questions were compiled and written. Some questions were adapted from a published article by Martínez-Costa et al., (2011) which posed similar questions to family members. The remaining questions based on the research question and gaps in literature. The questions were structured using the four features of the Organisational Framework by Van Houtven et al., (2011). Therefore, the initial questions focused on the caregivers and care recipients' characteristics. This was followed by the caregiver's activities and decision-

making process, with focus on the SLT's role. The last two sections looked at the outcomes on the caregiver and the care recipient. The questionnaire was uploaded into the online *Flesch Kincaid Reading Ease Test a*nd was analyzed using their algorithm. This provided the questionnaire with a score of 65.7% and a grade level of approximately grade 8 (Readable, 2020).

Next, a self-developed electronic questionnaire was distributed to SLTs who worked with children with gastrostomy tubes (see appendix A.2). This provided insight into SLT's experiences in guiding caregivers through their decision making, together with their perceived understanding of the caregiver's needs. Eleven questions were created starting with closed-ended contextual questions followed by open-ended questions uncovering the SLT's experience and confidence when supporting these caregivers. The questions were based on personal experience and adjusting questions from similar studies noted in literature.

All questionnaires were created on *Google Forms* due to its ease of use for both the researcher and the participants. Google is a commonly used platform that translates its design language across all services, and therefore participants would be comfortable and familiar with its user-friendly interface. It must be noted that the use of online questionnaires may have excluded participants with reduced access or technological skills; but it was selected for the following reasons:

- The COVID-19 pandemic resulted in social distancing and reduced the possibility of contact with patients and families.
- Faster response times.
- Reduced financial implications.

- Extended the access to a broader group of participants.

(Hanley, 2011)

Lastly, a follow-up focus group was done via the *Zoom* platform by selecting willing participants from the caregivers questionnaires. An online focus group allowed participants from anywhere in SA to communicate and identify various views and shared experiences (Litosseliti, 2003). Topic points or open-ended questions were identified, based on the responses given in the questionnaire, in order to generate deeper insights in the discussion process (see Appendix A.3). These were semi-structured with some planned topic areas, based on the researcher's findings, together with flexibility to follow participants' conversational lead (Creswell, 2013). The researcher acted as a facilitator with partial participation by initiating talking points, gently prompting to provide for equal participation, and prompting for details, while remaining impartial (du Plooy-Cilliers et al., 2014). A focus group was selected for the following reasons:

- It allowed for a deeper understanding of participants' opinions from people who come from similar situations.
- It may have assisted in generating solutions for future improvements.
- It allowed for richer data by exploring deeper for insights in areas that were investigated.
- It assisted in clarifying points made from the questionnaires for a deeper understanding.

(du Plooy-Cilliers et al., 2014).

Both of the questionnaires, and the talking points for the focus group, were presented to a peer expert to critique to ensure improved rigor (du Plooy-Cilliers et al., 2014).

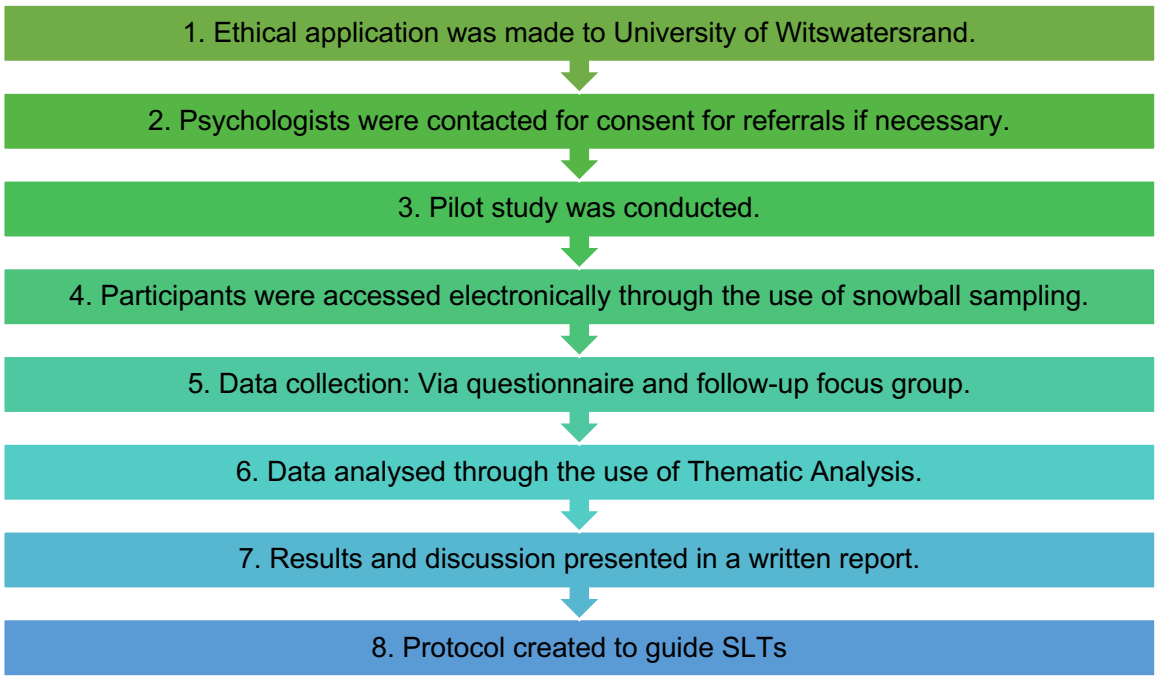
The questionnaires were also trialled in a pilot study which will be discussed in *3.7. Pilot Study*.

3.6. Data Collection Procedure.

The data collection procedure was carried out as seen in Figure 6 and the steps are discussed in detail thereafter.

Figure 6

Outline of the research procedure



1. The proposal for the study was presented to the University of Witwatersrand's non-medical Human Research Ethics Committee and any required revisions were made.
2. Once ethical clearance was granted; the SLT contacted psychologists for consent to refer caregivers who requested emotional support. The psychologists were all available for teletherapy and had varying costs. These

ranged from providing their service for medical aid rates to support services which charged no cost.

3. The pilot study was conducted. Initially, the questions were reviewed with a peer expert and then through a representative sample. After each step the appropriate amendments were made. The details are discussed in 3.7 '*Pilot Study'*.
4. Participants were selected in the following phases:

    Phase 1: Caregivers were identified via social media support groups or directly by their treating SLTs identified on social media. Members were asked to forward the questionnaire to any appropriate participants. This allowed the questionnaire to be distributed by snowball sampling in order to identify appropriate participants who shared similar traits, without bias (Hale & Napier, 2013).

    Phase 2: SLTs who met the inclusion criteria were identified on social media groups and spread through snowball sampling. The questionnaire was distributed on these platforms and readers were requested to forward to appropriate participants.

    Phase 3: Caregivers who were interested and willing to participate were contacted for a focus group via '*Zoom'*, which was facilitated by the researcher. Participation was voluntary and consent was obtained. Caregivers were informed that video recordings were being made to record the responses.
5. The data was collected via open-ended questionnaires, and the follow-up focus group with the caregivers. Firstly, the questionnaire was distributed to caregivers and SLTs. It began with an information page followed by an informed

consent form. The participants were able to complete the questionnaire in their own time via *Google Forms*.

Any caregivers who agreed to participate in the online focus group were contacted. They were able to select suitable dates and times and they were notified of the final mutual selection. The topic points for the focus group were based on the information gaps after the questionnaires were returned and had begun to be analysed. It was carried out via *Zoom* and was recorded to ensure accurate recall and to allow for transcription. Participants were able to choose whether to show their video or keep themselves unseen. Participants were advised to use pseudonyms, however this was at their choice.

6. The data from the open-ended questionnaires was saved. For the focus group, a transcriber was used to transcribe the forty-minute conversation using the coded identifiers. The transcriber signed a confidentiality agreement (see appendix E) before receiving the footage. Thematic analysis was used to identify key elements in order to logically group the problems presented by the caregivers into themes.
7. The data was analysed as discussed under the heading '3.7. *Data analysis'* and the results were presented in the written format. A discussion on the finding was presented in a written format.
8. Lastly, a protocol was created for SLTs to assist caregivers in their decision-making for potential gastrostomy feeds. This could be a useful tool for future use.

3.7. Pilot Study

A pilot study was done in order to identify fallouts in the study's design and to trial the proposed questions (du Plooy-Cilliers et al., 2014). Initially, a SLT who is considered an expert in the field was asked to critically analyse the questionnaires, to provide insight, and to identify areas of potential conflict or misinterpretation. Some of the suggested alterations were made to the caregivers' questionnaire. This included adding questions to prompt further detail or to seek additional clarity in order to improve credibility.

The questionnaire was sent out as a trial to one caregiver and one SLT, who acted as a representative sample. Once the questionnaire was completed the participants were asked for feedback on any ambiguities or the difficulties they faced when answering the questions in the online questionnaire.

The caregiver who was used as the representative sample described the questionnaire as '*clear and easy to understand'*. The SLT noted no difficulties with the user experience. Suggestions were made on discussing the SLT's role which was indirectly addressed by asking: *'What do you feel the caregiver's information needs are?*'. As no major changes were required to be made the results were able to be included in the study.

The agenda for the focus group, along with broad topic areas, was designed based on the results of the caregivers questionnaires. These were also be critiqued by the same identified expert in the field. Possible expansion points were suggested and appropriate edits were made.

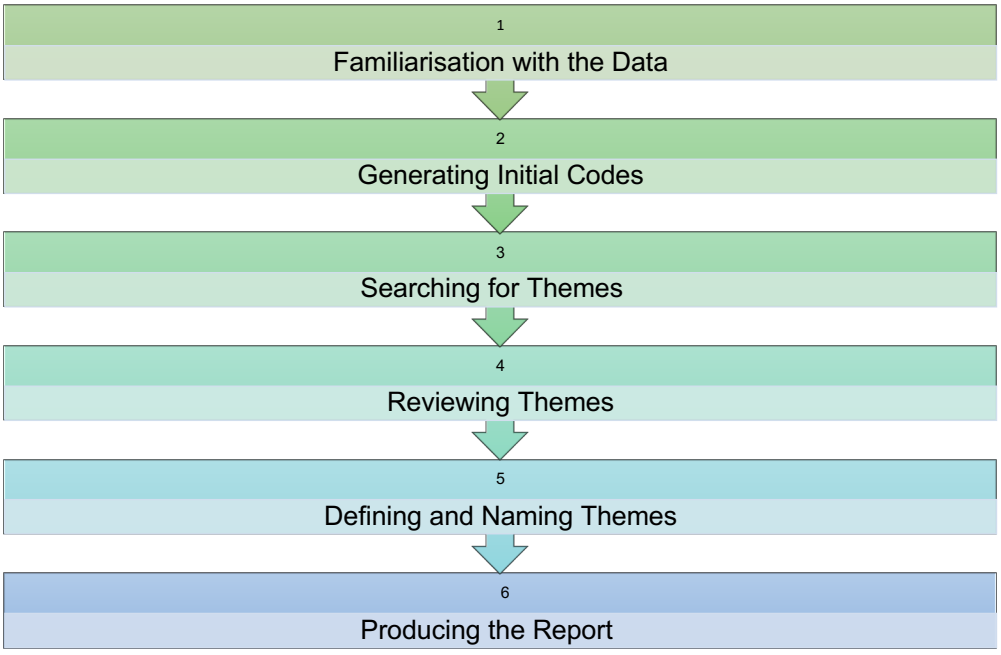
The pilot study allowed for improved rigor in preparation of the study by ensuring the analysis was well planned and tested for improved outcomes (Creswell, 2013).

3.8. Data Analysis

Braun and Clarke's Thematic Analysis was used to interpret data individually; then drawing out unifying themes (2020). Thematic analysis is the process of analysing data by finding patterns that expose significant trends (Braun & Clarke, 2020). Reflexive Thematic Analysis was employed using inductive reasoning to identify the appropriate themes (Braun & Clarke, 2019). This demonstrated a 'bottom-up' approach which was completed using four phases of theme development that are discussed below (Braun & Clarke, 2020).

Figure 7

Phases of Thematic Analysis



Note. This model was produced by Braun and Clarke in 2006, summarising the phases of thematic analysis. From 'Using thematic analysis in psychology' by V. Braun and V.

Clarke, 2006, *Qualitative Research In Psychology*, *3*(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

In first phase, '*initialization',* the information from the questionnaires as well as the transcribed dialog from the follow-up focus group was scrutinised (Vaismoradi et al., 2016). The SLT's questionnaire responses were analysed separately, although linking themes were identified. The information was read and dissected into codes using colours and key-words (Braun & Clarke, 2020; Vaismoradi et al., 2016).

In the second phase, the data was analysed and compared against the research question through the five phases of '*construction'*. Clusters of similar code were labelled, and themes began to emerge which were linked to the research objectives (Vaismoradi et al.,2016). The themes arising from the participants' experiences were identified from the data rather than focusing on specific questions in the questionnaire. The themes identified included the impact on the family system, the support system, and societal issues. These were broken into sub-themes as required.

Next, in the '*rectification*' phase the data was verified by establishing links throughout the data to existing literature. Eventually the '*finalization'* phase occurred by developing the narrative when writing up the discussion, with clear connections throughout (Vaismoradi et al., 2016).

This form of analysis was used to allow structured analysis by using 'inference interpretation' of explicit descriptions within the data (Vaismoradi et al.,, 2016). This prevented the use of generalised and random themes from implied statements on the surface of the data.

3.9. Triangulation & Trustworthiness.

Triangulation of data in a study was done by the use of a variety of sources of information to ensure validity (Lemon & Hayes, 2020). Therefore, not only was an online questionnaire distributed to collect information from SLTs, but data was also collected by both an online questionnaire and a follow-up focus group with the caregivers. The researcher attempted to converge various participants' perspectives when selecting and justifying themes (Creswell, 2013). Using different sources and perspectives allowed improved data triangulation in this study, which resulted in improved credibility and reduced bias (Brink et al., 2018; Lemon & Hayes, 2020).

The caregiver focus groups acted as a form of 'member checking', being when participants are given the opportunity to confirm the accuracy of their perceived ideas by the researcher (Creswell, 2013). This was done by using key elements and gaps in the data to create the focus group as speaking points. These points were checked by the peer expert for further insight before creating an agenda for the focus group as discussed in the pilot study. The focus assisted the researcher to identify possible consensus on certain experiences or feelings when identifying themes.

To ensure further 'trustworthiness' in studies the researcher looked more specifically at the credibility, transferability, confirmability and dependability as discussed below (du Plooy- Cilliers et al., 2014).

3.9.1. Credibility: Internal Validity

Credibility is required to ensure that the findings correlate with participants' perspectives (du Plooy-Cilliers et al., 2014). The credibility of the data was ensured

through the use of different data collection instruments, such as the questionnaires and the focus group, in order to provide a more holistic view.

Not only were multiple 'sites' accessed through online data collection, but by collecting data from the SLTs and the caregivers, multiple perspectives were also uncovered. This allowed for method triangulation which increased the credibility and generalisability (Creswell, 2013)

3.9.2. Transferability: External Validity

Transferability is essential in order to ensure that the observations made in this study are applicable to individuals with the same challenges in other contexts (Brink, et al., 2018). Literature was used to support data along with the use of detailed descriptions of the participants and their circumstances to provide for the richness of the data (Merriam & Tisdell, 2016). In addition, the use of online questionnaires allowed for a variety of sites to be targeted. These included both government and privates settings across SA, which allowed for increased transferability.

3.9.3. Confirmability

In order to ensure confirmability, the researcher sought to avoid bias and remain objective (Brink et al., 2018). When interpreting the results it was essential that the views of the participants were voiced to remove the personal tone or expression of the researcher (du Plooy-Cilliers et al., 2014). This was also done by ensuring verbatim transcriptions from an external transcriber, which were thereafter checked by the researcher in order to eliminate misconceptions and errors. This assisted in making

findings more accurate (Creswell, 2013). Additionally, consistent supervision throughout this study assisted in maintaining objectivity.

3.9.4 Dependability: Reliability

Reliability should be practiced throughout a study to improve the trustworthiness of the methodology and the data produced (Creswell, 2013). This was achieved in this study through consulting with a peer expert before finalising the research instruments, by conducting a pilot study, and by checking the transcriber's transcriptions (Creswell, 2013). The rigor was a focus throughout the data collection and analysis and even ensuring ethical data management (du Plooy-Cilliers et al., 2014).

3.10. Ethical considerations

The research proposal for this study was submitted to the University of Witwatersrand's non-medical Research Ethics Committee. The necessary suggested changes were made and submitted.

3.10.1. Informed consent

Once ethical clearance was received; the study commenced and the questionnaire was circulated on various platforms. The questionnaire began by explaining the purpose of the research and what it would entail from participants (see appendix B.1 and B.2). A consent form was provided to each potential participant on the first page of the online questionnaire (see appendix C.1 and C.2). Caregivers completing the form were also able to agree to joining the focus group via video call. Thereafter, they received an information sheet and a consent page to read and complete prior to participating in the focus group (see appendix B.3 and C.3).

3.10.2 Confidentiality

Participants received confidentiality when reporting the research results. Caregivers and SLTs were given coded identifiers as this has been proven to reduce social bias (Marsden & Wright, 2010). Therefore participants were referred to as ‘CG1’ etc (in the case the caregivers), and ‘SLT 1’ etc (in the case of the SLTs involved) in order to preserve confidentiality.

The participants identified themselves to the researcher by providing their email addresses if they had future communication or contact needs. This included indicating their willingness to participate in the focus group, to receive psychological support, or to receive the research results. Participants in the focus group were requested to use a pseudonym on the Zoom call in order to protect their confidentiality and were made to consent prior to the agreed upon date. All research data will be stored on a password protected computer. No identifying data will be revealed in the written material in order to comply with the Protection of Personal Information Act (POPIA) (Adams et al., 2021).

3.10.3 Reporting findings

All results obtained from the study were sent via email to the participants who had requested them. Any additional questions were answered, as appropriate. The researcher hopes to further publish the findings through local conferences and academic journals.

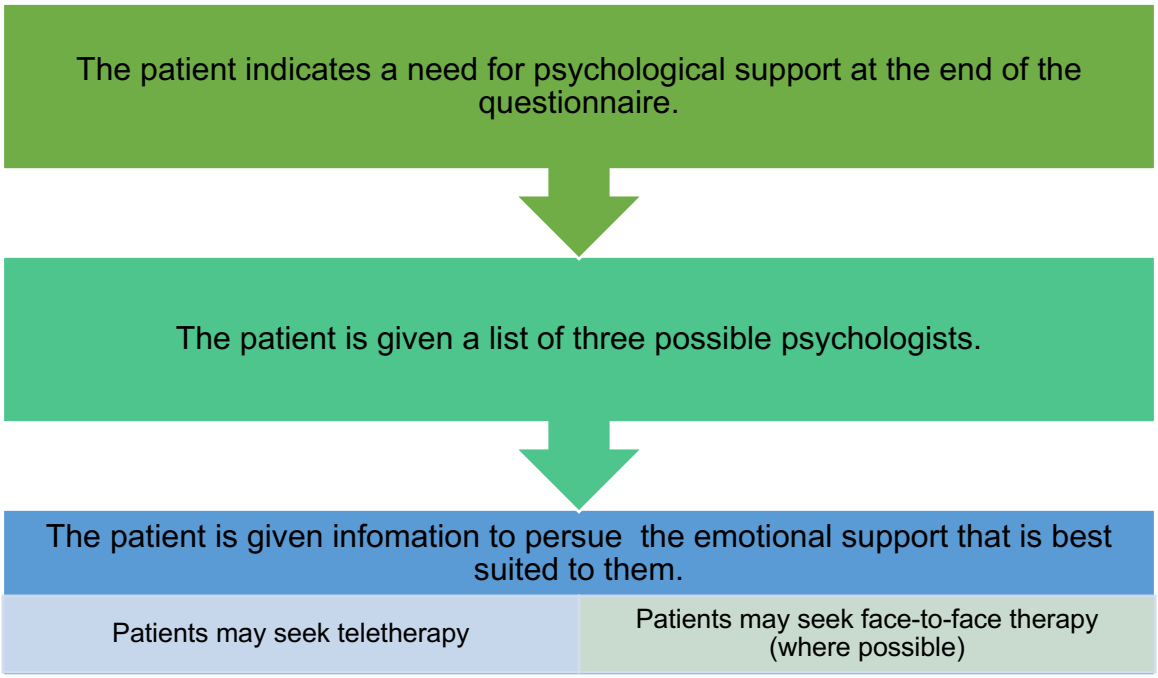
3.10.4 Non-Maleficence

Throughout the study no intentional harm was inflicted on participants. The study was designed to ensure all participants had no exposure to COVID-19. All participants were given the opportunity to request psychological services if they felt overwhelmed or in need of support. They were subsequently given a list of three possible psychologists.

3.10.4.1 Distress protocol

Figure 8

Distress protocol



Permission was obtained from three psychologists, including two in private practice and one from a free counselling service. Caregivers were able to indicate their interest in the psychologists details at the end of the questionnaire. The three professionals were randomly provided, in no particular order, in the event required, and participants were able to independently seek appropriate support. Only one participant indicated interest and the information was sent to the email address provided.

3.10.4.2 Right to withdraw

Participants had the right to withdraw form the process at any point if they felt uncomfortable or were unable to complete the study (Adams et al., 2021). Two participants chose to opt-out of the focus group after indicating initial interest.

3.11. Data Management

Participants' psychological comfort is a priority (du Plooy-Cilliers et al., 2014). For this reason, participants were informed of how their information was to be protected. The caregivers' email addresses were retained by the researcher only to provide participants with the results, the psychologists' details (if required), or to invite them to the focus group if they indicated an interest in attendance.

All data will be stored on iCloud storage for 2 years post-completion, and thereafter will be erased. Only the researcher has access to this information which includes notes, transcriptions and the completed research report. If this research is published as an article the storage period may be extended until the completion of any article. This was clearly stated in the consent form.

Chapter 4: Results

The purpose of this investigation was to identify caregivers' experiences during the decision-making process when considering gastrostomy feeds for their child in the South African context. In this section; the results obtained are discussed in detail. The results include information obtained from the online questionnaires distributed to caregivers as well as to the SLTs, and information obtained from the caregivers' focus group.

Within this chapter the objectives will be broken down into themes according to the results obtained, as seen in Table 5. Themes identified included: Impact on the family system; the support system; and societal issues.

Table 5

Outline of the themes that emerge in relation to the objectives of the study

Objectives of the study	Themes of the study
4.1 To identify caregiver's general needs in the decision-making process before their child's gastrostomy insertion.	Impact on the Family System a) Resource strain (finances, caregiver needs and time) b) Quality of life
4.2 To describe the support and information caregivers require from their SLTs during the decision-making process.	The Support System a) Team development b) Adapting to family's needs
4.3 To describe SLT's experiences of the decision-making process when working with caregivers of children with gastrostomy tubes.	Societal Issues a) Teamwork b) Stigma

Initially, the study's participants will be discussed and described in detail in order to generate an understanding of the context of the information obtained.

4.1. Participant Description

Caregivers of children from 2 - 6 years old who have a gastrostomy tube were selected to participate, as well as SLTs working within the paediatric dysphagia population. It is important to consider the participants' contextual information when analysing the results. Table 6 and Table 7 are provided to give context before the participants details are analysed.

Table 6

Participant information: Caregivers

Caregiver	Province	Relationship to child	Age of child (years)	Child's condition	Time since gastrostomy placement
CG 1	Gauteng	Mother	5	Neurological impairment	2.5 years
CG 2	Western Cape	Mother	2	Failure to thrive, feeding aversion	1 year
CG 3	Gauteng	Father	5	Malnutrition	9 months
CG 4	Gauteng	Mother	2y 10m	Down syndrome (medically complex)	18 months
CG 5	Gauteng	Mother	3y 1m	Oral sensitivity	12 months
CG 6	Gauteng	Mother	5	Near Drowning (neurological impairment)	4 years
CG 7	Mpumalanga	Mother	4	Cardiac Dysfunction	3.5 years
***CG 8**	Gauteng	Mother	3	Neurological impairment	2.5 years
CG 9	Gauteng	Mother	6	Neurological impairment	2 years
CG 10	Gauteng	Mother	4	Cystic Fibrosis	2 years
CG 11	Kwa-Zulu Natal	Mother	6	Neurological impairment	5 years
CG 12	Kwa-Zulu Natal	Mother	5	Neurological impairment	4 years
***CG 13**	Gauteng	Mother	3	Neurological impairment	3 years

Participants that were a part of the focus group.

Table 7

Participant information: SLT

SLT	Setting	Province	Years of experience
SLT 1	Private hospital	Gauteng	5-10
SLT 2	Private practice	Kwa-Zulu Natal	Over 10
SLT 3	Private hospital	Gauteng	Over 10
SLT 4	Government hospital	Western Cape	Over 10
SLT 5	Private practice	Eastern Cape	Over 10
SLT 6	Government hospital	Gauteng	1-5
SLT 7	Other	Gauteng	5-10
SLT 8	Government hospital	North-West	Over 10
SLT 9	Government hospital	Gauteng	1-5
SLT 10	Private practice	Gauteng	Over 10
SLT 11	Private hospital	Western Cape	1-5
SLT 12	Government hospital	Mpumalanga	1-5
SLT 13	Private practice	Gauteng	Over 10
SLT 14	Government hospital	Kwa-Zulu Natal	1-5
SLT 15	Other	Gauteng	5-10
SLT 16	Private practice	Gauteng	1-5
SLT 17	Government hospital	Gauteng	1-5
SLT 18	Government hospital	Gauteng	1-5
SLT 19	Government hospital	Western Cape	Over 10
SLT 20	Other	Gauteng	5-10
SLT 21	Government hospital	Gauteng	1-5
SLT 22	Private hospital	Gauteng	1-5
SLT 23	Government hospital	North-West	1-5

4.1.1. Caregiver description

The caregiver is the person who is usually responsible for the decision-making on behalf of the minor child. Thirteen caregivers (CG1-CG13) took part in the online questionnaire. Contextual information about the caregivers are seen in the figures and the table below.

Figure 9

The provinces in which caregiver participants resided

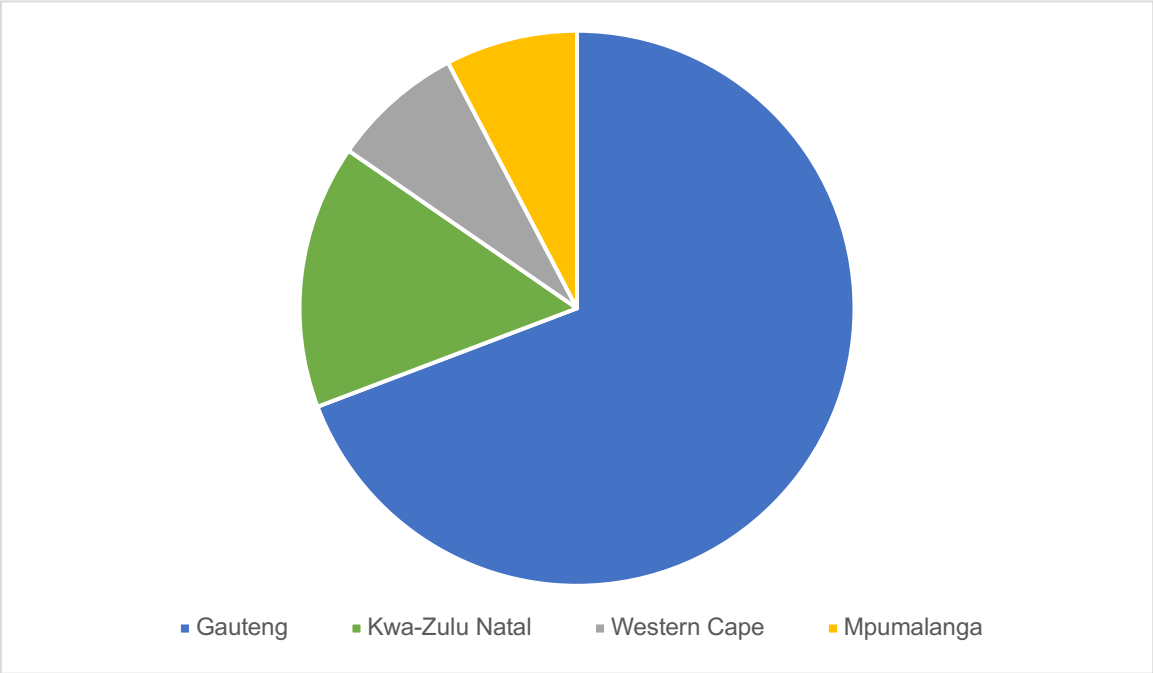
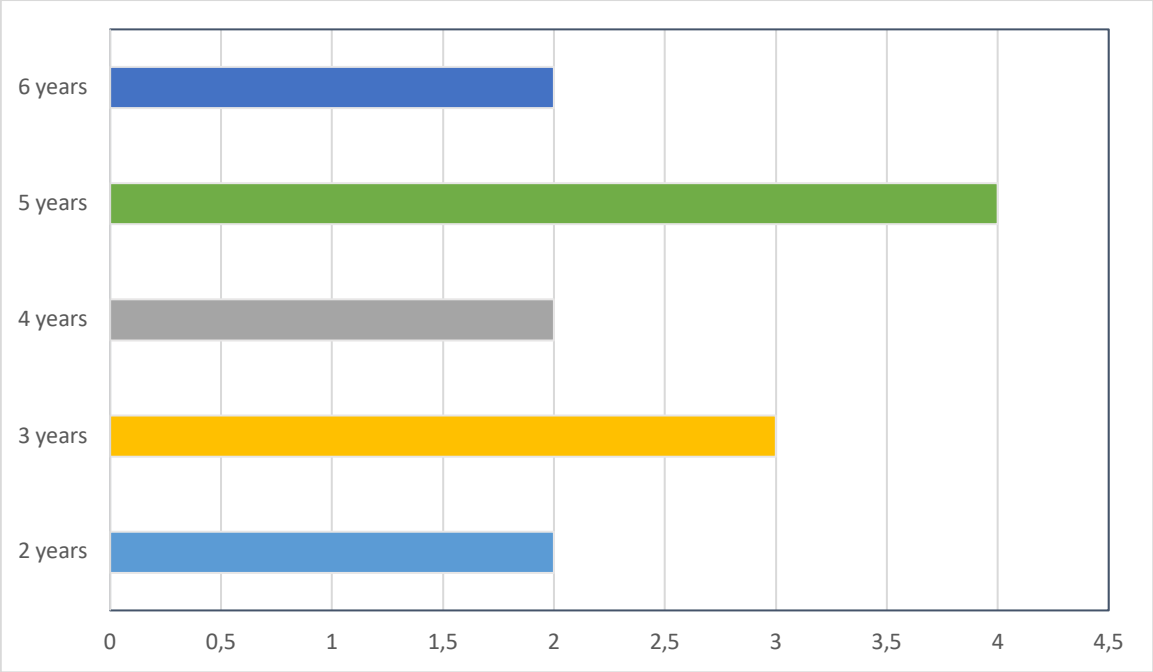


Figure 9 depicts the distribution of the participants across SA. Participants were only obtained from 4 of the 9 provinces in SA. Two participants resided in KwaZulu-Natal, while one participant was from the Western Cape and Mpumalanga respectively. Most of the participants (n=9/13) were from Gauteng which may be due to accessibility to social media, lesser social restrictions and greater access to support groups. All of the participants were mothers except for one father.

Figure 10

Ages of the children with the gastrostomy tube



As per the inclusion criteria the children of the caregivers ranged between 2-6 years old with a fair distribution of children of each age as seen in Figure 10. All of the children had their gastrostomy tubes inserted between nine months to five years ago. This indicated that all of the caregivers would have some experience with gastrostomy tubes within their daily environments after the education process.

Figure 11

Conditions of the children who required gastrostomy tubes

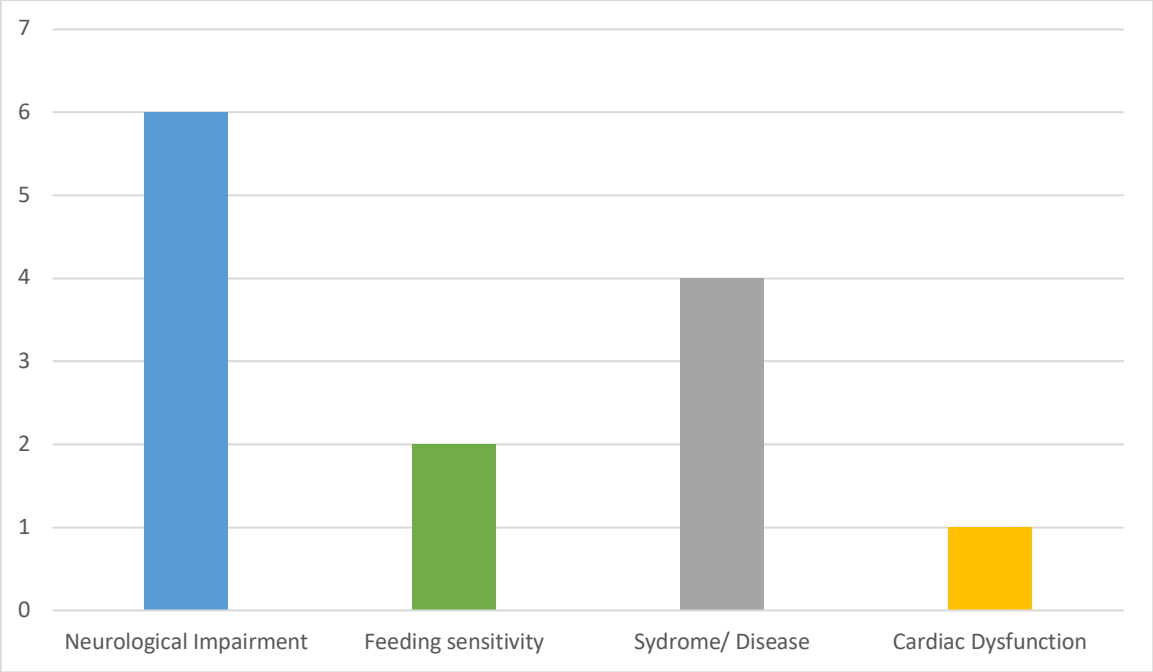


Figure 11 depicts the medical conditions of the children in the study. From the 13 caregivers children; six of the children had a neurological impairment, which included a previous hypoxia or Cerebral Palsy. Four of the children displayed with a syndrome or diseases such as Down Syndrome or Cystic Fibrosis. Three of the children had unique conditions, including feeding sensitivities and a cardiac dysfunction, resulting in the need for enteral feeds.

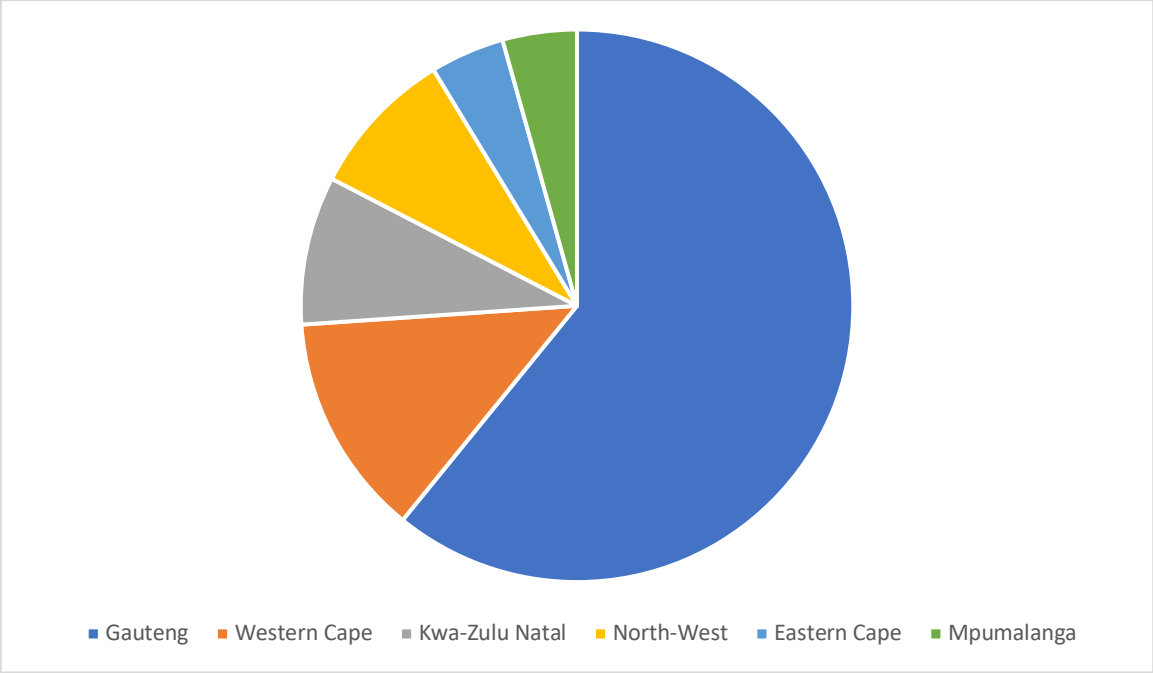
Two of the caregivers (n=2/13) who completed the questionnaires agreed to participate in the focus group. Both of the participants were mothers living in Gauteng who had participated in the online questionnaire.

4.1.2. SLT participant description

Twenty-three SLT's (SLT 1 - SLT 23) participated in the online questionnaire. Figure 12 depicts the distribution of the participants across six of the nine provinces in SA.

Figure 12

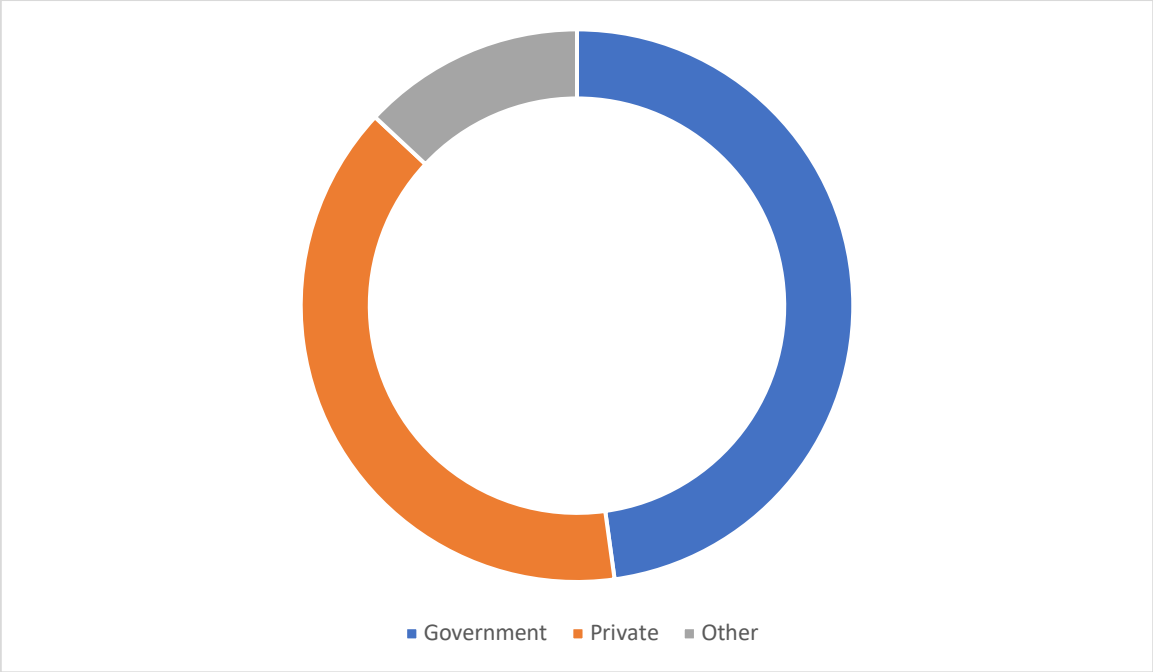
The provinces in which SLT participants resided



Most of the participants (n=14/23) appeared to be from Gauteng, which may be due to accessibility and activity on social media platforms. The remaining participants were from the Western Cape (n=3) Kwa-Zulu Natal (n=2), North-West (n=2), the Eastern Cape (n=1) and Mpumalanga (n=1).

Figure 13

Distribution of work settings of the SLT's



As seen in Figure 13, the participants were fairly equally distributed between working in the government (n=11/23) and private sectors (n=9/23). Three participants (n=3/23) were in other sectors, including in the education sector.

Figure 14

Number of years of experience of the SLT's

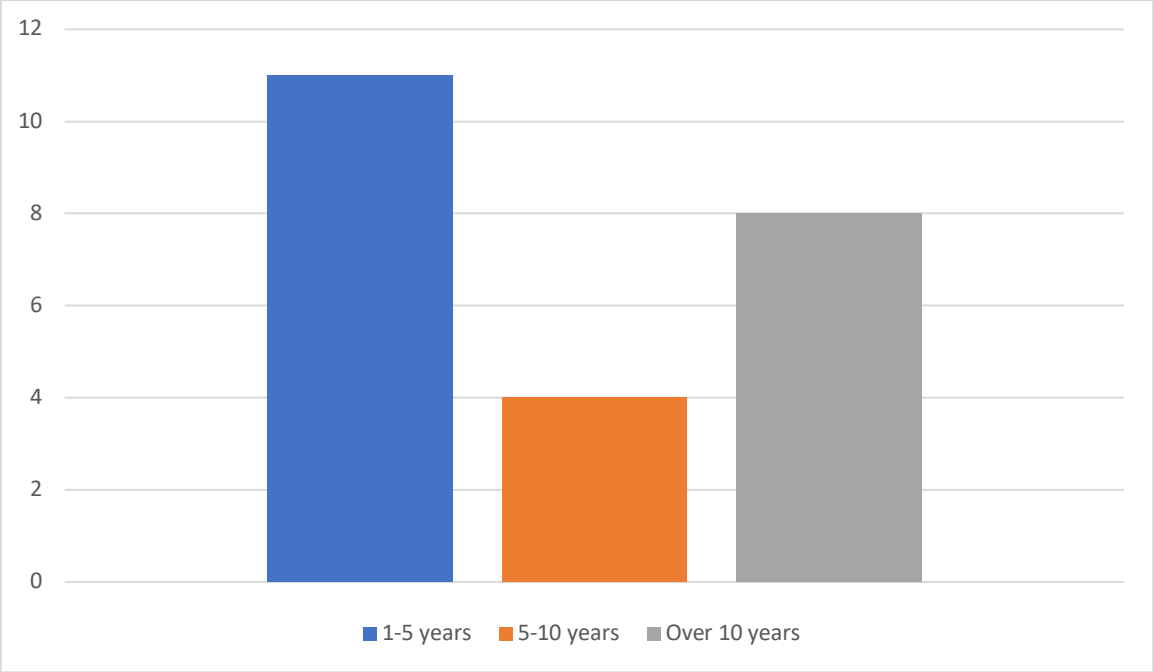


Figure 14 shows the number of years of work experience the SLTs had in the speech therapy field. Most of the participants were comparatively divided between less than five years' (n=11/23), and more than ten years' (n=8/23) experience. This provided a broader range of insight and experience. It is important to note that fifteen of the twenty-three SLTs had less than ten years' experience, which highlights the need for younger therapists to be trained to approach this complex process of education and guidance.

The information concerning the participants provides a deeper insight into the results obtained, so providing a greater understanding of the socio-economic context as well as the population category of participants for the research purposes. The objectives are discussed according to the themes identified.

4.2. To identify caregivers' general needs in the decision-making process before their child's gastrostomy insertion.

There is a heavy burden and responsibility placed on the caregiver to make decisions on behalf of the care recipient. Therefore, identifying caregivers' information needs is essential. As expected, caregivers discussed the importance of being provided with the appropriate medical information. This included information concerning possible *'…infection and side effects'* (CG 10, personal communication, February 7, 2021), information concerning the surgery and '..*what could go wrong'* (CG 7, personal communication, January 1, 2021) as well as '..*other options*' (CG 12, personal communication, February 24, 2021) that could be investigated with the treating team. CG 11 stated that they '*…would have liked to have [received information concerning] other options and therapy/treatments before..*' their decision had to be made (personal communication, February 22, 2021).

Further analysis of the findings exposed the need for the patient's family to understand more about the impact that the PEG could have on the family system. Two sub-themes were identified in the data which conveyed the additional issues the families wished to understand prior to the procedure taking place. These included the potential resource strain on their family, as well as the impact on their quality of life.

4.2.1 Impact on the family system

The Organisational Framework for Caregiver Interventions highlights the importance of the caregiver having support, knowledge and skills in order to provide appropriate care to the care recipient (Van Houtven et al., 2011). As a result, note should be made

of the impact this decision has on the care recipient and the caregiver, as well as the impact on the family system as a whole.

4.2.1.1 Resource strain

The decision to obtain a gastrostomy tube is primarily for the well-being of the care recipient, however it is essential that a caregiver understands the additional strain it may place on the family system (Russel et al., 2017). The sub-theme is discussed below by identifying the caregivers possible financial strain, staff or caregiver needs and time strain.

a.) Financial strain

In order to make an informed decision caregivers feel they should be informed on the financial consequences for the family. Almost half of the caregivers (n=6/13) specifically mentioned that they experienced a strain on the family's finances. CG 1 spoke about the '*…financial strain of purchasing new mickey tubes and the cost of the milk…'*, as well as the costs of additional consultations with professionals (personal communications, November 3, 2020).

Caregivers in the private sector reported that medical aid schemes assisted with the funding of feeds. However, even these families had to overcome financial obstacles. Two caregivers specifically discussed the continuous battle with medical aid schemes to pay for the feeds which is more expensive than normal food. It was noted that families may not receive appropriate medical aid cover without the correct diagnosis or proactive caregiver involvement. CG 3 noted that '…*eventually the medical aid paid for the feeds, but before that we had to pay for it out of our own*

pocket' (personal, communication, January 11, 2021). The initial cost increase experienced by caregivers can place financial strain on, and stress within, the family.

The financial burden, however, should not be an obstacle for patients who have access to government funding. Due to the demographic composition of the respondents answering the online questionnaire there was limited data on caregivers' financial strains in the government setting. However, SLTs working in the government sector noted that there was also financial stress for families who should be receiving government resources. SLT 21 noted '…*reduced resources and reduced staff … [affects] the value of information and education provided to caregivers*…' (personal communication, February 24, 2021). SLT 19 reported that even when feeds are funded, the '*…government patients who are tube fed are at the mercy of the organisation providing the milk if the family has no funds to get their own… Clinics run out regularly'* (personal communications, December 11, 2020).

Caregivers felt that this was an area they should have been prepared for, or assisted with, by the professionals supporting them. CG 1 noted it is a '…strain financially ..' and caregivers would benefit form team members should assist the family in prepare for possible adjustments (personal communication, June 5, 2021). Although it is clear that there are additional costs and financial implications to consider, it is important to note that caregivers also discussed reduced medical costs due to other factors. They reported reduced risks of chest complications and improved weight gain amongst their children, which would have reduced associated medical costs.

b.) Staff or caregiver needs

Additional financial and emotional demands on the family may be involved in finding appropriate supporting or secondary caregivers to assist the primary caregiver. A secondary caregiver could be a family member or an employed caregiver who can assist with the required tasks. One primary caregiver stated that selecting an appropriate support caregiver is a challenging task as a person with '…*a special aptitude for special needs children'* is required (CG 7, personal communication, January 17, 2021). Another primary caregiver stated they '…*would love someone to teach and care for [their] son during the day'* to allow for time to *'…work or [for] respite from time to time, but it is not financially possible'* for them (CG 4, personal communication, January 16, 2021).

Although this is not the conventional role of an SLT; linking primary caregivers to the appropriate professionals, caregiver support groups, or educational resources, as well as ensuring appropriate education may be a necessary ancillary support function. SLTs in the study noted the importance of holistic patient management and the importance of referring families to appropriate professionals.

c.) Time strain

Primary caregivers also report a change to their daily routine and time allocation. Little support from secondary caregivers can impact on the time burden they face in order to attend to their child. A few of the caregivers (n=4/13) noted they have no assistance with feeding their child. Another four caregivers mentioned that only one other family member is able to assist them with tube feeding the child. This adds to the additional burden and a strain on the primary caregiver's time.

One of the caregivers mentioned the impact that the set schedules required for feeding regimens have on their lives. They described it as '*tiring*' as some said they had to feed their child up to six times a day; showing the significant impact that the feeding regimen has on their schedule. In the focus group, FG CG 1 noted that other than their sister '*there is no one else that can take care of [their] child'*, which impacts greatly on their routine (personal communication, November 3, 2020). They stated that if one meal runs late it can affect the whole day. It is to be noted that these caregivers with children with existing conditions may have already have had difficulties with feeds. For example, CG 12 noted *'…months of hospital stay[s], trying to get him to orally feed on amount of food required'* (personal communication, February 24, 2021).

Another caregiver mentioned that training for additional family members is, therefore, essential in order to reduce the time burden on one caregiver. This is why CG 7 noted that '*..every person in the household needs to know how to use the mic-key, [and] what to do..*' when the caregiver is not available (personal communication, January 17, 2021). One caregiver noted that '…*it is quite expensive and takes up a lot of time, but it is worth it to see her healthy and getting in her food safely*' (CG 11, personal communication, February 22, 2021).

There appears to be a dearth of information to inform and guide caregivers on the potential resource strain they may endure. The team is required to identify caregivers' concerns and to assist where possible to advise, or refer caregivers to the appropriate professional to ensure that the family receives holistic, sustainable and beneficial care to best suit their family dynamic.

4.2.2. Quality of life of the family system

The second sub-theme identified when looking at caregivers' information needs was the impact on the quality of life of the caregiver as well as on the care recipient. The majority of the caregivers (n= 12/13) noted that the gastrostomy tube allowed for their child to improve their weight and reduce their chances of chest infections, and so they were able to '*flourish'*. More than half of the caregivers (n= 8/13) noted that, with the benefit of obtained knowledge, they would have wanted to receive the gastrostomy tube earlier. The caregivers in the focus group discussed how they now feel inclined to recommend gastrostomy tubes to other parents they now observe struggling with feeding issues. The FG CG1 noted that they '…*wish they could consider it because it was life saving for [them]'* as knowing their child has safe and sufficient intake (personal communication, June 5, 2021). The improved intake allowed their children to have increased energy and reduced the stress within the family system. This also resulted in an improved quality of life and reduced chest infections. These all have beneficial impacts and these ancillary potential benefits should be discussed as part of the education process.

There were also challenges that caregivers faced that impacted on the quality of life of the family system and the care recipient. Some caregivers felt that their families considered the tube a '*failure'* or questioned the process. CG 12 also noted that although '*it is a more convenient way to feed…'* (personal communication, February 24, 2021), when they are in public settings *'…it is very embarrassing'* (personal communication, February 24, 2021). CG 3 even stated that their child *'…had to stop playing sports and he feels embarrassed about the tube'* (personal, communication,

January 11, 2021). CG 6 also felt that it impacted negatively on the child, making the child '*lazy [or reluctant] to eat'* (personal communication, January 16, 2021). The perceived lack of participation in daily activities may concern parents and therefore this appears to be an important part of the long-term planning. SLT 10 noted how important it is to include '…*transitioning to oral feeds'* as part of the education process (personal communication, December 10, 2020).

When caregivers make the decision to select a gastrostomy tube for their child healthcare providers must understand that they need to give the family a holistic overview of the procedure and the effects of the implementation thereof. The evidence obtained in this study made it clear that the caregiver needs to understand how the tube will impact both positively and negatively on the child, as well on as the family system. This potentially could increase burden on family resources as well as impact on the quality of life of the child and their family. This will be discussed in more detail according to the framework in the discussion section.

4.3. To identify the caregivers support and information needs from the SLT in the decision-making process

The decision-making process for the caregiver concerning the provision of a gastrostomy tube for a the child is a daunting and multi-faceted one and requires that ongoing support and attention be given to caregivers. Caregivers need support from SLTs from the beginning and throughout the decision-making process, and then further ongoing support in order to continue educating and supporting their feeding journey. SLT 11 stated that caregivers '…*need to know that they are supported'* in the process in order to feel secure in their decisions (personal communication, December

10, 2020). The theme of support systems was, therefore, identified to uncover the caregivers' support needs from the SLT as a team member in this process.

4.3.1 The support system

As seen in '*3.4.5. Participant description'*, most of the children who required gastrostomy tubes initially were diagnosed with neurological impairments (n= 6/13), syndromes/ diseases (n= 4/13), or oral aversions/failure to thrive (n=2/13). This population of children have pre-existing feeding concerns or difficulties. For this reason intervention relating to feeding issues should take place in advance of the decision to insert a gastrostomy tube. SLT 10 noted that one must develop '…*a trusting relationship with parents from the beginning…'* for improved trust and susceptibility in order to digest new information and guidance (personal communication, December 10, 2020). Therefore, the theme of 'the Support System' can be discussed by looking at the development of the team, as well as how to adapt education to the family's needs.

a.) Team development

The Organisational Framework for Caregiver Interventions highlights that the caregiver's activities are influenced by the caregiver's knowledge and support seeking, all of which impact on the quality of their caregiving (Van Houtven et al., 2011). Gastrostomy insertion should only take place when other options have been exhausted. SLT 9 noted that caregivers require 'emotional support and care management' (personal communication, December 10, 2020). CG 4 discussed how the SLT acted as a team leader and '*spoke to specialists involved, got the necessary tests, wrote reports, and helped to arrange most of what we needed*' (personal

communication, January 16, 2021). CG 12 also discussed how the SLT '…*made sure the tube was the last resort…'* and made sure to trial '…*oral techniques prior to the insertion of the tube'* (personal communication, February 24, 2021). Many caregivers were aware of why the tube was needed as they were involved in swallowing studies, which many SLTs had noted as an important part of caregivers' education.

There is a clear sense that caregivers require a general understanding of what the gastrostomy tube is, and why it is needed. Half of the SLTs in the study (n= 12/23) specifically noted the importance of the family understanding the reason for insertion. SLT 21 noted: '*Caregivers need to know what the tube is, why it is inserted and how they can take care of it (e.g. cleaning it) [as well as] how to use it (e.g. administering feeds)*' (personal communication, February 24, 2021). SLT 11 noted '[caregivers] also need to know the reason behind alternative feeding methods so that they are better able to comply…' with recommendations and treatmemt (personal communication, December 10, 2020). It is implied by the SLT's that as a caregiver's knowledge and understanding of the reason for the insertion of gastrostomy tube increases, so compliance is improved.

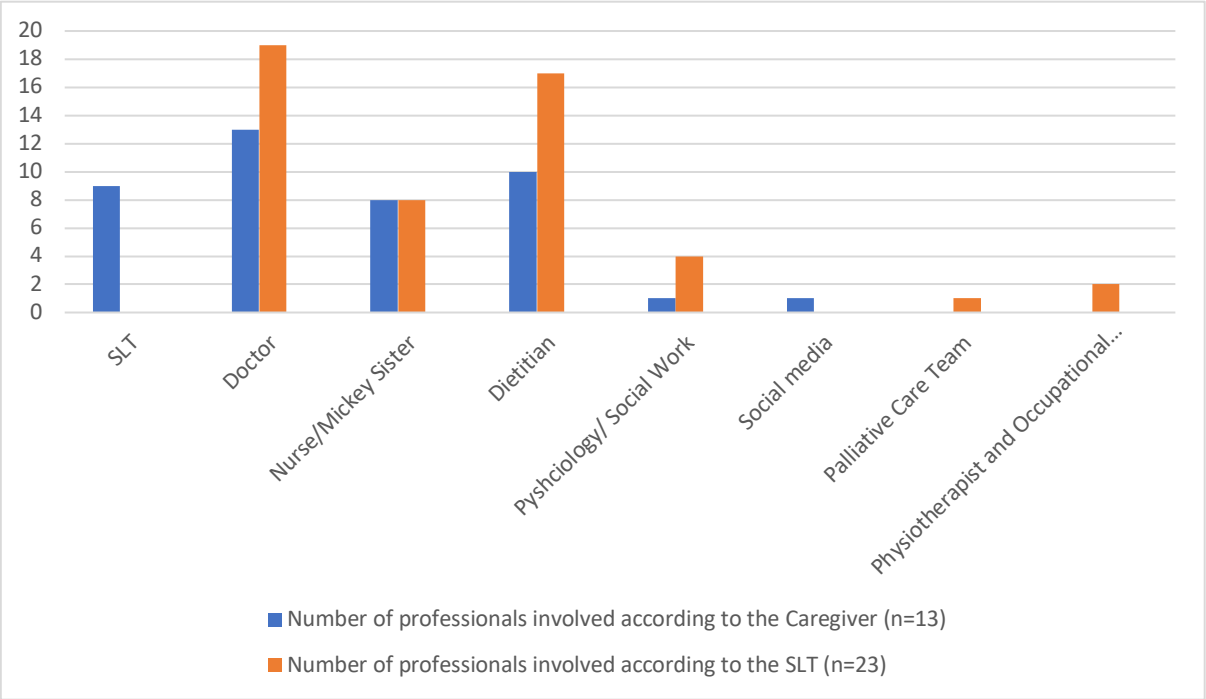
Figure 15 compares which team members are involved in caregivers' education and training from the respective perspectives of the caregiver and the SLT. Initial support is essential in the decision-making process. In Figure 15, it is clear that most of the caregivers had received some level of education from doctors (n=13/13), dietitians (n=10/13), and SLTs (n=9/13). Many of the caregivers (n= 8/13) indicated involvement from a nurse or MicKey sister. These appeared to be ongoing support providers. One

caregiver noted using social media, such as Facebook support groups, as a form of information. Few psychologists (n=1/13) appeared to be involved in the preliminary decision-making processes, which is concerning as the process involves emotionally complex decisions.

Most SLTs discussed the importance of multiple team members being involved in the process. Considering Figure 15 from the SLT's perspective; most SLTs (n= 19/23) worked in an environment where doctors were a part of the process. Doctors' specialisations varied, with most being paediatricians or surgeons (n= 15/23), although some team members mentioned gastroenterologists (n= 1/23), Neuro-developmentalists (n= 1/23) or Ear Nose and Throat Specialists (ENT) (n= 2/23) specifically. This did not appear to be specific to a context. There was also involvement from dietitians (n= 17/23), nurses/ MicKey sisters (n= 8/23), and psychologists (n= 4/23). Three of the four SLT's who worked with psychologists or social workers were from private settings. A few of the SLT's (n= 2/23) mentioned that physiotherapists and occupational therapists had been involved in the process. Lastly, one SLT mentioned that they work with a Paediatric Palliative Care Team in some cases. Depending on the child's condition this could be an essential and under-recognised addition to the team.

Figure 15

Comparative chart showing team members involved in training according to caregiver's and the SLT's.



It is clear, from the perspective of the SLT and the caregiver, that the main support and involvement was from doctors, nurses, dietitians and SLTs. Doctors were an active team member for all caregivers, however four of SLTs did not mention their involvement in the process. Nurses and Mic-Key sisters appeared to play a greater role for the caregiver. A few caregivers mentioned how nurses and Mic-Key sisters had played a role as ongoing team members, providing support and guidance with the gastrostomy tube. The caregivers did not directly confirm how long each professional had been involved in the process, however it is to be assumed that allied professionals would have a longer-term relationship with the patient and caregiver, whereas doctors' interventions may be over a shorter period. This may be because of the nature of the

consultative process in the professional relationship. This will need to be considered in future research.

Many of the caregivers (n= 9/13) noted that they received some guidance from the SLT in the decision-making process. Only 2 of those caregivers stated that it was not beneficial: CG 9 noted that there '…*wasn't much support' f*rom their treating SLT (personal communication, January 24, 2021). Education needs from the caregivers related to positioning for feeds, funding for feeds, and assisting caregivers in helping their child to start to '*enjoy food and start eating better'*. CG 10 noted their initial SLT '…*was more concentrated on making [their] daughter fit the [norm] instead of listening to [their] problems and helping'*, which was very damaging to their progress (personal communication, February 7, 2021). Half of the caregivers who received SLT support felt supported and well prepared. CG 12 noted that their SLT ensured they felt it was the '…*last resort'* (personal communication, February 24, 2021). However, four of the caregivers reported no support from a SLT. This did not appear to be associated with a particular setting.

Team set-up for ongoing support is essential and will be explored in the following section. Most caregivers received SLT support as the process progressed, but they did not necessarily receive such support initially or lacked a stable team. Ongoing support is essential in order to allow for caregivers to ask informed questions. SLT 19 stated that '*counselling is ongoing'* (personal communications, December 11, 2020). Many SLTs discussed the importance of 'slowing down' the process of counselling and proceeding '*slowly and patiently with multiple opportunities for discussion with all the team members'* (SLT 3, personal communication, November 3, 2020).

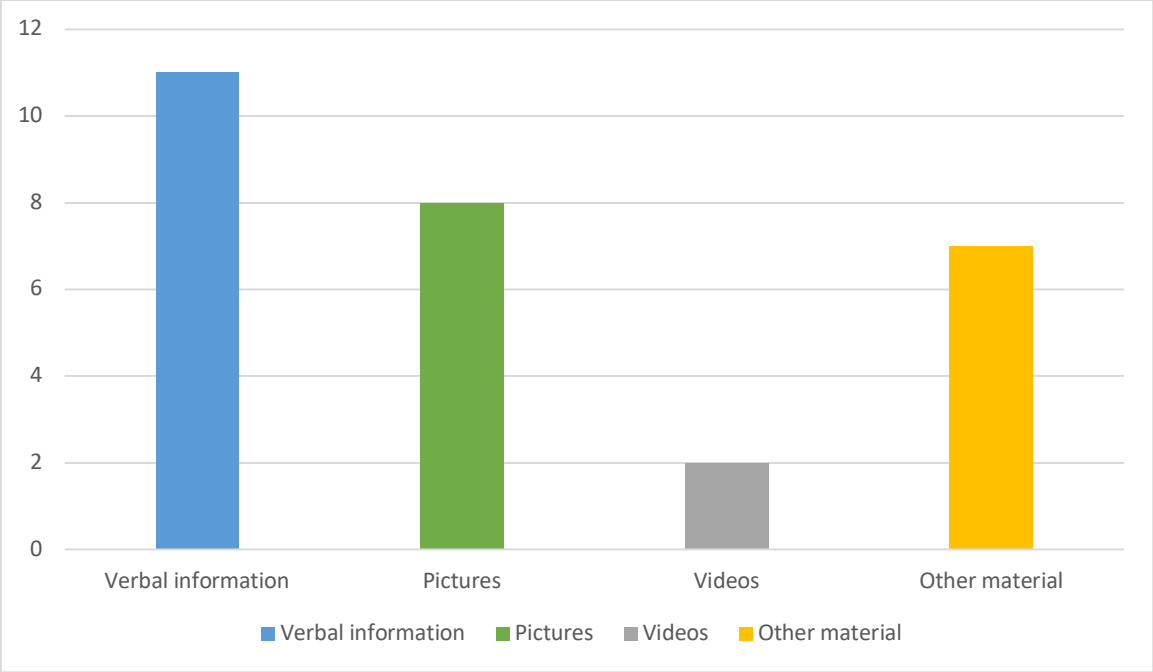
b.) Adapting education to the family's needs

When providing education, it is essential that SLTs adapt their styles and the intensity of the education provided in order to suit the family's needs. It is noted that many caregivers feel '*overwhelmed in a single session when they are needing to make a decision'.* SLT 10 noted that education should involve a *'…gentle step-by-step process as a team where the parent is allowed time to digest information and ask questions'* (personal communication, December 10, 2020). CG 1 also noted that *' time to accept and digest the information'* was important, highlighting that SLTs and caregivers both regard this as a vital consideration (personal communication, June 5, 2021).

A few of the SLTs (n= 2/23) recognised the importance of using a '*quiet environment'* with privacy, and ensuring that the caregiver has time to process the information. SLTs discussed how handouts or reading materials are important in order that the caregivers can '*refer back*' to the information when they consider and process it at a later stage. Written information may also have greater value after practical experience has been obtained. This aligns with the information obtained from caregivers in Figure 16. The majority of the caregivers appeared to receive some form of handout (n= 7/13) or visual material (n= 10/13), together with verbal information (n= 11/13).

Figure 16

Educational material received in training according to the caregivers



There are challenges that may be faced when adapting education sessions to the family's needs. SLT 3 noted that in reality '…*logistics around meetings and visiting hours'* play a role in shortened educational sessions (personal communication, November 3, 2020). SLT 23 mentioned that owing to resource constraints in hospitals (such as theatre cancelations and lack of beds), there may be delays in gastrostomy insertions, resulting in '*mothers [becoming] very frustrated and sometimes [changing] their minds about agreeing to a [gastrostomy tube]*' (personal communication, February 25, 2021). In situations where resource difficulties exist SLTs may struggle to find the optimal time to train caregivers, despite the clear need for such training. A few of the SLTs (n= 4/23) discussed that time availability is essential as caregivers may easily become overwhelmed in one session, and need '*time to digest'* information for improved buy-in. Therefore, it is ideal for training to be done slowly and in stages.

Some caregivers' support needs differed. For this reason it is essential to focus on the individual families' support needs and to tailor the information that is given to the needs of the families concerned. This will ensure that the family system feels well supported when caring for their child. The SLT, therefore, plays a major role in the team in ensuring that education and support is provided throughout the process, but also appears to play a role in referring to, and liaising with, other team members in order to ensure that the family is well supported by all disciplines. Connecting the family with supportive team members may be a significant part of the support structure required by the caregiver.

4.4. To identify SLTs' experiences of the decision-making process when working with children with gastrostomy tubes

The SLT plays a significant role in the process of managing a patient's feeding plan. This involves recommending a gastrostomy tube, educating the family throughout the process, and assisting them in the decision-making process. It was thus important to explore the SLT's perceptions of their role during the process and to consider the challenges they may face, as this may impact on the education given to the caregivers.

4.4.1. Societal issues

SLTs may become involved at the various stages of the medical process of the caregiver and their child. For this reason, SLTs may face a variety of obstacles, including preconceptions and challenges with teamwork, which may impact on the care provided by them. SLTs must, therefore, be cognisant of the challenges they may face in order to attempt to overcome or compensate for them, where possible. The theme of societal issues was identified.

a.) Teamwork

Most of the SLT's (n= 22/23) noted the importance of team-work throughout the education and recommendation process, with only one SLT noting that she provides counselling alone, with few '*…instances where the doctors [are] involved too'* (SLT 17, personal communication, December 10, 2020). Many SLT's stated that every team member was expected to have their own '*individual roles and responsibilities'* (SLT 3, personal communication, November 3, 2020*)*. Although SLT's value the importance of teamwork, it may not be an actuality in practice.

In reality, the results obtained suggest that cohesive teamwork may not always be the norm: Few of the SLTs (n= 5/23) reported that they independently trained caregivers. This appeared to be due to time restraints faced by the teams, and a lack of collaboration among team members. The remaining SLTs (n= 18/23) noted that they train caregivers with at least one other team member or even a '*PEG team'*. SLT 11 noted that '*…each discipline discusses their role (e.g. positioning during feeds, how to prepare meals, etc). Having the MDT present ensures that all the caregiver's questions can be answered appropriately*' (personal communication, December 10, 2020). It was further noted that every '…*person is involved with counselling and support which falls within their scope of practice'* (personal communication, December 10, 2020). As previously discussed the SLTs noted that explaining '*why*' a gastrostomy tube is required is an essential part of their counselling. SLT 10 noted that families need to know '…*possible options, outcomes, [the] effect of the tube on their family life, transitioning to oral feeds …[and] therapy needs'* (personal communication, December 10, 2020).

A few of the SLT's (n= 6/23) specifically mentioned '*combined counselling'* or '*team meetings',* demonstrating collaborative discussions leading to joint decision-making and collaborative education. Many of those SLTs (n= 15/23); worked in hospital settings, implying more access to collaboration in a hospital setting, which would allow for more holistic care to be provided. All of the private hospital SLT's noted three or more team members being involved in the education process for caregivers, with both simultaneous and independent training sessions noted. SLTs in government hospitals all had more than two members, usually doctors and dietitians, involved in the decision-making and education process. There is no clear reason indicated for this difference between government and private hospitals, however it may be attributed to the resources available.

Almost half of the SLTs (n= 10/23) highlighted that ideally a team approach should be utilised. In reality, SLT 2 felt there is a '*..lack of MDT work amongst professionals' (*personal communication, November 3, 2020). Some difficulties were identified in the process of SLTs receiving referrals from their team members. SLT 17 noted that some children were '…*sent for a gastrostomy without ever having been evaluated by an SLT'* (personal communication, December 10, 2020). Another SLT identified that a late referral can result in insufficient time to train the caregiver. Insufficient therapy and training may even result in the need for a gastrostomy tube that could have been avoided had earlier feeding intervention occurred. Providing caregivers with additional time for education and training could optimise treatment time and reduce the strain on the national healthcare system. This issue is linked to the sub-theme of '*Resource Strain'* discussed in the previous section.

Another area of difficulty identified by a few of the SLT's (n= 6/23) during the training process is that of the '*language barrier',* which is often a challenge in the South African context. One of the SLTs noted that access to, and assistance from, other team members, such as nurses, to act as translators can be beneficial to the education provided and that '…*counselling in [the caregivers] language'* is beneficial (SLT 23, personal communication, February 25, 2021). Team members should possibly consider identifying a key person who can assist with translating where possible in order to ensure improved education and improved understanding.

b.) Stigma

Lastly, societal stigma and misconceptions that arise from having a gastrostomy tube can have a significant impact on parents' susceptibility to new information. SLT 10 noted that '…*society's preconceived ideas about tube feeding…*' acts as a barrier in the education process (personal communication, December 10, 2020). Both of the caregivers in the focus group described that their respective families initially found the gastrostomy tube '…*quite shocking…',* and that they had shared their knowledge with family members for improved acceptance of the feeding aid (FG CG 1, personal communication, June 5, 2021). SLTs noted that caregivers '…*need to know the reason behind alternative feeding methods so they are better able to comply'*. SLT 22 noted that the '..*more educated [people are] about it, the less stigmatized it would be'* (personal communication, February 24, 2021).

SLT 17 noted: 'In my experience, most of the care givers have never heard of a gastrostomy and are very fearful of it. A lot of caregivers are initially very against their

child having a gastrostomy as they lack understanding of why their child needs it or due to cultural beliefs/norms. They need to be well informed about the need for the procedure and usually their biggest concern is how to take care of the gastrostomy and feed the child through it. This has affected my intervention greatly (personal communication, December 10, 2020)

SLT's own preconceived ideas may also have an impact on their own recommendations. It could further effect the referral systems and processes if other healthcare providers have misconceptions about the gastrostomy tube and the involvement of SLTs in the decision-making and counselling process, and therapists noted that they are often faced with late referrals, or even a lack of referrals. Most of the SLTs (n= 22/23) noted that they rely on referrals to treat this population. Within hospital settings, two of the SLTs (one in the private sector and the other in the government sector) noted that they also did screening in their respective settings, as well as receiving referrals. Few of the SLT's (n= 2/23) received their patients through self-referrals from families seeking support. It appears that referrals are the main means of connecting this population to SLT's services, which is concerning as appropriate referrals may not be made. The fact that four of the caregivers had SLT involvement infers that these patients may not be referred appropriately. This indicates a high need for the role of the SLT to be advocated for in all settings.

The majority of the SLT's (n= 20/23) noted feeling '*unprepared',* and with insufficient education in their undergraduate training concerning enteral feeds and how to approach the counselling process (personal communication, December 10, 2020). This is concerning since half of these SLT's noted they provide treatment in this setting with less than 5 years' experience, highlighting possible omissions in undergraduate

training. SLT 17 noted they had '…*no idea what a big part this would play in [their] role as an SLT'* (personal communication, December 10, 2020). Many SLTs (n= 21/23) noted that they grew in confidence and knowledge over time. The SLTs noted that they overcame the challenge of a lack of personal experience by receiving additional support or '*mentorship'* from more experienced SLTs, (SLT 9, personal communication, December 10, 2020*)*, or from '*postgraduate courses'* (SLT 2, personal communication, November 3, 2020), or from additional learning materials, and advanced their own practical knowledge through '…*various practical situations and dysphagia courses'* (SLT 15, personal communication, December 10, 2020*).*

SLT 21 noted that insufficient training made many SLTs perceive discussing gastrostomy tubes with parents as '*taboo',* making it '…*difficult to counsel the parents and to get them on board'* (personal communication, February 24, 2021). A gastrostomy is often seen as a last resort. If SLTs lack of information concerning gastrostomy tubes and feel daunted by the counselling and decision-making process, then this will certainly affect the education that is passed on to caregivers.

4.5. A brief summary

As predicted, it was found that caregivers conveyed a need to understand the clinical reasoning for a gastrostomy tube and the procedure and the basic mechanics thereof. However, in addition, the research indicated the need for caregivers to understand the impact on the child as well as on the family system as a whole. Teamwork is required to ensure the family receives holistic and comprehensive treatment and education. The ideal of a cohesive MDT does not appear to be the reality in all settings, with a

discrepancy between team members being acknowledged by the caregivers and the SLTs.

Another key finding was that caregivers and their families found that they initially were stigmatised by their families or their surrounding communities concerning the gastrostomy tube. It was expected that caregivers may feel overwhelmed and lack the necessary education on the relevant issues. However, it also emerged that the SLTs also faced challenges navigating this delicate process owing to a defficiency in skills and training, with a perceived lack of exposure or experience provided in undergraduate training. This is likely to impact on the care provided.

The research results indicate a lack of communication and awareness amongst healthcare providers as well as among caregivers. It is clear that SLTs would benefit from a protocol to guide them in the process of assisting caregivers in the decision-making process when selecting a gastrostomy tube for their child.

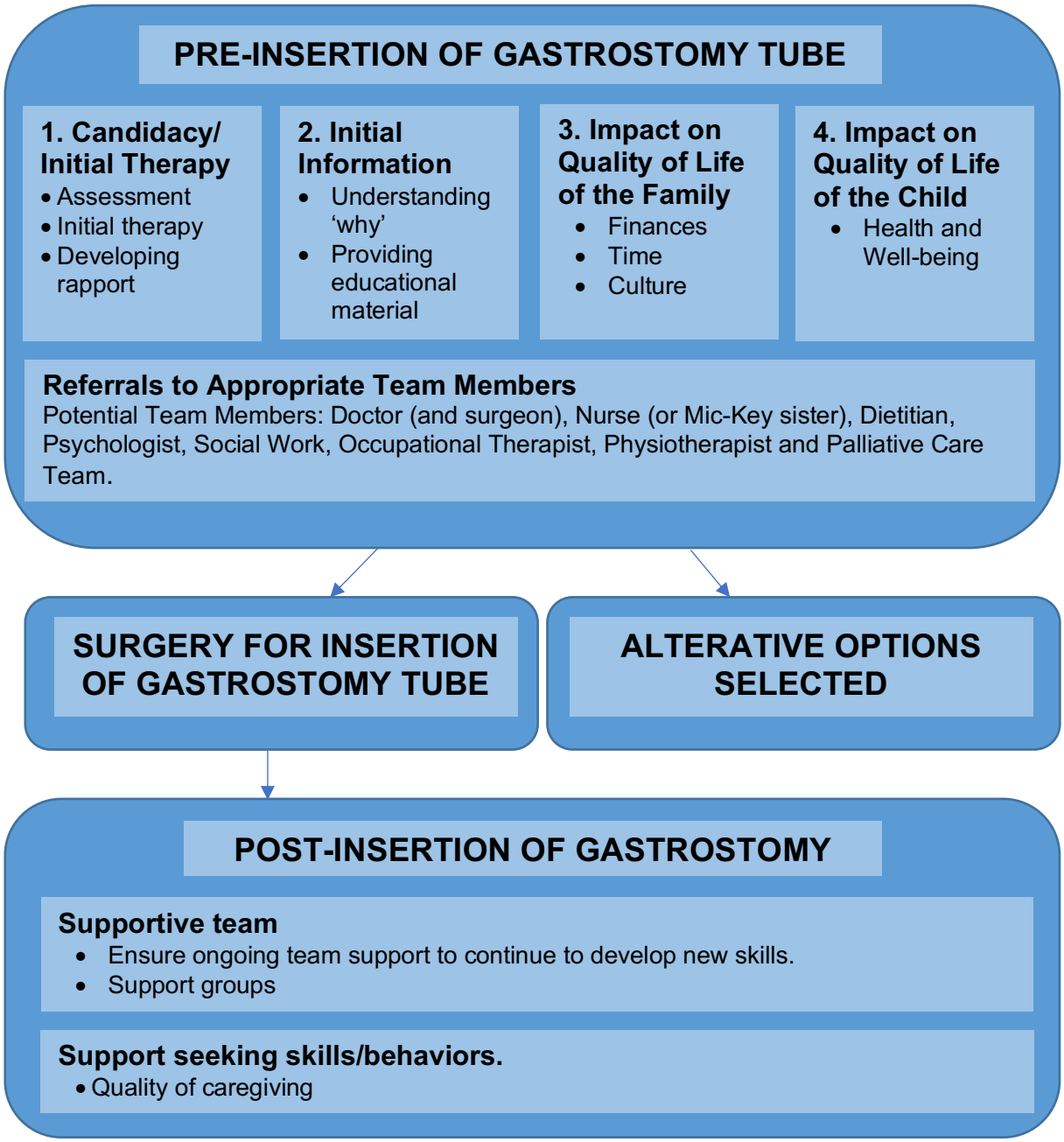
Chapter 5: Discussion

The Organisational Framework by Van Houtven et al., (2011) was used to frame the initial study, including the caregivers' questionnaire. However, it became evident that this lacked significance in the paediatric context within SA. Within our complex context and the specific population group discussed; the researcher felt a new framework was required. The framework lacked specificity and did not fully consider team collaboration in the caregivers experience as it was created to compare caregiver intervention models (Van Houtven et al., 2011). In this Chapter; a new protocol will be proposed to assist SLTs in guiding the caregiver through the decision-making process, specifically when selecting a gastrostomy tube. This protocol was designed after considering the literature which was uncovered in the literature review, the framework discussed as well as the results of the study. The elements such as 'equality of caregiving' considered within The Organisational Framework were incorporated as appropriate (Van Houtven et al., 2011). This was done to ensure that a protocol is contextually responsive to the needs of the SA caregivers and the SLTs who serve this population, while making noted of the important features noted in literature. This included taking note of the family system as a whole in order to understand the child and the caregiver's needs and concerns (Sezer et al., 2020). In addition, the framework was designed to encourage teamwork and collaboration throughout the process.

The protocol below looks at the support required from the SLT across the decision-making process. The main focus is on the support required pre-insertion as this study focussed on the decision-making process within that phase as that was the focus of the study. The other areas are interlinked but will be discussed concisely.

Figure 17

Suggested protocol for SLT's to guide caregivers



This proposed protocol can be used to assist in formulating a discussion of the results of the research while linking these to the findings from literature. Many common threads in the findings support the article written by Yeh et al. (2013), which also evaluated caregivers' decision-making processes concerning gastrostomy tubes in

Taiwan. Although they both looked at the decision-making process within developing countries, Yeh et al., (2013) looked at the decision-making process within the adult population which alters many of the elements explored.

5.1 Pre-insertion of the gastrostomy tube

The first section of the protocol considers pre-insertion of the gastrostomy tube. This section is of the greatest significance as this was the focus of the study. Additionally, the SLT's role in assessing and communicating the available options to the family is essential for finding solutions to a child's feeding difficulty (SASLHA, 2011).

In the study the experience of the decision-making process for a gastrostomy tube was explored from the perspective of the SLT. The caregiver's insights were essential as the caregiver is considered to be a crucial team member as their success in the adjustment process has a large impact on attitudes to the treatment and potential future complications (Russell et al., 2017). Taking note of the SLT and the caregivers' perspectives allowed for a more holistic view of the components that are essential for incorporation into research. However, initially the aspects of candidacy for a gastrostomy tube must be explored.

5.1.1. Candidacy

The initial therapy and assessment is essential in providing the best possible treatment options for a patient (HPCSA, 2017). It is within the initial therapy that the SLT would assess whether the child would be an appropriate candidate for a gastrostomy tube or whether alternative solutions are available (SASLHA, 2011). Although this area was not a direct focus of the study it does substantially impact on the findings. The literature

highlighted that children requiring intervention are known to experience a swallowing concern, inadequate intake, or have special feeding requirements (Frohlich et al.; Martínez-Costa et al., 2011). In this study, the children concerned mostly appeared to have neurological impairments, syndromes and diseases, which accords with the expected population as discussed by Frohlich et al., (2010) and Pars & Soyer (2019). The children and their families face different barriers and challenges based on the child's neurological functioning as well as the burden of care (Figueroa at al., 2017; Norman et al., 2011).

The results of the study noted the importance of SLTs building rapport with the caregivers to produce better outcomes. It is essential to develop '…*a trusting relationship with parents..'* (SLT 10 personal communication, December 10, 2020). Literature concurs that early intervention by, and collaboration with, an SLT leads to improved joint decision-making (Lee et al., 2015; The Speech Pathology Association of Australia Ltd. [SPAA], 2012).

SLTs need to have a good understanding of their role in order to identify and educate potential patients. The results of this study made it evident that some SLTs initially held misconceptions or a poor understanding of enteral feeds and their role as an SLT in the education process. Many of the SLTs (n= 20/23) noted that they initially felt ill-equipped to tackle the sensitive and significant process of guiding a caregiver. They felt they '…*were not given the tools to counsel caregivers*...' (CG 21, personal communication, February 24, 2021). It must be highlighted that eleven of these SLTs have less than 5 years' experience. This is resonant with the article by Coutts (2019) in which it was found that South African junior SLTs do not feel equipped to manage

dysphagia patients. However, this study noted that twenty-one of SLTs grew in confidence through ongoing mentorship and training courses. This is in agreement with the proposed solution by Singh et al., (2015), which also suggested ongoing training on a post-graduate level. The SLT's role in paediatric dysphagia is less commonly discussed in literature. Singh et al., (2015) expressed the importance of tertiary institutions investing in education in this field. Using protocols and models as part of undergraduate training can assist in producing more confident SLTs (Schie et al., 2019).

Understanding the role of the SLT in feeding and swallowing disorders is essential to ensure that candidates for therapeutic intervention can be identified (HPCSA, 2017). The protocol therefore examines how SLTs can identify such patients in order to ensure that they are better equipped for this challenging process.

5.1.2. Initial information

In this study's results it was found that half of the SLTs (n= 12/23) specifically mentioned the importance of caregivers understanding the reason behind insertion, and therefore the fallout in feeding. This sentiment was mirrored in other studies which discussed how families should understand the reason for gastrostomy insertion, as well as the subsequent impacts thereof, in order to make an informed decision (SPAA, 2012, Erci, et al., 2016; Yeh et al., 2013). Popejoy et al., (2017) noted that a lack of understanding of the diagnosis and prognosis can increase uncertainty, and therefore affect the caregiver's decision-making. SLTs play a role in the swallowing diagnosis specifically, but they rely on the team for timely collaboration and expertise (HPCSA, 2017). Yeh et al. (2013) found that delaying providing gastrostomy tubes as an option

could also create future difficulties when approaching education on gastrostomy tubes. Improved communication and education throughout the process results in receptivity and awareness of the family in their decision-making process. This can be seen with CG 12 who felt prepared for the gastrostomy insertion; they noted that the SLT '…*made sure that the tube was the last resort*…' and '…. *tried many oral techniques prior to insertion of the tube'* (CG 12, personal communication, February 24, 2021).

The research indicated that both SLTs and caregivers noted the importance of providing basic information via different materials in order to give the family time to process the information. Over half of the participants received pictures or other materials, such as handouts, together with verbal counselling. The SLTs in this study concurred with a study by Rodrigues et al., (2020) which indicated that reading material not only allowed time to revisit and digest information but it also provided the caregiver with a sense of participation. Caregivers of adults in the study by Nund et al. (2015) discussed how reading information is beneficial, but can lack specificity or have sematic discrepancies without additional training or discussions. It is noted that the participants in this study appeared to more written or verbal information than visual material (videos: n= 2/13; pictures: n= 8/13) which could assist with comprehension of verbal discussion (SPAA., 2012). Despite this study examining a different population, the findings are applicable and echoed in this study's findings. SLTs suggested education session with various mediums of information along with discussions could become more generalisable for caregivers. Literature recommends making use of multifaceted education methods which may include a variety of instruments, including educational handouts, videos, pictures as well as peer support (Green et al., 2019). With language barriers being a complication within SA, SLTs could assist in increasing

patient and family understanding of the process by using various educational modalities, preferably making use of a translator where required.

SLTs should adapt their training to support the specific patient and family. This will allow SLTS to provide the required information and permit caregivers to make an informed decision. Professionals must strive to understand the potential risks or impacts on the child and the family system (SPAA., 2012). Therefore, the protocol focuses on the initial information to ensure the family is a joint team member and understands the treatment process.

5.1.3. Impact on the quality of life of the family

The Organizational Framework depicted the correlation between caregiving activities and the impact these in turn have on the care recipient and the caregiver (Van Houtven et al., 2011). This emphasizes how the decision is not only known to impact on the care-recipient, but also on the family system as a whole. This is reminiscent of the information found in the results of this study which emphasized how a gastrostomy tube can impact on the families' resources, including finances and time, as well as on the family and the child's quality of life. Caregivers and SLTs indicated areas which should be a part of the information received by caregivers as part of their decision-making processes. Improved preparation and adjusting the treatment to address quality of life issues can result in a better 'buy-in' and in better adaption by the family (Martínez-Costa et al., 2010).

Yeh et al. (2013) compared the decision-making process to '*gambling*' for caregivers as it is perceived to carry risk. The results of this study indicated that most of the

caregivers (n= 11/13) directly mentioned that they felt intimidated by, and fearful of, the daunting decision they faced. As seen in Figure 4, the Shared Decision-Making model by Adams & Elias, (2014) is discussed as a possible solution to these issues in some studies. This model looks at the decision-making through an investigation of the patient context and values, as well as the process of care (Adams & Elias, 2014). However, Lee & Corden (2019) discussed how this is not always feasible as extra time and repetition are required to investigate the proposed features. Creating joint goals and having frequent discussions with other team members, as well as the family, can be more beneficial (Green et al., 2019; Lee & Corden, 2019). This can provide caregivers with a 'therapeutic alliance' for the best possible support with each discipline providing their expertise (Sullivan, 2013). Yeh et al., (2013) made note of the benefits of family meetings to ensure the family is part of the discussion and decisions. The results highlighted families' unique concerns, and challenges ranged from concerns with the public's perception to the child's level of inclusion. Therefore, the areas which are most concerning or pertinent to a family need to be addressed or considered when assisting a family through the decision-making process. The adaptability of this study's proposed protocol allows this process to be more flexible and responsive to a family's needs to assist in highlighting the key elements to be considered.

Rigid textbook-based education may not suit a family's routine and therefore healthcare professionals need to adapt proposed solutions and education to suit a specific family's needs (Russell et al., 2017). SASLHA (2011) notes that professionals should include the family and their circumstances as essential elements when making a clinical decision. Some studies have discussed how the training provided to the caregiver might differ according to the influence of the extended family (Martínez-

Costa et al., 2010; Yeh et al., 2016). First-time mothers report improved decision-making which may account to factors including time and stress (Erci, et al., 2016). Therefore, families require that their SLT be willing to adjust in the education process and refer them to the appropriate professional when there needs fall out of the SLT's scope.

Western procedures and protocols may not consider some of the challenges within the South African context and therefore it is necessary to adapt protocols and procedures in response to local cultural norms and practices and societal conditions (Ned et al., 2015). The care and treatments must provide for the contextual, cultural and socio-economic reflection of the family system and specific cultural norms and practices (Ned et al., 2017). The family's finances, time, and cultural norms and practices should therefore be considered. These three areas will be discussed below in detail.

a.) Finances

Caregivers and SLTs in this study spoke about the potential increased costs arising from the therapy, difficulties with private funders, and financial reliance on the government. Caregivers making use of private medical aids noted that although they received financial support, navigating how to access that support could be challenging. SLTs in the government sector noted that although caregivers were able to access support, they were at the mercy of their local facilities and reliant on the availability of services and feeds. In both the private and government systems caregivers appear to face challenges making decisions which may require external guidance from their healthcare team in connecting with government services, supportive team members and families who have had similar experiences.

Literature discusses the potential long-term financial benefits for caregivers and funders of selection of a gastronomy tube. These include reduced hospitalisation and reduced chest infections, which in turn result in less medication and treatment being required (Green et al. 2019, Khalil et al., 2016, Martínez-Costa et al., 2011; Sullivan, 2013). According to Green et al. (2019), costs are lowered with a gastrostomy tube due to less costly therapies and interventions being required. This view may be noted with a clinician's objective foresight and perception of the medical or long-term implications due to their training and experience. However, it is still important that the potential change to, or effect on, the family's expenses or planning is noted as an information requirement.

Ned et al. (2015) discussed the concept of 'third-party disability', which examines the strain placed on the caregiver. Literature, which also focused on the paediatric populations, has begun to note the high levels of caregiving or 'nursing' skills required from the caregiver, as well as the potential adjustment to the family's synchrony (Pedrón-Giner et al., 2013; Russel et al., 2017). Caregivers feel this is an area which on which they should receive information and support. Referrals to social work could also benefit in this area through assistance with financial planning and advice on appropriate benefits. Although this was not directly identified in the research this is a referral gap that should be explored.

b.) Time

The results indicated that caregivers felt that the gastrostomy tube impacted on their available time with longer, more frequent feeds being required. Without supportive and trained family members, the sole caregiver is required to make increased personal

sacrifices and adjustments to their daily routine. Caregivers felt they should have been informed about this issue. In a study by Coutts & Solomon (2020), a caregiver highlighted that their required time sacrifice resulted in the caregiver forfeiting their own employment opportunities. This study looked specifically at caregivers of adult patients with dysphagia. It is inferred that caregivers of children would willingly make major sacrifices for their child's well-being; however, this does not detract from the effect the procedure will have on those caregivers.

Russell et al., (2017) discussed the difficulty of aligning families' mealtimes with the feeds. Adaptions to the family routine must be considered in order to make adjustments to the family's schedule. With increased patient dependence on meals caregivers may also have to sacrifice a greater amount of time, and particularly so with dual feeders (Shune & Namasivayam-MacDonald, 2020). In a study by Shune & Namasivayam-MacDonald, (2020) it was noted that a child having both oral and enteral feeds placed additional burdens on the carer when required to make the appropriate diet modifications.

Therefore, it is essential that additional caregivers are trained and educated within the family unit to offset some of these challenges. A supporting caregiver or carer, who has been appropriately trained by the MDT, can assist in various care-giving tasks, including assisting with the gastrostomy feeding. In this way the burden of care and the accompanying emotional and stress burdens can be reduced for the primary caregiver as well as for the family. This could be a beneficial adjustment to SLT education sessions. Involving more family members throughout the process may, therefore, assist in the process of planning to reduce the burden of care.

c.) Culture

The SLT faces additional challenges within the South African context given the diverse population, differing cultural norms and practices, wide-ranging socio-economic conditions, and limited state resources. Although this was not a major theme in the researchers findings; in this context it is important that the SLT encourages a collaborative approach to intervention as well as continuing to expand their own clinical knowledge. Vawda, (2017) notes how making use of traditional medicine and incorporating culture and religion allows for more holistic treatment and for a greater connection to the caregiver and their context. Successful integration can only take place if cultural elements are also understood (Ned et al., 2017). This is important to consider within the study's findings as both of the caregivers in the focus group directly noted experiencing stigma or judgmental responses from their extended families.

Yeh et al. (2013) discusses the essential role the family network plays in the family's decision concerning the gastrostomy tube. In the study, family consensus was noted as more important than the care recipient's best interests (Yeh et al., 2013). Family approval can differ according to the needs of the family. Challenges with familial understanding may have a large effect. In certain cultures mealtimes play a large role in family interaction. Sensitivity to the family's needs, as well as ensuring the inclusion of the child into the family's routine, may impact on the efficacy of the counselling provided. Calderon et al. (2010) noted that the caregivers who were more susceptible to anxiety perceived an increased burden and longer periods were required for caregiving. The results from this study indicated that the decision concerning the gastrostomy tube was mostly made within the nuclear family, however it was clear that

occasional disapproval from the extended family presented a challenge to the caregiver.

The study by Yeh et al. (2013) continue to highlight how a lack of education and knowledge leads to misconceptions and difficulty with decision making. Caregivers in this study also noted although they initially were fearful about the concept of a gastrostomy tube their perceptions changed with improved understanding.

5.1.4. Impact on the quality of life of the child

The education provided to caregivers should focus on finding the best possible solutions to benefit the quality of life of the child. Team discussions are required in order to support the best interests of the child and to make the specific decisions required. Ongoing research and team development may be necessary to assist in making these complex, multifaceted decisions.

a.) Health and well-being

The quality of life of the child is one of the largest considerations when selecting gastrostomy tubes. Van der Merwe (2003) discussed the increased number of gastrostomy tubes being inserted in SA owing to increased awareness. In this study, most of the caregivers (n= 12/13) noted positive changes to their child with the application of a gastrostomy tube. These included noting the child's improved health, energy, and weight gain. This also impacted positively on the parents as they noted reduced anxiety in themselves with the improved health of their child. A few caregivers (n= 3/13) noted the reduced need to push for increased intake when a child is unwell, unable, or unwilling to take meals, which may further reduce stress. This aligned with

the studies which indicated reduced parental stress post-gastrostomy insertion (Calderon et al., 2010, Mooi, 2020; Russell et al., 2017).

In the study by Yeh et al. (2013), it was reported that caregivers generally felt that the decision for the gastrostomy tube had benefitted the child and the family system. More than half of the caregivers (n= 8/13) in the present study noted that they would have received the gastrostomy tube earlier with the knowledge they now possess. This echoed the findings of Martínez-Costa et al., (2010).

The Organisational Framework for Caregiver Interventions highlights the importance of the physical health as well as the psychological health of the care-recipient (Van Houtven et al., 2011). The predominant feature in selecting a gastrostomy tube should be the child's health. However, it is also imperative to assess the impact of the intervention on the well-being of the child and the family.

Team members including SLTs should make sure to undertake a planning process at in the initial stages to ensure better plans for a child's social and environmental integration. This includes reintegrating the children into educational and leisure settings, as caregivers had raised less participation and involvement by the child in sporting activities. Therefore, it is essential to have participation from other professionals, such as occupational therapy and social work, to assist with improved participation (Russell, 2017). The results showed these clear gaps in the referral system and therefore the protocol created hopes to guide caregivers to consider expanding their referral base or 'PEG team'.

5.1.5 Team development

An MDT is essential to the process as the members thereof are able to provide assistance to caregivers from various areas of expertise (Cornwell, Kelly and Austin, 2010; Schwarz, Coccetti & Cardell, 2019). This study appeared to conform with literature in which MDTs comprise of as doctors, nurses/ Mic-Key sisters, dietitian and SLT's as the main team members (Cornwell, Kelly and Austin, 2010 Sevilla; M. W. & McElhanon, B., 2016). Additional team members as identified by the caregivers and SLTs may include psychologists, social workers, occupational therapists, physiotherapist and a palliative care team, where appropriate. These referrals may differ based on the child's condition. Each team member can offer unique perspectives for holistic care.

This study indicated that there appeared to be a gap in the emotional support provided to caregivers. Very few SLTs (n= 4/23) and caregivers (n= 1/13) mentioned collaboration with a social worker or psychologist. More than half of caregivers (n= 8/13) discussed how the initial transition to PEG feeding was a stressful and daunting process. Literature notes the importance of caregivers receiving emotional support however, there appears to be a lack of literature on the emotional support needed as well as on guidance for healthcare workers (Calderon et al., 2010; Russell, Jewell, Poskey & Russell, 2017). This protocol may act as a guide to prompt SLTs to ensure that the appropriate referrals or considerations are made when examining holistic care for the patient and their family.

a.) The SLT

The support provided by an SLT as a part of the team is essential. Half of the caregivers in this study felt that they were well supported by their SLTs. It was noted that five of the caregivers indicated that they felt better equipped to face the feeding transition process with SLT support as this improved their understanding of the challenges faced by the child and the changes in therapy. Allowing a caregiver to be referred to the appropriate professionals at an earlier stage could impact on their feeling of being in control of the process and empower them in the decision-making process.

In reality this study indicated that some SLTs noted difficulties with timely or appropriate referrals. This could impact on the services patients receive and the treatment time they require. Literature discusses the importance of referrals between team members (Ayoob & Barresi, 2007; Mooi et al., 2020; Ned et al., 2017). Net et al., (2017) discussed how community service SLTs could play a greater role in advocating for the services of an SLT within the process, and so improve referrals. Referrals were shown in the study to be the most likely way SLTs would receive such patients (n= 22/23), thereby reinforcing that it is essential to emphasise this aspect as part of the therapeutic process. Better teamwork was noted in hospital settings, which may be due to the accessibility of team members. Encouraging an improved referral process and team collaboration in setting such as schools, clinics and private practices appears to be and area which should be investigated and encouraged.

A cohesive support system is important in supporting and guiding caregivers through this decision-making process. The SLT may act as a team leader or coordinator. In this study, CG 4 specifically indicated that their SLT was involved throughout the

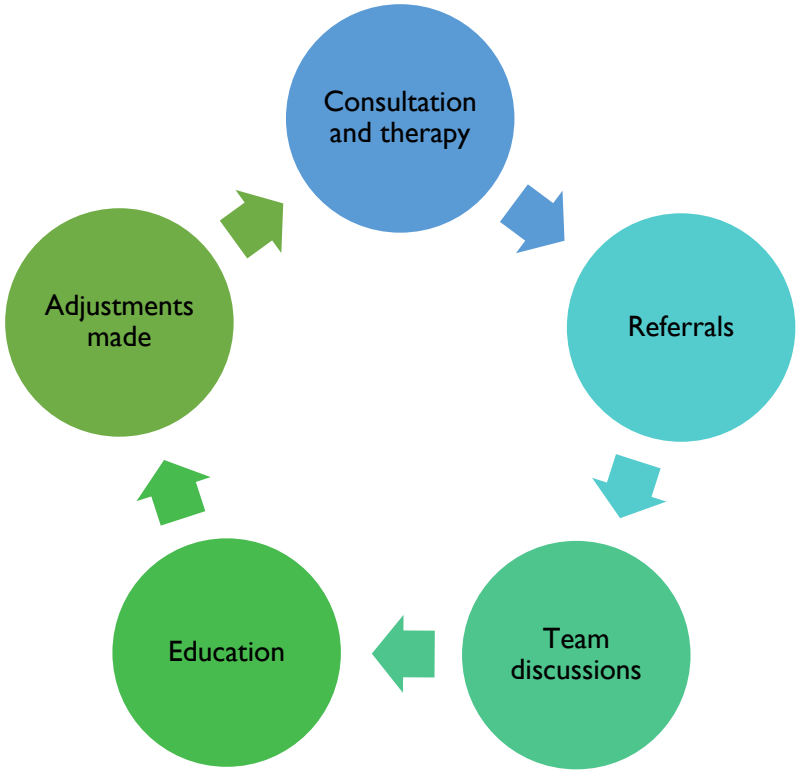
process by arranging the appointments and calibrating between the various professions. According to the HPCSA guidelines, SLTs may act as '*service delivery coordinators*' to ensure the best possible collaborate care for patients (HPCSA, 2017). Unfortunately, SLTs and caregivers indicated that this is not always the case in practice. Mooi et al., (2020) acknowledged the need for more research in support initiation, referrals and in planning for the discharge of the patient. This study, together with the study by Green et al., (2019), emphasized that ensuring a supportive team for ongoing patient support is also essential.

Ongoing education concerning the role of the SLT as a member of the MDT is essential for improved future teamwork and improved service provision. This will allow for a better caregiver experience.

Below is a guide of the progression that could assist the SLT in team collaboration which should be used when considering referrals and throughout the protocol:

Figure 18

A proposed SLT's guide for improved team collaboration



This guide notes the importance of early referrals to appropriate team members. This model was created by noting the caregiver and SLT's responses as well as guidelines for practice (HPCSA, 2017; SASLHA, 2011). Initial consultations by SLTs should be followed by referring the patient to the appropriate healthcare providers (SASLHA, 2011). Team discussions are recommended to ensure unified and holistic goals for a patient. Education for caregivers should be provided by team members and should ideally be done in a joint session. Inclusion of the caregiver as part of the team is important for improved collaboration and understanding (SASLHA, 2011). Literature notes reduced medical costs through team interventions (Green et al. 2019). Cornwell et al., (2010), discussed how treatment should not only focus on one component or

discipline, but rather on a unified goal. Adjustments should be made from the treatment plan and ongoing therapy should continue.

This model is in line with recommendations in more recent research which encourages aspiring beyond multidisciplinary teamwork towards transdisciplinary teamwork for more holistic treatment (Ned et al., 2017). This involves more communication between different professionals as well as referrals to other disciplines. Literature notes that a transdisciplinary team (TDT) may be led by any professional, with the focus being on joint goal setting and discussions, whereas the MDT approach may generally lack direct contact between team members (Galvin et al., 2014). This allows for more fluidity and collaboration between roles (SPAA., 2012; Galvin et al., 2014). Currently, from this study it is noted that a TDT is seldom a reality, however closer teamwork was noted in hospital settings which is probably due to easier access of professionals for team discissions, collaboration and training.

In the study it was clear that families did not receiving consistent and holistic team interventions. It is hoped that application and use of the proposed flow chart will encourage improved collaboration and communication amongst team members, resulting in a more holistic and beneficial intervention (Cornwell et al., 2010). In certain settings this could improve potential for TDT discussions, decisions, and family education. Challenges may be noted in certain overburdened settings with reduced time, finances, and resources such as government hospitals. Research shows that TDT collaboration is more beneficial to the child's treatment and ongoing care and may be more cost effective (Galvin et al., 2014).

5.2. Gastrostomy insertion

Data and literature was not critically analysed concerning the surgical process of insertion of a gastrostomy tube as the SLT does not play an active role in this phase of the decision-making process. This is a medical process in which a surgeon performs the surgery. SLTs in the study noted that the caregivers need to understand the surgical process for improved understanding and to assist with reducing fear, however there was little mention of exactly what education caregivers should receive from the medical team. The SLTs themselves are responsible for the care and guidance before and after the process, and can provide information to the caregiver at various stages of the procedure (HPCSA 2017, SASLHA, 2011).

The doctor and surgeon are responsible for providing medical advice and education to the caregiver and the patient; however, this may sometimes be a rushed process or lack depth. CG 10 noted that they wished they had known about possible *'…infection and side effects…'* as a part to the training provided to them (personal communication, February 7, 2021). Literature makes note of the importance of the doctor and surgeon counselling the family before the surgery to ensure they are well informed and prepared for the process and the changes affected by it (Adams & Elias, 2014; Kazmierski, et al., 2013).

5.3. Alternative solutions

Based on the evidence it is clear that it is important for SLTs, as professionals, to provide families with the necessary information and the evidence to permit them to make informed decisions. CG 11 noted that they would have been benefited from '…*other options and [available] therapy/treatments..'* before they made their decisions

(personal communication, February 22, 2021). Caregivers in the study noted that they needed to feel well supported throughout the process. A therapeutic relationship can assist a caregiver in understanding that the proposed procedure was the '*last resort'* or the recommended solution for their child's feeding problem (CG 12, personal communication, February 24, 2021). Caregivers still may feel pushed into the decision with insufficient time and insufficient alternatives being provided to them. Greater information about alternative available solutions will result in greater confidence in the caregiver and the family concerning the decisions to be made by them.

Guidelines make it clear that it is the SLT's role to provide a family with various possible solutions suited to the child and the family system (HPCSA, 2017; SASLHA, 2011). This would involve providing alternative solutions, such as positioning, consistency and feeding changes, should a family be opposed to enteral feeds as an option (SASLHA, 2011; SPAA., 2012). Working as a team is essential in order to ensure that all aspects of the process and the alternatives available to the child are set out for the decision-maker. Each team member should ensure support for one another within their own specific field, and improved collaboration and greater fluidity of roles may ensure more a holistic service is provided to patient and caregiver (Galvin et al., 2014). Therefore, the role of the SLT as a member of the MDT/ TDT is to provide the appropriate information to the caregiver and other members of the team. The MDT/ TDT must comply with the family's final decision and support them as a team (Yeh et al., 2013).

5.4 Post-insertion of the gastrostomy tube

The caregiver's support post-insertion of the gastrostomy tube was not the main focus of this research, however the data shows the importance of ongoing care and therefore this was an important part of the protocol. Supportive care from an SLT is essential in order for the initial treatment and education to be beneficial (Adams & Elias, 2014). The two important elements identified in the protocol include ensuring a supportive team for ongoing support and development of skills, and secondly assisting the caregiver in obtaining support seeking skills or behaviours.

5.4.1 Ongoing support

For the SLT therapy should continue to focus on the development of skills to assist with the child's feeding as appropriate (SASLHA, 2011). However, assisting in ensuring the family is supported in the appropriate areas is still important. The results of this study indicated that five of the caregivers did not feel well supported by a team on, and after, discharge. The remaining caregivers (n= 8/13) indicated that they connected with at least one health care professional for continued support. Encouraging team collaboration and communication should be an area of greater emphasis in the SLT's role within their given scope of speciality.

It is clear that caregivers must make use of prior interactions with professionals to allow families to have a support base when requiring advice or care. This is essential and is mentioned frequently in literature for support and prevention of complications (Coetzee, 2018, Sevilla, M. W. & McElhanon, 2016; Sullivan, 2013) Support groups have also been recognised in literature as a useful tool (Craig et al., 2003).

5.4.2 Support seeking skills/behaviors

Many of the caregivers (n= 10/13) indicated that they felt they knew where to find support from when needed post-discharge. However, 40% of those only mentioned having access to a Mic-Key sister or parent support group, which may not result in sufficient or appropriate levels of care being received. In this study some unsupported caregivers researched issues independently or relied on social media for information. This may result in misinformation and there is little research on the impact it may have on therapeutic 'buy-in', as well as on the family's understanding of the relevant issue, as reliability of the materials they locate cannot be confirmed. Ensuring therapists and other professionals have access to online support groups may help to regulate the information given or encourage caregivers to seek intervention where needed. Introducing caregivers to families with similar challenges may also be beneficial to them, although this phenomenon was only noted in three of the participant's cases. Green et al., (2019) discussed how improved support services results in less hospitalization, which is why it is an essential part of the post-procedure care.

When caregivers are not referred appropriately, or not provided with appropriate support, their 'support seeking' skills become important to ensure that they become their own advocates (Van Houtven et al., 2011). Yeh et al., (2013) discussed the importance of involving the family in the solution-seeking process and setting them up to ensure they are well supported and know where to access services as required. Therefore, the protocol designed in this study hopes to encourage SLTs to empower caregivers to adopt support-seeking behaviours.

5.5 Brief summary

In summary, through scrutinizing literature and the results it is clear that the phenomenon of the burden of the decision on a caregiver is often overlooked.

Caregivers require greater support and more input from a collaborative team. Within the paediatric population there appears to be greater consideration to these issues than those in other populations as there is an impact on the child as well as on the family system as a whole. In the South African context, a lack of resources appears to further complicate the care given and therefore the education process may be limited.

The SLTs play a clear and valuable role in information provision, guidance, decision-making and problem-solving processes. Unfortunately, it is clear that the SLT's role is often forgotten, neglected, or misunderstood. This protocol was created to guide a SLT through the areas to be considered in the process of educating and guiding a caregiver through the decision-making process. The focus of the study was to look at caregiver's information needs. These extended from a basic understanding of gastrostomy tubes and their need, to understanding the impact on the quality of life of the child and on the family system. Although this was not the main focus of the study the protocol also included the role of the SLT after the decision has been made. This was because the study indicated the importance of ongoing support and skill development in order for successful adoption, maintenance, and acceptance of the gastronomy tube.

Chapter 6: Conclusion

The decision-making process for a caregiver to grant consent to obtain a gastrostomy tube for their child is complex and emotionally traumatic. It is fundamental that healthcare providers are aware of how emotions and attitudes affect the family's overall experience of a gastrostomy tube. Support and counselling are therefore vital throughout the process in order to ensure improved outcomes.

A SLT plays an essential role in the process as they can help the family understand the reasoning behind, and necessity for, the tube (SASLHA, 2011). The SLT can act as a team coordinator or can facilitate communication and teamwork between the various professional disciplines, and advocate for the patient throughout the process (HPCSA, 2017).

Support from an MDT is essential for holistic and supportive care for the family. Transdisciplinary teamwork is the gold standard that professionals should strive towards to develop communication and improve holistic referrals (Ned et al., 2017).

SLTs working with patients with paediatric dysphagia note that their undergraduate training may not provide them with the required skills necessary to face the complex intricacies of this process. Adjustments to training or coursework may be required to ensure more confident and competent therapists (Singh et al., 2015). The proposed protocol may assist in providing some guidance to SLTs when treating this population.

This study hopes to have established a protocol to allow the SLT to navigate the complex and delicate process of supporting the family through their decision. Ongoing

research may be required to look at the effectiveness of this protocol as well as the impact it may have on the support provided to this population.

6.1. Limitations

Limitations of the study were identified in order to attempt to maintain objectivity throughout the study. The researcher noted that the population group accessed is a small and unique group, meaning that limited participants were experienced, resulting in a smaller sample of data to analyze. This may mean that data is less generalizable.

The largest limitation was that COVID-19 restricted accessibility to hospitals, resulting in the use of an online study. This resulted in participants requiring access to the internet, as well as a basic understanding of English. In our context, this resulted in reduced participation. Although participation guaranteed no risk or exposure for participants it did restrict access from lower-income families which may have impacted on the results obtained.

6.2. Strengths

The strengths of the study must also be considered to reflect on the results obtained. It is noted that the use of an online questionnaire ensured that the population of participants were from a broader context, allowing for improved generalizations. Less in-person contact may have also assisted in reducing any potential bias as well as ensuring no potential COVID-19 exposure throughout the study.

The protocol designed from the results of the study may also have practical benefits for future SLT's and patients. This could help to improve the SLT's approach to intervention.

6.3. Possible Implications

The researcher hopes to have positive effect on future caregiver education through various means: Firstly, the researcher hopes to create awareness of the gaps in SLT training and education. It is important to raise awareness and to improve knowledge of caregivers information needs, as well as of the SLT's role in addressing these issues. This is essential to ensure improved family-centred practice in the future. Potential adjustments to undergraduate training may examine increasing the practical exposure, providing lectures on approaching counselling, as well as case study discussions on implementing treatment adjustments according to a family's needs. Making use of a semi-structured approach, such as the proposed framework in this study, can assist in providing some consistency in treatment. SLTs can adjust the specific approaches based on specific family needs.

Secondly, the researcher's clinical implication from the study was to design a framework to assist SLTs in counselling, guiding and understanding the caregiver's needs. This could assist in SLTs approaching the education process with improved direction and result in a level of standardisation in SA. This could challenge policy changes within hospitals well as changes in educational frameworks for SLT students within their tertiary training.

Lastly, this study hopes to advocate for the SLT role in supporting caregivers in their decision-making processes concerning gastrostomy tubes. This could assist in improved caregiver and family understanding, and in better informed inter-disciplinary referrals. This could be further highlighted through presentations, discussions and potentially published work which could potentially inflict change in theory.

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Appendix A.1: Caregivers Questionnaire



Caregivers Experiences of Gastrostomy feeds: A Speech-Language Therapist's Role.

A. Caregiver and care recipient baseline characteristics:

1. Which province do you live in?

   (Gauteng, Kwa-Zulu Natal, Northern Cape, Eastern Cape, Western Cape, North-West, Mpumalanga, Limpopo or Free State)

2. What is your relationship with the child?

   (Mother/ Father/ Sibling/ Grandparent/ Other)?

3. What is the age of your child?

4. What is your child's condition?

   (Neurological impairments (including Cerebral Palsy)/ Cardiac Dysfunction/ gastrointestinal deficits/ structural impairment (e.g.: cleft lip or palate)/ Other)

5. How long has your child had a gastrostomy tube for?

   **Gastrostomy tube (GT)= any long-term feeding tube that is placed directly through the skin and into the stomach (e.g. a PEG or MicKey).*

B. Caregiver Activities:

6. Who was involved in the process for you?

   (Doctors/ Nurses/ Speech Therapists/ Dietitian/ Religious or Cultural leader/ If other please add).

7. In leading up to the decision for the gastrostomy tube; explain the support and education you received from your child's treating team?
8. Were any of the following forms of reference provided by anyone in your team?

   (Discussion/ Pictures /Video /Other material (elaborate))
9. What information would you have liked to receive?
10. Did you feel supported by family and the treating team when making the decision? Please explain further.
11. Were you introduced to another parent with a child with a gastrostomy tube and, if yes, was it helpful?
12. If a Speech Therapist was involved in your decision-making process, please explain the role that they had?
13. In which areas do you wish the Speech Therapist had provided more support or education?
14. On discharge, were you aware of where and how to find support if you needed it?
15. Did you find the decision and the transition scary or did you feel well prepared?
16. Do you feel more confident now?

Caregiver outcomes

17. Describe how gastrostomy tube feeding has impacted on your life?
18. Have there been changes in feeding times, costs, routine and roles in your household?

19. Do you have assistance in caring for, and feeding your child? If yes, please elaborate.

Care recipients' outcomes

20. How do you perceive the change in your child's general health and well-being after receiving a gastrostomy tube?
21. Did you receive ongoing support and follow-up therapy after insertion until you felt comfortable? If not, please mention what would have been useful.
22. What are some positive and/or negative changes you have noted since your child received a gastrostomy tube?
23. Would you have agreed to earlier gastrostomy tube placement with your current knowledge of the procedure's benefits? If yes, why?

Thank you for your valuable input. Your participation is greatly appreciated.

Are you interested in any of the following:

☐ I would like to receive the research results when the study is completed.

☐ I would like to receive information for psychological support I could follow up with relating to any emotional distress in response to the information discussed above.

☐ I am interested in a follow-up focus group/ discussion. This will be via the online platform *Zoom.* Please provide you email address and you will be contacted with more details.

If you have selected any of the above, please provide your email address:

_____.

**Some questions were adapted from Martínez-Costa et al., (2011).*

Appendix A.2: Speech Therapists' Questionnaire



Caregivers Experiences of Gastrostomy feeds: A Speech-Language Therapist's Role.

1. Which of the following settings do you work in?

   (Private hospital, Private practice, Government Hospital, Government clinic)
2. Name the province you work in?

   (Gauteng, Kwa-Zulu Natal, Northern Cape, Eastern Cape, Western Cape, North-West, Mpumalanga, Limpopo or Free State)
3. How many years experience do you have?

   (1-5, 5-10, Over 10)
4. Do you feel that you were adequately prepared in your community service year to counsel and provided guidance to caregivers who have a child that requires a gastrostomy tube?
5. Has that changed now? Please elaborate.
6. Are these patients referred to you or do you find them alternately (e.g.: in screenings)?
7. When counselling caregivers on gastrostomy tubes do you work with other healthcare providers? If so, who? How do you work with them?
8. What do you feel the caregiver's information needs are? Does this effect your intervention?

9. In an ideal world how do you personally feel the education process should be carried out?
10. What is working well for you?
11. In reality, what are the challenges we may face?

Thank you for your valuable input. Your participation is greatly appreciated.

Appendix A.3: Caregivers Focus Group Agenda



1. Greetings and introductions

2. Researcher to describe reason for research

3. Caregivers to briefly explain circumstances and connection with gastrostomy tubes

4. Possible topic points to be discussed:

**note: as these are guiding 'topic points' these may be adapted according to the discussion as the researcher is just the facilitator of conversations*

- **Education process.** How was it? Would it have been best carried out all together or separately? Was it ongoing? Do you wish others were involved

- **Speech Therapists support** given and utilised?- what do you wish they educated or guided you on

- **Financial impact**? Did medical aid assist or government facilities? Was oral or peg feeding financially stressful? *Did they also assist financially with specialized feeds if required, or continues feeding pumps if needed, PEG replacements and changes.*

- Did it improve the **quality of caregiving**

- Did it contribute to **psychological health** or you or the child?

- Did your perceptions of the PEG change? Previous stigma

Appendix B.1: Information Sheet for Caregivers Questionnaire



Caregivers Experiences of Gastrostomy feeds: A Speech-Language Therapist's Role.

This questionnaire forms part of a study which aims to explore caregivers' experiences of the decision-making process when selecting gastrostomy tubes (e.g. PEG or MicKey feeding tubes) for their child. This will help to develop an improved understanding of caregiver's support and information needs when making this difficult decision for their child.

Please take the time to fill out this questionnaire. It will take approximately 10-20 minutes to complete. Descriptive information is encouraged as the study looks to identify your experiences to try to understand your perspective and areas of need. This could help the Speech-Language Therapist's approach to education and care in the future.

information:

Participants must include caregivers of children with gastrostomy tubes. The caregiver refers to the person making the important decisions for the child (2-6 years old). The caregiver must be over 18 years old, a South African citizen and must have a basic understanding of English.

Voluntary Participation: At any point in the study the participant has the right to

withdraw from the study with no explanation.

Participant Confidentiality: Participant's information will only be seen by the researcher and her supervisor. All data will be stored on a password protected computer.

Participant's benefit: There is no direct benefit to the participant. This study hopes to contribute to improved understanding of a caregivers needs so that Speech-Language Therapists can improve their support to caregivers in the future.

Queries:

If contact is made with the researcher for any question's confidentiality will be maintained. No person out of the research process will come to know of any questions asked by the participant.

For any questions please feel free to make contact with any of the following people:

Researcher: A. Potgieter: anna.potgieter@icloud.com

Research Supervisor: Dr K. Coutts: kim.coutts@wits.ac.za

Human Research Ethics Committee: Shaun.Schoeman@wits.ac.za

Appendix B.2: Information Sheet for SLT's questionnaire



Caregivers Experiences of Gastrostomy feeds: A Speech-Language Therapist's Role.

This questionnaire forms part of a study which aims to explore caregivers' experiences of the decision-making process when selecting gastrostomy tubes (e.g. PEG or MicKey feeding tubes) for their child. This will help to develop an improved understanding of caregiver's support and information needs when making this difficult decision for their child.

Please take the time to fill out this questionnaire. It will take approximately 10-15 minutes to complete. Descriptive information is encouraged**.** This could help to shape the Speech-Language Therapist's approach to education and care in the future.

Participant information:

Participants must include registered Speech-Language Therapists working in the public or private sector that are involved in treating the paediatric dysphagia population. Participants must have been trained in South Africa. Participants may include community service Speech Therapist's.

Voluntary Participation: At any point in the study the participant has the right to withdraw from the study with no explanation.

Participant Confidentiality: Participants information will only be seen by the researcher and her supervisor. All data will be stored on a password protected computer.

Participant's benefit: There is no direct benefit to the participant. This study hopes to contribute to improved understanding of a caregivers needs so that Speech-Language Therapists can improve their support to caregivers in the future.

Queries:

If contact is made with the researcher for any question's confidentiality will be maintained. No person out of the research process will come to know of any questions asked by the participant.

For any questions please feel free to make contact with any of the following sources:

Researcher: A. Potgieter: anna.potgieter@icloud.com

Research Supervisor: Dr K. Coutts: kim.coutts@wits.ac.za

Human Research Ethics Committee: Shaun.Schoeman@wits.ac.za

Appendix B.3: Information Sheet for Caregivers Focus Group



Caregivers Experiences of Gastrostomy feeds: A Speech-Language Therapist's Role.

This is a platform speak with other caregivers facing similar obstacles and triumphs to you. The researcher will act as a facilitator to conversation. The session should last approximately 40-45 minutes.

Viewing options: Participants may decide whether they would like the video function on or off. It would be appreciated if the audio function remains on.

Voluntary Participation: At any point in the study the participant has the right to withdraw from the study with no explanation.

Participant Confidentiality: Participants information will only be seen by the researcher, her supervisor and the transcriber. The video footage from the discussion will be recorded to ensure appropriate recall of the session. No names will be used in the written reports or transcriptions. Videos will be stored on a password protected computer for two years after the completion of the project. This will only be extended if the information is required for publication.

Participant's benefit: There is no direct benefit to the participant. This study hopes to contribute to improved understanding of a caregivers needs so that Speech-Language Therapists can contribute for the best of the family.

Queries:

If contact is made with the researcher for any question's confidentiality will be maintained. No person out of the research process will come to know of any questions asked by the participant.

For any questions please feel free to make contact with any of the following sources:

Researcher: A. Potgieter: anna.potgieter@icloud.com

Research Supervisor: Dr K. Coutts: kim.coutts@wits.ac.za

Human Research Ethics Committee: Shaun.Schoeman@wits.ac.za

Appendix C.1: Consent Sheet for Caregivers

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

'Caregivers Experiences of Gastrostomy feeds: A Speech-Language Therapist's Role'.

Research conducted by Anna Potgieter

I, _____, agree to participate in this research project. The research has been explained to me in the information sheet and I understand what my participation will involve. I agree to the following:

I have read the participation information and met the requirements.	Yes ☐	No ☐
I understand the nature of the study.	Yes ☐	No ☐
I understand that you may withdraw from the study at any time with no reason provided. Participation is appreciated but is not compulsory.	Yes ☐	No ☐
I understand that there will be no significant benefit to me as a participant.	Yes ☐	No ☐
I agree that my participation will remain anonymous	Yes ☐	No ☐
I agree that the researcher may use anonymous quotes in her research report.	Yes ☐	No ☐

By clicking 'agree' you will consent to participate in this study along with the all of the above information:

☐ I agree.

☐ I disagree and would like to opt out.

Appendix C.2: Consent Sheet for Speech-Language Therapists



Consent Sheet for Speech-Language Therapists

'Caregivers Experiences of Gastrostomy feeds: A Speech-Language Therapist's Role'.

Research conducted by Anna Potgieter

I, _____, agree to participate in this research project. The research has been explained to me in the information sheet and I understand what my participation will involve. I agree to the following:

I have read the participation information and met the requirements.	Yes □	No □
I understand the nature of the study.	Yes □	No □
I understand that you may withdraw from the study at any time with no reason provided. Participation is appreciated but is not compulsory.	Yes □	No □
I understand that there will be no significant benefit to me as a participant.	Yes □	No □
I agree that my participation will remain anonymous	Yes □	No □
I agree that the researcher may use anonymous quotes in her research report.	Yes □	No □

By clicking 'agree' you will consent to participate in this study along with the all of the above information:

☐ I agree.

☐ I disagree and would like to opt out.

If you would like to receive the results of the study please provide your email address: _____.

Appendix C.3: Consent Sheet for Caregivers participating in the focus group



Consent Sheet for Speech-Language Therapists

'Caregivers Experiences of Gastrostomy feeds: A Speech-Language Therapist's Role'.

Research conducted by Anna Potgieter

I, _____, agree to participate in this research project. The research has been explained to me in the information sheet and I understand what my participation will involve. I agree to the following:

I understand the nature of the study.	Yes □	No □
I understand that you may withdraw from the study at any time with no reason provided.	Yes □	No □
I understand that there will be no significant benefit to me as a participant.	Yes □	No □
I agree that the researcher may use anonymous quotes in her research report.	Yes □	No □
I understand that the researcher's supervisor and the research assistant may also access and view parts of the data.	Yes □	No □
I agree that the discussion may be video recorded. I can choose whether my camera is left on or off	Yes □	No □

By clicking ‘agree’ you will consent to participate in this study along with the all of the above information:

☐ I agree.

☐ I disagree and would like to opt out.

Appendix D.1: Permission Letter for Psychological Referrals



University of the Witwatersrand,
Department of Speech Therapy and Audiology
27 (11) 717-4577

26/05/2020

Dear Sir/Madam,

Re: Permission to refer research participants for psychological intervention.

My name is Anna Potgieter. I am a Speech-Language therapist working in a hospital in Johannesburg.

I am studying for a Masters in the Speech Therapy at the University of the Witwatersrand. The title of my master's is 'Caregivers Experiences of Gastrostomy feeds: A Speech-Language Therapist's Role'. I am seeking permission to refer patients to you if they seek psychological services.

I am conducting research to identify caregivers' experiences of Speech-Language Therapy support during the decision-making process of considering gastrostomy feeds for their child (ages 2-8 years-old). In the paediatric population, caregiver's burden and the decision-making processes for their child's gastrostomy tube is not well explored. This can increase their feelings of burden and affect the information that they receive.

The research will entail collecting data from Speech-Language Therapists' and caregivers of children with gastrostomy tubes. As I will be discussing emotional and possibly sensitive information, I am requesting permission to refer caregivers to you for teletherapy. This will allow for patients in all areas to access your services with limited contact, therefore, reducing possible COVID-19 exposure.

I, therefore, request permission in writing to refer caregivers expressing distress to your services if requested. The permission letter should be on your organization's headed paper, signed, dated, and specifically referring to myself by name and the title of my study. Please also state the name and contact details of the person who will assist my participant should it be needed, if they feel distress.

Please let me know if you require any further information. I look forward to your response as soon as is convenient.

Yours sincerely,



Anna Potgieter

0769945394
795222@students.wits.ac.za

Supervisor: Dr Kim Coutts
27 (11) 717 4572
kim.coutts@wits.ac.za

Appendix E: Confidentiality Agreement for Research Assistant for Transcriptions.

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

University of the Witwatersrand,
Department of Speech Therapy and Audiology
27 (11) 717-4577

26/05/2020

Dear Sir/Madam,

Re: Confidentiality Agreement for Research Assistant for Transcriptions for the study: Caregivers Experiences of Gastrostomy feeds: A Speech-Language Therapist's Role

In consideration of the disclosure of information, relating to the transcriptions of the dialog from the focus groups, I Vashnie Govender agree to keep this information confidential. I understand I should not disclose this information to anyone other than the researcher. I understand that this is personal and confidential material and discussing this with anyone outside of the research project would be unethical.

Yours sincerely,
Signature: _____.
Anna Potgieter
(Researcher)

Date of agreement: 07/06/2021
Name: Vashnie Govender
Signature: _____.