

HEALTH PRACTITIONERS' PRACTICES, PERCEPTIONS, AND EXPERIENCES REGARDING GASTROSTOMY PLACEMENT IN A PAEDIATIC SETTING

by

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Author's Note

This thesis is dedicated to Beverley, Erin and Joneve- the three beautiful souls responsible for transforming my understanding of cerebral palsy, and giving life to my love for children with special needs.

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Referencing Style

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

Glossary

Enteral Feeds

Non-oral feeding administered via a tube (Arvedson & Brodsky, 2002).

Fundoplication

Gastric fundoplication is a surgical treatment option for children with gastroesophageal reflux disease (GORD) and is often a consideration when a decision has been made to insert a gastrostomy tube (Fox et al., 2012).

Gastrostomy

Surgically creating a tract between the stomach and abdominal surface (Kazmierski, Jordan, Saeed, & Aslam, 2013). A tube is inserted directly into the stomach through an opening in the anterior abdominal wall (El-Matary, 2008; Gauderer, 2002).

Gastroesophageal Reflux (GOR)

The retrograde movement of gastric contents from the stomach to the oesophagus (Arvedson & Brodsky, 2002; Sullivan, 2008.)

Health Care Practitioners

A health care professional, health practitioner or healthcare provider is an individual who provides preventative, curative, promotional or rehabilitative health care services to people, families and/or communities (WHO, 2007). The health care practitioners working with children with gastrostomies in the paediatric setting includes a paediatrician, surgeon, gastro-enterologist,

speech therapist, dietician, social worker and nurse practitioner (specifically trained in gastrostomy and stoma care) (Edwards et al., 2016; Majika et al., 2014; Marchand et al., 2006; Sevilla & McElhanon, 2016).

Percutaneous Endoscopic Gastrostomy (PEG)

Percutaneous endoscopic gastrostomy placement is an endoscopic technique during which a feeding tube is placed directly into the stomach from the skin through the guide of a fiber-optic endoscope (Gauderer, 2002; Sullivan 2008).

Stoma

An artificial permanent opening in the abdominal wall made in a surgical procedure (Merriam- Webster's Collegiate Dictionary, 1999).

Stoma Sister

A nursing practitioner who specializes in stoma care. Also known as a stoma care nurse and enterostomal therapist (Baxter & Salter, 2000). The stoma sister (as referred to in South Africa) work with families during the decision-making process as they share information on i.e. gastrostomy tube care, stoma care and provide training to caregivers before and after the tube is placed.

Abstract

Health practitioners' practices, perceptions and experiences regarding gastrostomy placement in a paediatric setting.

Background

Since its introduction in the 1980s, reports show an increase in the placement of gastrostomies in children, particularly in those with disabilities, due to its many benefits. To date, little has been reported on the practices, perceptions and experiences of the health care practitioners when engaging in the management of children with gastrostomies.

Research aims

This study aims to provide insight into the practices as well as the perceptions and experiences of the health care practitioners working with gastrostomies in a paediatric setting.

Method

A qualitative interpretative design was used. Eighteen healthcare practitioners, who form part of the multidisciplinary team working with paediatric gastrostomies, from one of the two prominent tertiary institutions in Cape Town, South Africa were recruited for this study. Semi structured interviews were conducted after which data analysis took place.

Results

Four themes emerged from the data collected; experience of better patient health evolving post gastrostomy despite complications, health care practitioners' perceived change to a family's quality of life, the gastrostomy process: just as you think it's going right then something goes

wrong; and experiencing multidisciplinary team work, and its influences on the management of patients with gastrostomies.

Conclusion

The health care practitioners reflected on their practices, perceptions and experiences of gastrostomy management as being a process. During the different stages of the process, they engaged with the advantages and disadvantages the gastrostomy has on the health of a child; the positive and negative influences on the quality of life for families and identified the importance of but also the lacking in the provision of education and ongoing support for caregivers. An effective multidisciplinary team is a requirement for the management of the gastrostomy; inadequacies within the team contributed to undesirable service delivery and poor health outcomes for the child. This study highlights the importance of and the need for the implementation of best practice guidelines for gastrostomy decision-making, placement and management in the paediatric setting.

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1. Introduction

This thesis consists of six chapters. Chapter 1 frames the research by providing an introduction to gastrostomy care in the paediatric setting and positions the researcher in relation to this area of interest. An outline of the research question and discussion of the need for research within this field of interest is provided. In Chapter 2, the literature review represents areas identified in the interviews as having relevance to the practices, perceptions and experiences of health care practitioners. Chapter 3, the methodology, discusses the rationale and methodological foundation of this study, along with the outline of the process followed and the methods used to collect and analyse data. In Chapter 4, the results of this study are outlined in four themes, followed by the discussion in Chapter 5. Finally, Chapter 6 provides a summary of the health care practitioners' practices, perceptions, and experiences and the implications for clinical practice, as well as recommendations for future research.

1.1 Framing the research

The area of interest in this research study is the practices and experiences of health care practitioners when engaging with gastrostomies in the paediatric population and this topic is explored from the perspectives of practitioners working in two paediatric tertiary institutions in Cape Town South Africa. A search of available, current literature indicated a need for more research on this topic of interest, which led to the question: *What are health care practitioners' practices, perceptions and experiences when engaging with the patient with a gastrostomy in the paediatric population?*

1.2 The researcher

The qualitative research design process begins with philosophical assumptions that are made when deciding to undertake a qualitative study. Researchers also bring their own worldviews and beliefs to the research project, and these inform the execution and writing of the qualitative study (Creswell, 2007). The potential impact these worldviews may have on the research process, requires that the qualitative researcher explicitly identify and provide his or her biases, values, personal interests, professional perspectives and background (Creswell, 2007; Terre Blanche, Kelly & Durrheim, 2006a). Researcher related factors such as class, gender, culture and ethnicity may play a role and influence the adopted approach to a study and could bias the findings (Denzin & Lincoln, 2008). Given the central place and role as observer and interpreter, it is acknowledged that the researcher is the most important instrument in the qualitative research process. This role places an added responsibility to remain unbiased when describing and interpreting the phenomenon being studied (Babbie & Mouton, 2004). One way of addressing bias is for the researcher to make known his or her stances and provide background information that could possibly influence the research design chosen and interpretations made (Denzin & Lincoln, 2008).

I am a 32- year old, female Speech Therapist working in a public school for children with cerebral palsy in Cape Town. My caseload includes learners with learning and physical disabilities, 4 to 23 years of age, of which five currently have gastrostomies in place.

Before embarking on my study, I had never seen or worked with a gastrostomy and knew very little about this form of enteral feeding. Only well after my data had been collected, had I been introduced to a learner who had underwent gastrostomy placement. This learner's procedure was done in a private tertiary institution and the stoma sister who was a representative of the

company that made the tubes came to the school to give the hostel staff (the learner stayed at the school hostel) training. My second experience with a gastrostomy was very different and was based in the public setting. A new learner at the school, was referred to a paediatric tertiary institution as she was incredibly sick and a gastrostomy was recommended by the doctors seeing her. During her stay as an inpatient, my sister and I took on the role as stand in caregivers as she was a ward of the state, who was in the process of being placed with a foster family (who resided outside of Cape Town). As a speech therapist, many of the technicalities related to the gastrostomy were easier for me to understand and with this in mind, I made more of an effort to share information with caregivers.

The research supervisors have played a pivotal role in ensuring my analyses and written work reflects an objective, unbiased interpretation of the data collected. A reflective journal helped bracket personal feelings and opinions in an attempt to produce an unbiased research paper (Holloway & Wheeler, 1996).

1.3 Problem statement

Gastrostomy tubes have been reported to be used increasingly in children worldwide (El-Matary, 2008; McSweeney & Smithers, 2016; Sevilla & McElhanon, 2016), yet there is limited literature available on how health care practitioners engage with children with gastrostomies in the paediatric population, particularly in the South African context. Available literature provides insight into the caregivers' experiences and perspectives regarding the gastrostomy but very few on the practices of the health care practitioners. There is a need for information regarding the current gastrostomy practice in the South African paediatric setting to motivate for the development of a standardized protocol stemming from best practice guidelines.

In this study, the words gastrostomy and percutaneous endoscopic gastrostomy (PEG) were used interchangeably by the participants, but for the purpose of consistency in this document, the term gastrostomy will be used. The gastrostomy is a surgical procedure during which an opening is made into the stomach from the abdominal wall, for the introduction of food, while the PEG is an approach taken in surgery when placing the gastrostomy tube (Gauderer, 2002). The participants in this study have also referred to caregivers, carers and parents interchangeably. For uniformity, as well as an awareness that not all caregivers are the parents of a child, the term caregiver will be used throughout this study as the preferred term for the persons primarily responsible for caring for the child.

2. Literature Review

This literature review serves to provide the reader with a framework of existing literature, relevant to the research question. Given the descriptive nature of this qualitative study, an inductive approach to writing the literature review was taken (Creswell, 2014). In order to abate bias that could mount from predetermined views, or from studying existing literature, it is advised that a comprehensive literature review be conducted concurrently with the analysis of data, in an ongoing manner as new themes surface from the analysed data (Latham, 2004).

The areas reviewed in this chapter were guided by topics that emerged from the information shared by the health care practitioners. The context for gastrostomy placement is outlined along with the positive and adverse outcomes on the health of the child and the quality of life of the caregivers. Literature pertaining to gastrostomy related decision-making for the caregivers, information sharing and education provided by the health care practitioners and multidisciplinary team work is reviewed.

While this study aims to explore the gastrostomy practices, perceptions and experiences from the health practitioners view point, literature on the experiences of caregivers has been included in this review as family experiences and expectations influence health care practice (Sullivan, 2013).

A gastrostomy tube is a form of enteral feeding (Sumritsopak, Treepongkaruna, Butsriphum, & Tanpowpong, 2014; Wilson et al., 2009) that was first described in the 17th century but only in the 18th century (1846) was the first gastrostomy successfully performed by Charles Sédillot (Kazmierski, Jordan, Saeed, & Aslam, 2013; Minard 2006). Gastrostomy is the insertion

of a tube directly into the stomach through an opening in the anterior abdominal wall (Cunningham & Best, 2013; Gauderer, 2002; Kirk, Shelley, Battles, & Latty, 2014). Since the original technique was introduced, various modifications have come to the fore. The gastrostomy can be performed surgically, laparoscopically, with the assistance of radiological techniques or endoscopically (PEG) (El-Matary, 2008; Gauderer, 2002). The PEG has been reported to be the preferred route of feeding and nutritional support in patients requiring long-term enteral nutrition (Kazmierski et al., 2013) and the favourite choice because it has advantages over the other techniques, especially in young children (Gauderer, 2002). PEG placement, compared to the traditional open surgical gastrostomy, is considered to have lower costs, is a less invasive surgical approach and requires a shorter hospital stay which allows for a faster recovery (Sumritsopak et al., 2014). The primary purpose of the gastrostomy is to improve the physical well-being of an individual by providing optimal nutrition and preventing malnutrition (El-Matary, 2008; M.W. Gauderer, 2002).

Gastrostomy tube feeding is recommended for those who necessitate long-term supplemental or full enteral feeding (Cunningham & Best, 2013; Sevilla & McElhanon, 2016; Wu, Wu, & Ni, 2013). It is most commonly indicated in infants and children with dysphagia, whose safety to swallow is compromised resulting in aspiration (El-Matary, 2008; Fröhlich, Richter, Carbon, Barth, & Köhler, 2010; Norman et al., 2011; Sevilla & McElhanon, 2016; Sullivan, 2013). This form of alternative feeding is also indicated in children who fail to thrive, have weight gain issues as a result of poor oral intake, have structural abnormalities or those who are dependent on unpalatable medications (Fröhlich et al., 2010; Gauderer, 2002; Hannah & John, 2013; Kazmierski et al., 2013). In the presence of significant gastroesophageal reflux, gastrostomy tube placement is often accompanied by an anti-reflux procedure (Thomas et al., 2016; Wilson et al., 2009).

Gastrostomy placement is reportedly common in certain populations; children with neurological impairment (Arvedson & Brodsky, 2002; Fröhlich et al., 2010; (Marchand, Motil, & Nutrition, 2006; Sullivan, 2008; Sullivan, 2013; Thomas et al., 2016; Townsend, Craig, Lawson, & Spitz, 2008), cardiac defects (Fröhlich et al., 2010; Thomas et al., 2016), gastro-intestinal tract (GIT) abnormalities (Fröhlich et al., 2010) and pulmonary conditions (Thomas et al., 2016; Wilson et al., 2009). Infants and children fed via gastrostomy can be weaned from enteral feeding when oral feeds have been declared safe, or when they are able to tolerate adequate volumes or when the structural, GIT or cardiac conditions have been resolved (Fröhlich et al., 2010).

The primary benefits of the gastrostomy as described in literature are weight gain (Craig et al., 2006; Hannah & John, 2013; Sullivan, 2013; Sullivan et al., 2005; Wu et al., 2013), and improved nutritional status (Craig et al., 2006; El-Matary, 2008; Hannah & John, 2013; Martinez-Costa, Borraz, & Benlloch, 2011; Sevilla & McElhanon, 2016; Sullivan et al., 2005). Weight gain is considered a positive gastrostomy outcome by the health care practitioners (Morrow, Quine, & Craig, 2006) while some caregivers did not regard weight gain as a priority (they did not want their children to gain too much weight) (Craig & Scrambler, 2005; Mahant, Jovcevska, & Cohen, 2011). In addition, fewer respiratory infections have been reported in patients with gastrostomies (Brotherton, Abbott, & Aggett, 2007b; Fröhlich et al., 2010; Martinez-Costa et al., 2011; Sullivan, 2013). Gastrostomy feeding resulted in a decrease in hospitalization time and contributed to improved survival of infants and children with chronic diseases (Martinez-Costa et al., 2011). A longitudinal study by Sullivan et al. (2006) concluded that there was no evidence of increased respiratory morbidity in children with cerebral palsy once the gastrostomies had been placed. Common comorbidities in children with cerebral palsy are reported to increase the risk of

respiratory illness such as GOR and scoliosis (Blackmore et al., 2016) recurrent aspiration, impaired airway clearance and deformities of the spine and/or chest wall (Boel et al., 2018).

Gastrostomy insertion for enteral nutrition in children is reported to be an efficient and safe procedure while associated with an acceptable complication rate (Fröhlich et al., 2010). Complications are classified as either minor or major (Craig et al., 2006; McSweeney, Jiang, Deutsch, Atmadjia, & Lightdale, 2013; McSweeney & Smithers, 2016). Minor gastrostomy complications include wound infections, tube and/or stoma leakage, tube blockage, gastric outlet obstruction, inadvertent gastrostomy removal and peritonitis (Cunningham & Best, 2013; Hannah & John, 2013; Kazmierski et al., 2013; Martinez-Costa et al., 2011; Sullivan, 2013; Thomas et al., 2016; Wu et al., 2013). Major complications, although not common, can occur after the gastrostomy has been inserted (Sullivan, 2013). Furthermore Sullivan (2013), lists adverse anaesthetic events, oesophageal laceration, pneumoperitoneum, peritonitis, colonic perforation and cologastric fistula formation as major complications that can occur as a result of gastrostomy placement. Most major complications occur within the first year of placement (McSweeney et al., 2013; McSweeney & Smithers, 2016); while minor complications may occur at any time (McSweeney et al., 2013; Naiditch, Lautz, & Barnsness, 2010). The incidence of gastrostomy related complications has been reported to be between 73 % (Naiditch et al., 2010), 82 % (Craig et al., 2006; Nelson & Mahant, 2014) and 83 % (Schweitzer, Aucoin, Docherty, Thompson, & Sullivan, 2014). Approximately 10% of patients will have a major complication within 6 to 12 months of initial gastrostomy placement, many of which occur outside of the hospital (McSweeney et al., 2013). While the occurrence of complications decreased after the first year post placement, complications were still reported even 5 years following placement (McSweeney et al., 2013). The caregivers often return to hospitals, particularly emergency departments to access medical services

for assistance with the gastrostomy complications, which has resulted in increased health care utilization and has implications on the quality of life for child and caregivers (Correa et al., 2014; Sevilla & McElhanon, 2016). Increased gastroesophageal reflux has been associated with the gastrostomy and is considered a disadvantage (Naiditch et al., 2010; Nelson & Mahant, 2014; Sullivan, 2013). A large number of paediatric gastrostomy tube insertions are accompanied by a fundoplication (Fox et al., 2012). The caregivers, when aware of these complications, are able to prevent and better manage the complications experienced by their children with gastrostomies thus improving the quality of life for the child (Rahnemai-Azar, Rahnemaiaazar, Naghshizadian, Kurtz, & Farkas, 2014).

Caregivers' lived experiences suggest that the gastrostomy has both positive and negative implications on their home life (Brotherton et al., 2007b; Hewetson & Singh, 2009). Although most caregivers are initially resistant to gastrostomy placement, the majority are reportedly satisfied with the result of the procedure (Wilson et al., 2009). The gastrostomy has a positive impact on the quality of life for caregivers and their children with feeding problems (Brotherton et al., 2007b; Hannah & John, 2013; Morrow et al., 2006; Sullivan, 2013; Sullivan et al., 2004; Wilson et al., 2009). Feeding difficulties often lead to stress and frustration for both the child and caregivers, and the gastrostomy is said to relieve the pressure on the caregiver as it reduces the amount of time spent feeding, making meal times more relaxed compared to before gastrostomy placement (Brotherton et al., 2007b; Craig, 2013; Craig et al., 2006; Martinez-Costa et al., 2011; Morrow et al., 2006; Sullivan, 2013; Sullivan et al., 2004; Wilson et al., 2009).

Sumritsopak et al. (2014) reported that the caregivers in their study associated the improvement in the child's health with improved quality of life; the caregiver's quality of life was associated with satisfaction with information received before and after gastrostomy placement.

Morrow et al. (2006) investigated health practitioners' perceptions of the quality of life relating to feeding in children with cerebral palsy. The health care practitioners in that study believed that the quality of life of caregiver and child was inseparable as each would have significant influence on the other. They reported that while the gastrostomy offered relief in certain areas, it contributed to strain in others, particularly causing a barrier to social acceptability. They concluded that while there was a consensus that the gastrostomy had positively impacted the quality of life, the lack of support available to caregivers after gastrostomy placement, negatively influenced the family's quality of life and that as health care practitioners, they may not always have been mindful as to how invasive caregivers perceived the gastrostomy to be (Morrow et al., 2006).

Caregivers describe the burden of care as a challenge; they are unable to find day time carers willing to look after their child due to the technical skills required to maintain and administer gastrostomy feeds (Brotherton et al., 2007b). Caregivers therefore are solely responsible for looking after their child with the gastrostomy; as these feeds occur routinely throughout the day, the caregivers are faced with the challenge of managing their daily activities around their child's feeding schedule.

A South African study that looked into the lived experiences of mothers of children with feeding difficulties, reported that caring for child with feeding difficulties has implications for participation in social activities as well as employment status (Hewetson & Singh, 2009). Caregivers have to take time off work to access health care at tertiary institutions as medical assistance is not readily available at other levels of health care or community based care (Sevilla & McElhanon, 2016). Lack of access to health care for gastrostomy related issues was recognized as having a negative impact on the quality of life of caregivers (Morrow et al, 2006). Furthermore, the caregivers' ability to socialize was limited as they could not go to any place with their child

with the gastrostomy without thorough planning (Hewetson & Singh, 2009). The feeding regime is said to restrict caregivers' ability to go on holidays as the organizing required is viewed as being demanding; caregivers also reported difficulties finding places to eat that is gastrostomy feeding friendly (Brotherton et al., 2007b). The gastrostomy disrupts the social aspects of feeding for caregivers and the child with the gastrostomy and with reference to the International Classification of Functioning, Disability and Health, it has implications for activity and participation in public everyday life i.e. social value of gastrostomy feeding (Mahant et al., 2011).

The International Classification of Functioning, Disability and Health: Children and Youth version (ICF-CY), is the classification of the health components of functioning and disability of a child as it occurs in context (WHO, 2007). The ICF-CY acknowledges the role of environmental factors in the formation of disability, as well as the significance of associated health conditions and their effects on the functioning of a child. The aim of the ICF-CY tool is that it serves as an instrument for assessing health status and disability across different cultures, contexts and environments. In the ICF-CY, functioning and disability are multifaceted views relating to how the body functions and the structures of children and the impairments experienced. Activities as well as the activity limitations experienced by children; the involvement and participation of children in all areas of life, and the participation restrictions experienced i.e. social feeding with a gastrostomy are all considered and taken into account when using the ICF-CY framework (WHO, 2007; Mahant et al., 2011).

The stigma associated with tube feeding causes caregivers to feel like failures who are unable to meet their children's basic needs (Brotherton et al., 2007b; Craig & Scrambler, 2005; Hannah & John, 2013; Marchand et al., 2006; Sullivan, 2013). The study by Craig and Scrambler, (2005), explored the health practitioner and caregiver discourses in both disabled children and

gastrostomy feeding. Mothers in this study believed that children who were tube fed were 'constituted as not normal'. They believed that they had failed and blamed themselves for the feeding difficulties their children were experiencing, which resulted in them requiring a gastrostomy. Craig and Scrambler (2005), reported that the mothers also blamed themselves for not having acted sooner in getting treatment for their child when they realized the benefits of the gastrostomy after it had been placed. Mothers felt stigmatized by their communities for having a thin, ill looking child. They were also uncomfortable with tube feeding their children in public (Craig & Scrambler, 2005). This study concluded that tube feeding challenged the culturally available narratives about what 'good' mothering is and in most cases, the fear of being judged as a poor mother and the stigma attached to gastrostomy tube feeding, had a negative impact on the quality of life of mothers (Craig & Scrambler, 2005). Despite the challenges experienced, most caregivers reported satisfaction with gastrostomy feeding tubes and wished they had considered it earlier (Fröhlich et al., 2010; Martinez-Costa et al., 2011; Sullivan, 2013).

The decision-making procedure for gastrostomy placement in children is complex and difficult (Brotherton & Abbott, 2012; Guerriere, McKeever, Llewellyn -Thomas, & Berall, 2003). A limitation in most of the published literature in the field of decision-making with regards to the gastrostomy is that the process is represented as being one-dimensional and static, with the primary focus on clinical issues, failing to consider the psychosocial aspects of gastrostomy placement (Brotherton & Abbott, 2012).

The decision-making process for caregivers is often described as a period of indecisiveness, anxiety and conflict (Guerriere et al., 2003; Mahant et al., 2011; Sullivan, 2013). Caregivers should

be included from the beginning in the decision-making process for gastrostomy placement (Cunningham & Best, 2013; Fröhlich et al., 2010; Marchand et al., 2006). A systematic review on caregiver participation in decision-making in health-services for children was conducted by Aarthun and Akerjordet (2012). A shift from a paternalistic decision-making model (where practitioners make the decisions) to a shared model, in which health practitioners and caregivers both play an active part by sharing information and reaching consensus is emphasized (Aarthun & Akerjordet, 2012). The review revealed that while caregivers wanted to partake more actively in the process, health practitioners were dominant in the decision-making process (Aarthun & Akerjordet, 2012). Thorne, Radford, and McCormick (1997), reported on the importance caregivers assign to decision-making. Avoidable miscommunications and misunderstandings regarding the perceived caregiver convenience between caregivers and health care practitioners complicated the process (Thorne et al., 1997). The tension between oral feeds being seen as easier than gastrostomy feeds by caregivers while health care practitioners consider placement of the gastrostomy, in an attempt to ease the effortful and time-consuming feeding process have been reported to contribute to misunderstanding (Thorne et al., 1997).

Caregivers shared concerns about the implications for oral feeding and the permanency of the feeding tube as well as possible surgical complications (Guerriere et al., 2003; Mahant et al., 2011; Sullivan, 2013). It is important for health care practitioners to be aware of caregiver concerns regarding gastrostomy placement as this can assist in preoperative counselling (Wilson et al., 2009).

Some mothers did not always make an informed decision about their child undergoing gastrostomy placement as they only learned significant information after the procedure had taken place (Guerriere et al., 2003). The purpose of informed consent is to enrich the patient's care by giving the patient comprehensive information on the benefits and burdens of tube feeding before

gastrostomy insertion (Rahnemai-Azar et al., 2014). Informed decision-making is made with the support of additional information, consulting others and a sense of control over the process. (Jackson, Cheater, & Reid, 2008). Caregivers have expressed a need for conversation and support from health care practitioners (Aarthun & Akerjordet, 2012; Jackson et al., 2008; Sjöberg, Nygren, & Svedberg, 2017). Decision-making for caregivers is complex and a lack of information regarding the gastrostomy tube and the procedure itself can make the process difficult for them.

The provision of information by practitioners regarding the benefits and risks of the gastrostomy is often inadequate (Brotherton, Hurley, & Aggett, 2007a; Guerriere et al., 2003; Mahant et al., 2011). Health care practitioners involved in the management of the child often fail to communicate adequately with the patient's family (Morrow et al., 2006). The information provided by the health care practitioners to the caregivers has been reported as lacking, conflicting and is often shared at an inappropriate time (Hewetson & Singh, 2009; Jackson et al., 2008; Mahant et al., 2011; Sjöberg et al., 2017). Caregivers require comprehensive information about gastrostomy tube feeding during the decision-making process (Sullivan, 2013).

Another way of facilitating the decision-making process is to introduce caregivers of potential gastrostomy candidates to caregivers of children with gastrostomies. This method is said to be an effective practice done by the health care practitioners in getting caregivers on board with the decision to place the gastrostomy (Martinez-Costa et al., 2011). However, caregivers are not always afforded this opportunity to meet caregivers who are already caring for children with gastrostomies (Guerriere et al., 2003; Hewetson & Singh, 2009; Mahant et al., 2011). Caregivers may then not always be able to ask questions from others who they feel they can relate to on a personal level, leaving them uncertain and uninformed about the surgery itself and what living with and caring for a child with a gastrostomy would be like.

Caregiver training on gastrostomy care and management is important (Correa et al., 2014; Kirk et al., 2014; Schweitzer et al., 2014; Sevilla & McElhanon, 2016), yet the provision thereof is reportedly inconsistent (Schweitzer et al., 2014). Sufficient education given to patients and families regarding tube site care and management can help lessen the risk of infection (Hannah & John, 2013). Adequate pre-procedure and post-procedure education improves patient outcomes, caregiver knowledge and confidence, while insufficient education can lead to unfavourable outcomes for both caregiver and child (Schweitzer et al., 2014). It is recommended that caregivers stay overnight for one to two days to provide all care self-sufficiently under the close supervision of hospital staff before discharge (Sevilla & McElhanon, 2016), as poor practices from caregivers can result in gastrostomy related complications, which has implications for the child's health (Evans et al., 2012).

The implementation of standardized gastrostomy education results in an improvement in the knowledge and competency of both nurses and caregivers (Kirk et al., 2014), which enhanced the overall health outcomes of the patient (Kirk et al., 2014; Schweitzer et al., 2014). Furthermore, the lack of access to resources and gastrostomy related services outside the tertiary setting and inadequate gastrostomy education was seen as contributing to the high emergency department visits for non-emergent complications (Correa et al., 2014; Kirk et al., 2014).

A study by Correa et al. (2014) hypothesized that most of the patient visits to the emergency department relating to concerns with the gastrostomy tube were not deemed medically urgent. Of the patients discharged with a gastrostomy, 20% returned to the emergency department 44 times within 30 days of discharge for tube related concerns most of which are avoidable or could have been treated at an outpatient clinic or at home had a comprehensive educational programme been implemented (Correa et al., 2014). Similar findings were reported by Kirk et al., (2014) and Clancy

(2009) which prompted the creation of the Reengineered Discharge (RED) project. The implementation of the RED project contributed to the reduction in preventable hospital readmissions and emergency department visits, which facilitated improved health care. The implementation of a hospital-wide standardized feeding tube protocol as reported in Richards, et al., (2006), significantly decreased postoperative hospital resource utilization. The protocol also assists in decreasing preoperative workup variability, ensures suitable referrals are made, and guarantees that patients receive the required, post-operative gastrostomy support between the different services (Richards et al., 2016). Sevilla and McElhanon (2016) identified an important constituent of discharge planning is to identify and ensure access to other essential services the patient and family may need.

The provision of ongoing support by the health care practitioners is important as it provides families with more confidence when dealing with the physical, emotional and psychosocial implications (Hannah & John, 2013) and complications associated with the gastrostomy (Brotherton & Abbott, 2012; Craig, 2013; Cunningham & Best, 2013; Fröhlich et al., 2010; Marchand et al., 2006; Sevilla & McElhanon, 2016; Sumritsopak et al., 2014). Gastrostomy patients require long-term healthcare as they are vulnerable to complications (McSweeney et al., 2013). However care and support should not only focus on the complications but also factors based on the ICF-CY framework (WHO, 2007). Morrow et al., (2006) reported that the support provided by the health care practitioners following gastrostomy placement was lacking largely due to limited access to medical services for the gastrostomy outside of the tertiary setting.

Caregiver education needs to be examined regularly (Sevilla & McElhanon, 2016) as the skills and techniques used by carers of children with enteral nutrition noticeably deteriorates over a period of three years (Evans et al., 2012). Issues with tube replacement, feed production and

gastrostomy related hygiene are amongst the practices reported to deteriorate over time (Evans et al., 2012). The health care practitioners, working in the multidisciplinary team, are responsible for ensuring that the caregivers receive a sufficient amount of quality training relating to the management and care of the gastrostomy as well as ongoing support.

Multidisciplinary team work is an essential prerequisite for meeting the holistic needs of patients (Doyle, 2008). The composition of the multidisciplinary team working with children with gastrostomies in the paediatric setting involves a paediatrician, surgeon, gastro-enterologist, speech therapist, dietician, social worker and nurse practitioner (specifically trained in gastrostomy and stoma care) (Edwards et al., 2016; Majika et al., 2014; Marchand et al., 2006; Sevilla & McElhanon, 2016). Caregivers are considered by most as an important part of the team (Doyle, 2008; Mahant et al., 2011). A team of practitioners, trained in gastrostomy care, have been associated with a decrease in gastrostomy related complications and morbidity after placement as the child's health and well-being is dependent on him/her receiving all necessary services from the different practitioners on the team (Townsend et al., 2008; Majika et al., 2014).

A five-year retrospective review (Norman et al., 2011) of children with dysphagia at a tertiary hospital in South Africa, reported that speech therapists were a key referral source for the placement of gastrostomies (64%), followed by doctors, surgeons, paediatricians and gastro-enterologists (32%) and dieticians (4%). Prior to gastrostomy placement, less than 15% of the caregivers were seen by the stoma sister, while 97% of the caregivers were seen by stoma post gastrostomy placement (Norman et al., 2011). A loss to speech therapy follow ups post placement was noted which is interesting considering that the speech therapists were the predominant referral source (Norman et al., 2011). On the surface, it would seem that patients have adequate

multidisciplinary team care but perhaps factors such as timing, coordination and continuation of care should be developed and implemented to ensure that the patients receive the care required.

Multidisciplinary team work is important but within every team there are challenges that are hindrances to effective team work such as limited time and resources, poor appreciation of the roles and responsibilities of others, limited information sharing and collaboration, and increased workload and poor communication (Danvers, Freshwater, Cheater, & Wilson, 2003; Doyle, 2008). While dedicated time and resources, good communication and information sharing, networking, establishing partnerships with children and families, awareness and/or appreciation of the roles of other team members are factors that enhance multidisciplinary team work (Danvers et al., 2003; Doyle, 2008).

Some practitioners may not have a complete understanding of multidisciplinary teamwork, referral and roles in the management of paediatric dysphagia (Seedat, Mupawose & Choonara, 2011). The health care practitioners in Seedat et al. (2011) showed awareness of the role of the speech therapist in the management of dysphagia, however further analyses indicated that few interdisciplinary referrals to the speech therapists were made. Hence Norman et al., recommended that team members must be made aware of the speech Therapist's role in ongoing follow up, support and management as well as the pre-operative role of counselling and information sharing that the stoma sister provides. The context in which health care practitioners working in the South African health care system will be briefly reviewed. Within the South African health care system, service delivery challenges exist notwithstanding efforts to restructure the public health care system in the 20 years since South Africa underwent a the transition from apartheid to a constitutional democracy (Mayosi & Benatar, 2014). Currently, the South African health care system comprises of a large public sector delivering services to the majority of the country's

population (Kautzky & Tollman, 2008). The public health system is divided in such a way as it aims to distribute health care services across 3 levels of care, namely primary or community based, secondary and tertiary care (Dookie & Singh, 2012). Different services are provided as each level is more specialized than the level below (Dookie & Singh, 2012) in order to lessen the high case load of tertiary levels and provide better access to services for all (South African Department & Health Provincial Government of Western Cape, 2007; South African Department of Health, 2011). Despite the implementation of primary health care, health care in the public sector is described as being rigged with inequalities and inadequacies in the coverage and quality of the services delivered (Dookie & Singh, 2012). Services are often only accessed at tertiary levels (Mojaki, Basu, Letskokgohka, & Govender, 2011) as community-based services and resources are limited (South African Department & Health Provincial Government of Western Cape, 2007). Furthermore, there is a critical shortage of medical staff in the South African health care system (Dookie & Singh, 2012; Kautzky & Tollman, 2008); Mayosi & Benatar, 2014).

Expert health services, such as gastrostomy placement and management are only available at tertiary level hospitals while the provision of enteral nutrition i.e. formula and milk, is available at primary health care facilities. Therefore, gastrostomy care is not readily accessible to all and poses a challenge for caregivers. They often have to take time off work and travel at their own expenses to seek help for their child at tertiary hospitals, because the health care for gastrostomy related difficulties is not available at community based or primary levels of care. Staff are not available or are often not adequately trained in gastrostomy management at lower levels of health care, forcing caregivers to return to tertiary hospitals. Despite progress made following the election of the Government of National Unity in 1994, South Africa remains far from realizing the Alma Ata's aspirations of 'Health for All' (Kautzky & Tollman, 2008).

The speech therapist, who is part of the multidisciplinary team who is responsible for the assessment and management of oral feeding plays an important role in the decision-making before gastrostomy placement and the follow up care (Norman et al., 2011). It is the goal of the speech therapist to maximize the quality of life of the child and family by working towards a safe return to oral feeding after the gastrostomy has been placed (Arvedson & Brodsky, 2002). While the speech therapist is responsible for the oral feeding aspect, gastrostomies in the paediatric population can only be effectively managed if done so using a team approach (Norman et al., 2011). Within the team, different health care practitioners have different opinions and practices regarding gastrostomies therefore a greater understanding of their experiences, practices and perceptions could lead to better team functioning, and improved patient and service delivery. With gastrostomy placement becoming more popular, there is a need for information regarding the current gastrostomy practice in the paediatric setting as more and more practitioners are working with gastrostomies without standardized guidelines.

3. Methodology

This chapter will describe the aims and philosophical foundation of the study. Described below is the process followed, method used to gather and analyse data as well as the ethical considerations relating to the research.

3.1 Aims of study

This study aimed to describe the practices, perceptions and experiences of the health care practitioners working with children with gastrostomies in a paediatric setting.

3.2 Research design

A descriptive qualitative research design, based on the interpretive paradigm was used in this study. The fundamental aim of descriptive research is to describe the phenomenon and variables under investigation (Kelly, 2006). A descriptive design was befitting of this study as the researcher provided a detailed picture of the health care practitioners' perceptions, experiences and practices with regards to gastrostomy management in the paediatric population (Neuman, 2013).

The purpose of qualitative research is to describe and understand rather than explain and predict human behaviour. Qualitative research is an approach to social inquiry in which the research focuses on the insider perspective of social action (Babbie & Mouton, 2004). The researcher's intent in qualitative research is to make sense of and interpret the meanings others have about their world (Creswell, 2014).

A qualitative research design was selected for this study as it allowed for an in-depth understanding, interpretation and description of the phenomenon studied (Creswell, 2014; Hansen, 2006). In the current study, the researcher interpreted data reflecting the driving factors that influenced how health care practitioners engage with children with gastrostomies in the paediatric population. Furthermore, the qualitative research design best suited this study as the primary aim was in-depth (“thick”) descriptions and understandings of actions and events (Hansen, 2006). The researcher attempted to understand these actions in terms of the participants’ beliefs, history and context (Hansen, 2006). A primary feature of qualitative research is to understand and describe social action in terms of its specific context rather than attempting to generalize to a larger population (Neuman, 2013).

Given the central place and role of the researcher as interpreter, it is acknowledged that the researcher is the most ‘important’ instrument in the research process (Babbie & Mouton, 2004). The central role of the researcher placed an added responsibility on the researcher to be unbiased in her descriptions and interpretations (Creswell, 2014). Biased results have been addressed by defining the role and philosophical stances of the researcher within this study. Continuous discussions with the research supervisors occurred throughout the research process and write up phase, to assure that the interpretations remained objective and reflective of the data collected (Hansen, 2006).

An interpretive paradigm was selected as it is an approach committed to studying meaning and human phenomena in context (Babbie & Mouton, 2004). A paradigm is a model or framework for observation and understanding, which guides the philosophical assumptions undertaken by the

qualitative researcher. In the interpretive paradigm, the researcher believes that the reality to be studied consists of people's subjective experiences of the external world.

3.3 Participants

3.3.1 Selection criteria

Inclusion Criteria

In order to participate in the study, the health care practitioners were required to be:

- a) Working with the paediatric population; and
- b) Worked as one of the following:
 - Medical Doctor working with the paediatric population, e.g. paediatrician, paediatric surgeon, paediatric gastroenterologist, paediatric neurologist;
 - Speech therapist;
 - Dietician; or
 - Stoma Sister.

Exclusion criteria

None.

3.3.2 Sampling procedure

Non-probability purposive sampling was used in this study as the researcher was consciously selecting participants who met the inclusion criteria (Babbie & Mouton, 2004; Nelson, 2009; Van der Walt & Van Rensburg, 2006). Neuman (2013) describes purposive sampling as being appropriate when the researcher wishes to select participants that are

especially informative or select members of a difficult - to - reach or specialized population. For the purpose of this descriptive study, the recruitment of information rich participants allowed the researcher to collect thick descriptions (Neuman, 2013). Furthermore, purposive sampling was appropriate as there are a limited number of health care practitioners providing services to the paediatric population with gastrostomies (they were also concentrated at the two tertiary institutions and thus not readily available at all health care facilities in the Western Cape). A potential limitation of purposive sampling is that the findings are not generalizable to the larger population. This study aimed to describe and share the perspectives and experiences of individuals working with the paediatric population who may require gastrostomies and hence generalization is not a goal (Nelson, 2009). Findings from this study may have valuable meaning for similar contexts, and may be applied in related sites involving paediatric gastrostomy.

Snowball sampling was used in addition to purposive sampling. This process of gradually accumulating a large sample through contacts, word of mouth and references is known as snowball sampling (Creswell, 2007). Snowball sampling was suitable for this study as it allowed the researcher to maximize participant involvement (those meeting the inclusion criteria), be informed about and introduced to those who might be information rich or keen to participate in the study (Babbie & Mouton, 2004).

3.3.3 Sample size

The sampling frame consisted of health care practitioners recruited from two tertiary facilities delivering health care services to the paediatric population with

gastrostomies in the Cape Metropole. Eighteen participants were recruited for this study. A sample size of 6 to 12 participants is considered adequate for a qualitative study as detailed experience rather than generalizability is sought (Kelly, 2006). Once data saturation was achieved, the researcher concluded the data collection process. Data saturation marks the point at which one stops collecting new data because it no longer adds anything new to the unfolding analysis (Kelly, 2006).

3.3.4 Recruitment

Health care practitioners, who met the inclusion criteria, were recruited for this study from two tertiary institutions in Cape Town, South Africa. Both institutions are the referral sites for gastrostomy placement in children and staff at these sites are involved in both the acute and chronic care of children with dysphagia and those requiring gastrostomy, e.g. cerebral palsy, neurology, medical wards, gastrointestinal disorders, feeding and speech therapy.

Following approval by the Faculty of Health Sciences Research Ethics Committee (Appendix A), recruitment began. This process entailed obtaining permission from:

- the hospital superintendents to conduct this study at the sites (Appendix B); and
- the heads of the various departments to contact staff and conduct interviews during working hours.

Once the necessary permission had been obtained, the researcher described the nature of the study and invited the health care practitioners to participate. Those who were

willing to participate were then provided with the necessary information and asked to provide written informed consent (Appendix C).

3.3.5 Participant description

The participants from this current study were members typically forming part of the multidisciplinary team working with gastrostomies in the paediatric population. A representative from each discipline was approached and invited to participate in the study. Of the 20 health care practitioners approached, 18 were available for the interviews.

Speech Therapist:	ST
Dietician:	D
Paediatrician:	P
Paediatric Neurologist:	PN
Gastroenterologist:	GIT
Paediatric Surgeon:	SUR
Stoma Sister:	SS

Their details have been summarized below:

Table 1: Participant description

Female	Male	ST	D	P	PN	GIT	SUR	SS
14	4	5	2	1	4	3	1	2

3.4 Data collection

Semi-structured interview

The purpose of interviewing as described by Patton (2002), allows the researcher to gain insight into the participants' perspective. Qualitative interviewing assumes that the perspective of others is meaningful (Patton, 2002). The interpretive research approach makes use of the interview as an inquiring tool to find out how people feel about or experience real life phenomena (Kelly, 2006). The interpretive researcher creates a trusting environment within which the interviewees are able to share their views and experiences as well as express themselves (Kelly, 2006). As this study set out to describe the practices, perceptions and experiences of health care practitioners engaging with children with gastrostomies, a semi- structured interview was the chosen method of data collection.

This method of data collection was best suited to the current study as the interviews provided information not otherwise available to the researcher, i.e. health care practitioners' practices, perceptions and experiences with children with gastrostomies (Babbie & Mouton, 2004). It allows for the exploration of depth and nuances of perspectives regarding gastrostomy within the paediatric population (Patton, 2002).

3.5 Data Collection Tool

3.5.1 Interview guide (Appendix D)

A list of topics that needed to be explored during the semi-structured interviews is referred to as the interview guide (Flick, 2010; Patton, 2002). It was prepared in advance so that the same basic questions and topic areas were pursued in each interview. It assisted in interviewing the participants more systematically and comprehensively by defining in

advance the issues that needed to be explored. In addition, the interview guide assisted in ensuring the participant did not drift off topic yet also providing an opportunity for the emergence of individual perspectives and experiences (Patton, 2002). Lastly, the interview guide encouraged the interviewer to carefully decide how best to use the limited time during the interview session (Patton, 2002).

Open-ended questions were selected as they minimized the imposition of predetermined responses when gathering data; allowing participants to answer using their own words and ideas (Patton, 2002). Since open-ended questions could lead to irrelevant information being shared by the participants, probe questions were included in the interview guide (Babbie & Mouton, 2004). Probe questions are follow-up questions used to deepen and increase the richness of the given responses (Patton, 2002). Probe questions in this interview clarified what the desired level of responses for participants were (Patton, 2002). Question 4 from the interview guide illustrates the relationship between the question and the probes:

In your experience, what are the options for long term management of feeding in children with gastrostomies?

Probing questions

- a. What are your experiences of a gastrostomy being removed?
- b. What are your experiences of children with gastrostomies feeding orally?
- c. What other options are there?

3.5.2 Credibility of the interview guide

Credibility refers to the extent to which the results are convincing and believable (Van der Riet & Durrheim, 2006). To address credibility, the interview guide was created by the researcher and discussed with her research supervisors (Babbie & Mouton, 2004). The guide was then presented to a group of masters students and staff (Communication Sciences Disorders) as part of a peer review. Feedback regarding the content, structure and appropriateness of the questions and probes were taken into consideration when refining and adapting the interview guide. The interview guide was also piloted on a group of speech therapists who attended a Dysphagia Special Interest Group at the University of Cape Town.

Topic areas selected for the interview guide were related to the aims and purpose of the study as well as the technical literature reviewed on gastrostomies in the paediatric population (Patton, 2002). The topic areas included the rationale for recommending a gastrostomy, other considerations or factors that influence health care practitioners when deciding to recommend a gastrostomy or not, health care practitioners' experiences regarding gastrostomy, options for long term management of feeding in children with gastrostomies, the team involved in the management of gastrostomies, and health care practitioners' experiences of caregivers' responses to gastrostomy placement.

3.5.3 Data collection apparatus

A Dictaphone (Speed Link PDR-3 Digital voice recorder) was used to facilitate a verbatim recording of the semi- structured interviews, and to verify that the written

transcripts were accurate during data analysis. It allowed the researcher to keep a full record of the interviews without being distracted by detailed note taking (Kelly, 2006).

3.6 Procedure

Following approval by the Research Ethics Committee (Appendix A), the researcher requested permission from the superintendents of the identified institutions to conduct the study at the proposed sites and requested permission to attend the health care practitioners' general meetings. At these meetings, the study was described and those willing to participate were provided with the necessary information, and consent forms were issued.

3.6.1 Pilot study

A pilot study was conducted with 5 speech therapists who work in a public tertiary institution, with some experience in gastrostomy management of adult patients. The pilot study participants did not meet the inclusion criteria for this study therefore the pilot study data was not used in the study. The purpose of the pilot study was not to collect data but rather to offer the researcher the opportunity to refine the interview process, assess the appropriateness of the of topics covered in the interview guide and whether they facilitate the collection of rich data. The Pilot study allowed the researcher to refine the interview process by working through logistical issues regarding the recorder and the audio tape recordings such as positioning the equipment closer to the speaker, the saving of audio files for transcription purposes and the researcher had a chance to assess the sound quality of the recordings. Furthermore the length of the interviews was established and feedback from

the pilot participants on the proposed methodology was considered. The researcher was able to practice conducting semi structured interviews and familiarise herself with the recording and note taking. Conducting a pilot study increased the trustworthiness of the current study (Babbie & Mouton, 2004).

3.6.2 Data collection process

Semi-structured interviews were conducted in various departments in the two tertiary institutions.

- The interviewer (researcher) began the interview by welcoming the participant and thanking him/her for their time and availability.
- The interviewer obtained consent for the use of a dictaphone, and provided a summary of the topic of the interview (Kelly, 2006).
- The interview took place during which the researcher asked questions and allowed the participant to answer.
- The digital recordings from the interviews were transcribed immediately after each interview, labelled with the participant number to ensure confidentiality.

3.7 Data analysis

Data analysis involved repeatedly reading through the material gathered and engaging in activities of breaking down (thematising and categorizing) and rebuilding (elaborating and interpreting) the data in new ways (Terre Blanche, Durrheim & Kelly, 2006b). The purpose of interpretive analysis is to provide a 'thick description', which

suggests a thorough description of the characteristics, processes and contexts that constitute the phenomenon being studied (Neuman, 2006). Interpretive analysis further entails examining the data using the language familiar to the phenomenon as well as providing an account of the researcher's role in constructing this description (Terre Blanche et al., 2006b). The current study adopted the 5 steps in interpretive data analysis set out by Terre Blanche et al. (2006b) which are identical to thematic content analysis described by Babbie and Mouton (2004). The researcher engaged with the process of familiarisation of the data: immersion, generating themes with categories, coding the data under meaningful headings and emerging themes, elaborating on the coded data and finally interpreting the phenomena and re-checking for a thorough analysis (Babbie & Mouton, 2004; Terre Blanche et al., 2006b).

Bracketing occurred before the commencement of data analysis. Bracketing required that the researcher set aside (brackets) her preconceived notions and prejudices as these could influence her outlook and interpretation of the data. Bracketing means temporarily 'forgetting' what the researcher knows or feels about the phenomenon and focusing solely on how the phenomenon presents itself (Terre Blanche et al., 2006b). The 5 steps to data analysis used are described in detail as follows.

Step 1: Familiarisation and immersion

The researcher transcribed the data collected after each interview. In a qualitative study, the collection and analysis of data happen simultaneously (Terre Blanche et al., 2006b). There is no clear point where data collection stops and data analysis begins

(Creswell, 2014). Therefore, when data analysis began, the researcher already had a preliminary understanding of the meaning of the data collected. Member checking took place as the transcribed recordings were returned to the participants to confirm the accuracy of the transcriptions (Babbie & Mouton, 2004). This phase of data analysis furthermore involved the researcher becoming immersed in the material gathered by working with the transcribed recordings, field notes and interview transcripts (Terre Blanche et al., 2006b). The transcripts were read repeatedly, notes were made, and diagrams drawn in order to enhance familiarisation of the researcher with the data collected (Babbie & Mouton, 2004). The process of immersion enabled the researcher to identify problems that could be affecting credibility of the results and to then adjust them accordingly (Babbie & Mouton, 2004; Terre Blanche et al., 2006b). By the end of this phase, the researcher had an idea of where certain texts, key words and emerging themes were found within the data.

In addition, peer debriefing enhanced the accuracy of the information gathered. The researcher shared transcriptions and analyses with fellow post graduate students at the research feedback and learning sessions (Babbie & Mouton, 2004; Creswell, 2014)

Step 2: Inducing themes

The induction of themes took a bottom-up approach in that the researcher looked at the material and identified the themes or organising principles that formed the foundation of the material collected (Terre Blanche et al., 2006b). While there are no set rules regarding what sort of themes or categories are best, nor is there one preferred way of organising the collection of raw data, Terre Blanche et al. (2006b) recommends the

following pointers which the researcher used as a guide to create themes: Firstly, the researcher used the language of the participants rather than abstract theoretical language when labelling categories. Secondly the researcher attempted to move beyond merely just summarising the content, but managed the information in terms of processes, functions and contradictions that arose from the data. For example the, researcher initially organised the material in chronological themes such as practices before and after gastrostomy placement, and then grouped them into advantages and disadvantages of the gastrostomy and influences on health versus quality of life and team involvement.

Step 3: Coding

During the development of the themes, coding of data co-occurred (Terre Blanche et al., 2006b). Coding refers to the breaking up of data in analytically relevant ways, by marking different sections of the data as being instances of, or relevant to one or more of the themes under construction (Neuman, 2006; Terre Blanche et al., 2006b). Coding is two simultaneous activities: mechanical data reduction and analytic categorization of data. The researcher also imposed order on the data (Neuman, 2006).

Neuman (2006), describes coding as it occurs in three phases, open coding, axial coding and selective coding. During open coding the researcher locates themes and assigns initial codes in a first attempt to condense the mass of data into categories (Neuman, 2006). Open coding brings to the fore themes from the data. At this stage, the themes were at a low level of abstraction and came from the researcher's initial research question, concepts in the literature, terms used by the participants or new thoughts stimulated by the immersion

in the data (Neuman, 2006). While engaging in open coding, the researcher focused on the actual data and assigned code labels for the themes. There were no concerns about making connections among themes or elaborating the concepts that the themes represented. By contrast, in axial coding, the researcher began with an organized set of preliminary concepts or initial codes.

Axial coding is the second phase of coding (Neuman 2006). During this phase, the focus lies on the initial coded themes rather than on the data. While additional codes may emerge from this phase, the primary task is to review and examine the initial codes. There is thus a move towards the organizing of themes and identifying the axis of key concepts in analysis (Neuman, 2006). Axial coding involved the linking and contrasting of codes; it also reinforced the connections between evidence and concepts. The connection between a theme and data is strengthened by multiple instances in empirical evidence (Neuman, 2006).

Lastly, selective coding involved the re looking at previous codes and data. The aim was to identify and select cases i.e. quotes or specific examples from the transcripts that illustrated themes and made contrasts after majority or all data was collected. The researcher then selected quotes that supported the conceptual coding categories that were developed during the previous two phases (Neuman, 2006).

Coding was facilitated by the use of different colour marker pens that highlighted pieces of text, or by cutting and pasting the material into the relevant themes or categories (Terre Blanche et al., 2006b).

Step 4: Elaboration

Elaboration involved exploring the themes more closely in order to ‘capture the finer nuances’ of meaning not captured by the original coding system (Terre Blanche et al., 2006b, p326). This provided the researcher with an opportunity to revise the coding system and to return to step 3 if needed. Coding and elaborating continued until no new significant insights emerged (Terre Blanche et al., 2006).

Step 5: Interpretation and checking

The final step in interpretative data analysis involved the formation of the written account of the phenomenon investigated, using the thematic categories from the analysis as sub headings (Terre Blanche et al., 2006b). The researcher closely reviewed the transcriptions and interpretations thereof and evaluated it for instances of over interpretation. She was given the chance to reflect on her role in the collection of the data and in the creation of the interpretation during discussions with the research supervisors (Terre Blanche et al., 2006b). Conclusions drawn were verified by the participants, by presenting them with what they had said thereby adding to the credibility of the results (Babbie & Mouton, 2004).

3.8 Trustworthiness and Rigor

Trustworthiness

In qualitative research, trustworthiness is the term used to describe the assessment of the quality of a research study (Ulin, Robinson & Tolley, 2005). A study is said to be of good quality if the findings can be trusted. Trustworthiness is thus the measures put in place

to facilitate the degree to which results can be trusted (Babbie & Mouton, 2004). Trustworthiness is present when the findings of a study are found to be credible, dependable, transferable and confirmable (Babbie & Mouton, 2004). The assessment of the quality of the research findings differ for quantitative and qualitative findings (Ulin et al, 2005). Trustworthiness is the qualitative research equivalent of validity and reliability.

Credibility

Credibility refers to the extent to which the results are convincing and believable (Van der Riet & Durrheim, 2006). Credibility was achieved through member checks, referential adequacy, peer debriefing and theoretical triangulation (Babbie & Mouton, 2004; Creswell, 2014). Member checking was used to determine the accuracy of the qualitative findings through taking specific themes or descriptions back to participants to confirm data and the interpretations thereof (Babbie & Mouton, 2004). Referential adequacy refers to the use of materials used to document findings; like the dictaphone that was used (Babbie & Mouton, 2004). The recorded interviews facilitated verbatim transcripts to improve the accuracy and detail of recall. Peer debriefing enhanced the accuracy of the information gathered. This process involved locating an individual (i.e. peer or colleague), who was outside the context of the study, who had a general understanding of the nature of the study and with whom the researcher reviewed perceptions, insights and analyses (Babbie & Mouton, 2004; Creswell, 2003). Theoretical triangulation, which is the reviewing of relevant literature furthermore enhanced the credibility of interpretations, was used in the current study (Creswell, 2007).

Dependability

Dependability is defined as the ability of the reader to follow the research process (Babbie & Mouton, 2004; Van der Riet & Durrheim, 2006). Dependability was established through the use of an audit trail, in which the step by step description of the data collection and data analysis process was provided. The audit trail should allow the reader to evaluate both the methodological and analytical decisions made by the researcher. The audit trail used to aid dependability included the researcher's notes, raw data, audio recordings, summaries and emerging themes (Babbie & Mouton, 2004).

Transferability

Transferability refers to the extent to which the findings can be applied in similar contexts (Babbie & Mouton, 2004). As qualitative research does not focus on generalizing results to the broader population, transferability of results becomes important. The researcher collected detailed descriptions of data in context and reported the data with ample detail and precision, thus allowing judgments regarding transferability to be made by the reader (Babbie & Mouton, 2004). Transferability was further achieved by using purposive sampling, as was done in the current study (Babbie & Mouton, 2004).

Confirmability

Confirmability is the degree to which the findings are the product of the focus of the inquiry and not the biases of the researcher (Babbie & Mouton, 2004). Clarifying researcher bias from the onset of the study is essential so that the reader understands the researcher's position and any biases or assumptions that might impact the research

(Creswell, 2007). Furthermore, the audit trail was used to enhance the confirmability of the current study (Babbie & Mouton, 2004). An adequate trail is available, enabling the reader to determine if the conclusions, interpretations and recommendations can be traced to their sources and if they are supported by the inquiry (Babbie & Mouton).

3.9 Ethical Considerations

Ethics approval was obtained from the University of Cape Town Faculty Of Health Sciences Human Research Ethics Committee prior to commencement of any part of the investigation (Appendix A). The current study adhered to ethical principles as outlined in the Declaration of Helsinki (World Medical Assembly, 2013) regarding research on human subjects. The research was performed with the full consideration of the rights of the participating health care practitioners. With this in mind the following ethical principles were observed:

Autonomy

Participation was at all times voluntary and participants could withdraw during any stage of the study. Autonomy was upheld by ensuring that all participants and institution superintendents were fully informed of the study procedures, commitments, benefits, and also of the option to refuse participation or to withdraw from this study (Dench, Iphofen & Huws, 2004).

Anonymity and confidentiality

The identifying information of all participants was protected by using representative codes instead of names of individuals and institutions in any written documents and reports that has originated from this study (Neuman, 2013). The participants were informed about the use of the dictaphone during the interview sessions.

Non-Maleficence

Participation in the current study did not cause the participants discomfort or harm them in anyway.

Beneficence

This study did not and will not provide direct benefits to the health care practitioners, but they may gain insights into how other health care practitioners engage with children who have gastrostomies. These insights may influence their practice regarding gastrostomy and patient outcomes. Service delivery to individuals with paediatric dysphagia and gastrostomy may be improved as a result.

Justice

All eligible participants were included thus meeting the requirements for the fair and equal inclusion of all participants. The ethical principle of distributive justice will upheld as the results from the study will be published and all the participants will have access to data and will be able to use the information.

4. Results

In describing the practices, perceptions and experiences of the health care practitioners working with gastrostomies in a paediatric population, presenting the data collected as a series of interweaving processes and experiences came to the fore.

The four processes and experiences are represented by the themes discussed in this chapter. The themes are: Experience of better patient health evolving post gastrostomy despite complications; Health care practitioners' perceived change to family's quality of life; The gastrostomy process: just as you think things are going right then something goes wrong; and Experiencing multidisciplinary team work; and its influences on the management of patients with gastrostomies.

Collectively these four processes portray the practices perceptions, and experiences of the health care practitioners working with children with gastrostomies as they transition from one phase - before gastrostomy placement into the next phase - after gastrostomy placement.

4.1 Theme one: Experience of better patient health evolving post gastrostomy despite complications

It is common practice for the health care practitioners who are working with gastrostomies to be involved in the management of the patient from the onset of the gastrostomy process; the decision-making process as well as the preoperative and postoperative care. During all of these periods, the health status and well-being of the child remains the primary concern of the team involved. This theme focuses on the evolving health of the child as experienced by the health care practitioners, before and after gastrostomy placement. The subthemes reflect the health care

practitioners’ perceived advantages, disadvantages, and the health-related implications for children with gastrostomies.

Table 2: Experience of better patient health evolving post gastrostomy despite complications

THEME 1	SUBTHEME	QUOTES
Experience of better patient health evolving post gastrostomy despite complications	1.1 Frequent hospitalization with failure to thrive.	“They [children] are underweight They are in and out of hospital with chest infections.” SS 1
	1.2 A healthier child (post gastrostomy placement)	“Your patients come back and they’ve gained weight, they look better. It [gastrostomy] makes a big difference.” PN 3
	1.3 Gastrostomy tube complications	“We sometimes have issues with stoma sites. Infection, mostly leakage or granulomas on the skin ... We do see [that] children have problems with reflux and then their respiratory status becomes compromised.” ST 2

1.1 Frequent hospitalization with failure to thrive

The health care practitioners spoke about their experiences regarding the health of their patients before gastrostomy placement.

“Their [the child] intake is poor; they are coughing, aspirating, um and that kinda thing. They fail to thrive.” D 1.

“They [children] are underweight ... They are in and out of hospital with chest infections.” SS 1

Both the stoma sister and dietician reported on the poor health status of their patients before gastrostomy placement. The dietician noted that a compromised respiratory status, poor intake of calories and failure to thrive contributed to the ill health of the children. The stoma sister reported that the children she saw prior to surgery were under weight and had recurrent chest infections.

1.2 A healthier child

The health care practitioners shared similar experiences regarding an improvement in the child’s health as a result of the gastrostomy. Improvements in weight gain, improved nutritional and respiratory status were commonly mentioned. The gastrostomy made the monitoring of the child’s caloric intake easier. Advantages of the gastrostomy versus the nasogastric tube were also mentioned.

“You can see the difference it makes. They have gained some weight and look healthier than before.” PN 1

“We do see some weight gain, but sometimes too much. That must be monitored” ST 3

“Like I said, [for] patients that are failing to thrive, it [gastrostomy] really does help. Especially when dieticians are trying to get in the right number of calories so that the child can grow, because if we don’t have the gastrostomy we continue to have the problem of weight loss, failure to thrive and readmissions.” D 1

“They [the child] don’t become dehydrated anymore because you are actually able to give them enough water which previously was a problem. Also, their nutrition improves.”
GIT 3

“There is improvement in the child’s respiratory status where the child was aspirating, or had recurrent aspiration pneumonia. Over all general health as well [improves].” ST2

“The gastrostomy avoids chest infection if the kid’s got an in-coordinated swallow and stuff, which is an advantage as it prevents hospitalization.” D 1

The health care practitioners reported on the advantages of a gastrostomy. The weight gain associated with the gastrostomy positively influenced the health and nutritional status of the child. While weight gain was a pleasing outcome for the patient, too much weight gain was something that needed to be monitored and avoided. The gastrostomy also made it easier to manage the child’s caloric intake where as this was difficult before placement. The health care practitioners recognized that the gastrostomy contributed to an improvement in the child’s health, specifically reducing recurrent aspiration pneumonia and malnutrition. Having a gastrostomy reportedly led to fewer readmissions as well as a reduction in the number of problems with weight loss, chest infections and failure to thrive. The GIT echoed the dietician’s observation that there was an improvement in the child’s nutritional as well as hydration status, which was a problem before the placement of the gastrostomy.

The gastrostomy rather than the nasogastric tube, was reported to be the preferred choice of enteral feeding.

“I mean the advantages [of the gastrostomy] are obviously avoiding all the disadvantages of managing long term nasogastric feeds. You know, erosions, risk of displacement and having to have them changed is quite laborious ... the advantage is that if you’re working on the swallow then you don’t want the irritation of a nasogastric tube while you are trying to do feeding therapy.” GIT 3

The GIT recognized that the presence of the nasogastric tube could have the potential to interfere with the physiological aspects of the swallow, cause irritation during feeding therapy, cause the erosion of skin or the nasogastric tube could be easily displaced. The gastrostomy eliminates the challenges posed by the long term nasogastric tube use and is therefore the preferred choice of enteral feeding.

1.3 The gastrostomy and its complications

The health care practitioners shared their experiences regarding the various complications observed in their practices. They regarded these complications as disadvantages associated with the gastrostomy.

Reflux

Health care practitioners reported that the presence of the gastrostomy often lead to an unwanted increase of gastroesophageal reflux in children.

“Um reflux gets worse; [the] vomiting afterwards. Gastrostomies sometimes do make reflux worse; so, a lot of them do get it [reflux] and then they want it [gastrostomy] taken out.” ST

“When one sometimes does it [placement of gastrostomy] in the CP [cerebral palsy] kids without doing

an anti-reflux procedure, it can often aggravate the reflux.” GIT 3

“A big controversial issue obviously is with the associated reflux. There is evidence showing that a gastrostomy tube causes more reflux, but there is also evidence showing that if the patient is actually undernourished and you put a gastrostomy tube in, the patient has better weight gain and so on.” SUR 1

Some health care practitioners experienced their patients' reflux worsening when an anti-reflux or Nissen fundoplication procedure was not performed during the placement of the gastrostomy. The increased reflux resulted in dissatisfied families who asked for the removal of the gastrostomy tube. The surgeon acknowledged that while the reflux was not a desirable outcome, the benefits associated with the gastrostomy far outweighed this disadvantage as a child that was malnourished then gains weight after gastrostomy placement.

1.3.1 Stoma site related complications

Health care practitioners shared experiences with gastrostomy related complications, particularly those related to the stoma site.

“Ah yes infections. Infections, granulations around the site, leaking and occasional

bleeding; which you obviously don't have if you don't have it [gastrostomy].” PN 1

“But mostly you can handle it [the complications] effectively.” GIT 2

“... a lot of caregivers want it [gastrostomy] to be taken out afterwards if it leaks

because they are not prepared to deal with the gross parts of it.” ST 2

Infections, granulomas and erosions of the skin were the most common gastrostomy placement complications seen in their patients. The GIT reported that in most cases, the complications can be medically controlled. Yet, as the speech therapist stated, caregivers were not always willing to physically manage the infected sites and would rather opt to have the gastrostomy removed.

4.2 Theme two: Health care practitioners' perceived change to a family's quality of life

This theme focuses on the perceptions that the health care practitioners have regarding the quality of life experienced by the families of a child with a gastrostomy. They shared views on the influences of feeding difficulties on families, before and after gastrostomies are placed. The health care practitioners described the families' quality of life as having an ebb and flow nature to it, the *ups* and *downs* of life with a gastrostomy. Subthemes describe both the perceived positive and negative changes in the quality of life brought about by the presence of a gastrostomy for families living with it.

Table 3: Health care practitioners’ perceived change to a family’s quality of life

THEME 2	SUBTHEME	QUOTES
Health care practitioners’ perceived change to a family’s quality of life	2.1 Feeding changes from being a time-consuming struggle to a quick, easy, less stressful part of the daily routine.	<p>“Caregivers take a long time to feed their child; most caregivers are brave and try their best. They struggle through it all ... Caregivers become more comfortable because it’s easier with a gastrostomy; it’s quick and easy to feed.”</p> <p>ST 2</p>
	2.2 Caregivers have limited support caring for their child and gastrostomy	<p>“Their lives are thrown upside down because no one will help you; no one will look after a child with a tube.” SS 1</p>
	2.3 There are cosmetic implications of living with a gastrostomy.	<p>“The long gastrostomy tube is cosmetically not attractive, but once they’ve got the mickey in, they generally accept it very well.” GIT 2</p>

2.1 Feeding changes from being a time-consuming struggle to a quick, easy, less stressful part of the daily routine

The health care practitioners shared their perceptions related to feeding as part of the daily routine; before and after gastrostomy placement. These were based on conversations and observations with caregivers of children requiring gastrostomies.

“Caregivers take a long time to feed their child. Most caregivers are brave and try their best; they struggle through it all.” ST 2

Prior to gastrostomy placement, the speech therapist perceived feeding to be a daily struggle for the caregiver of the child with feeding difficulties. Feeding was recognized as a time-consuming task requiring effort from the caregivers. Even though caregivers had difficulty feeding their children, the speech therapist acknowledged their perseverance as they struggled to complete the feed.

The health care practitioners made reference to feeding with a gastrostomy as being a less anxious and stressful task.

“There is less pressure, less anxiety around feeding times.” PN 2

“It relieves a lot of stress and tension involved with the feeding process.” ST 5

The participants in this study acknowledged that feeding with a gastrostomy has become a less stressful activity of daily living, echoing their shared perceptions that feeding posed a series of difficulties for the caregivers prior to gastrostomy placement.

Many health care practitioners perceived the gastrostomy to reduce the time taken to feed children with feeding difficulties.

“It [gastrostomy] speeds up the feeding time.” ST 5

“Caregivers find it an easier way of giving the feed, especially after spending up to an hour trying to feed the child.” GIT 2

“They [caregivers] have more time to do other things.” P 1

“They [caregivers] have more time available for themselves and for caring for their other children.” PN 2

Feeding, referred to earlier as the *time-consuming struggle* from before, was considered to have changed to a *quick and easy process* since the gastrostomy had been placed. As a result, the gastrostomy was perceived to allow the caregivers more time for themselves and their other children, therefore having a positive influence the quality of life of the families living with gastrostomies.

Not only is it the perception of the health care practitioners that feeding in itself becomes *easier to manage* with the gastrostomy, the relationship between the mother and child was viewed as having improved as well.

“I think the gastrostomy actually improves the relationship with the mother and child, there’s less anxiety.” PN 2

“They don’t have to be anxious about not getting enough [food] in. Like if they know they must get 150ml in. It’s a great peace of mind knowing they don’t have to struggle to get feeds in.” GIT 3

“For those in hostels and so on, I think the gastrostomy takes the pressure off the staff to some extent.” PN 2

The health care practitioners reported that the gastrostomy allowed caregivers to ensure their children meet their caloric requirements, resulting in reduced anxiety for the caregivers. As this activity of daily living became less of a struggle, the relationship between mother and child was believed to have improved.

While feeding as an activity of daily life was made easier and stress free for child and caregiver, health care practitioners reported that life with a gastrostomy had implications on the social aspects of feeding.

“Socially, if the child can’t participate during mealtimes, social interaction could be a problem. It’s an issue for some caregivers.” ST 2

“I think a lot of them are very unhappy with the fact that their child can’t eat like everyone else.” SS 2

The health care practitioners’ showed awareness that the presence of the gastrostomy excluded the child from participating in meal times with the rest of his/her family. This was seen as a limitation of the gastrostomy and was perceived to make caregivers unhappy because their child was not a participant in mealtimes and could not consume food in a natural, socially accepted

manner. The participants in this study felt that this negatively affected the quality of life as experienced by the child and his/her family.

2.2 Caregivers have limited support caring for their child and gastrostomy

It was a shared perception amongst the health care practitioners in this study that the presence of a gastrostomy resulted in the caregivers being solely responsible for the care of their child

“I think the big thing is their lives are thrown upside down because no one will

help you, no one will look after a child with a tube. As simple as it is, your life

becomes impossible because every 3 hours you have to be with your child.” SS 1

“A huge problem is that a lot of people are not willing to look after a child with a

gastrostomy, which means those mothers will have to stay out of work. They

lose their jobs.” SS 2

“They can’t leave their child with another person to be fed because that person

needs to be trained.” ST 1

The health care practitioners reported that the caregivers had difficulty finding day time carers for their children because of the gastrostomy. Others were not willing to look after a child with a gastrostomy, or did not have sufficient training regarding the management of the feeding tube. The health care practitioners were aware that the onus of care fell directly on the caregivers and jobs were often lost as they had to stay at home to look after their children. As simple as

gastrostomy feeding is, the stoma sister recognized that challenges do arise as caregivers have to administer tube feeds every few hours.

The gastrostomy was perceived to be an added aspect of caring for the child, another “thing” that had to be managed.

“They [the gastrostomy] are something to manage over and above the care of the child.”

P 1

Children who require gastrostomies often have other physical or health difficulties i.e. a child with cerebral palsy. Caring for a child with a physical and/or health impairment involves following a rigid routine; the presence of a gastrostomy adds to the already complex care regime.

A lack of gastrostomy related knowledge or limited help available at primary health care levels was observed as contributing to caregivers frequently returning to the hospital for help. These visits meant that caregivers had to take time off work.

“In general, people are poorly informed about the tubes. Even your general gp, day hospitals or schools. They [general practitioners, day hospital and school staff] don’t know what to do. Something that’s simple they don’t know how to answer then they [caregivers] have to come to us [with tube related issues].” SS 1

“I think about the tubes that need changing and so on. It often means that they [caregivers] have to come to hospital more often.” ST 5

“A tube comes out and then the caregivers have to rush the child to hospital, then

they cannot be at work again.” ST 2

The tube falling out was a common example provided by most health care practitioners as something that caused caregivers to return to hospitals frequently. Frequent visits to the hospital contributed to caregivers being absent from work, which had implications not only on the quality of life of the families living with gastrostomies but also on the caregivers’ ability to fulfill work related commitments.

Some health care practitioners spoke about an associated stigma attached to gastrostomies.

“There is a stigma attached to it [the gastrostomy]. A lot of moms you know hide it. They try not to tube feed in public places.” SS 2

“Some mothers feel that once the children do have it [the gastrostomy] they go out into the local community and people ask why they child has the gastrostomy and they don’t like the questions that they get. So, they come back. They wanna know when this tube is gonna come out, and it’s not that the mother doesn’t feel comfortable using it, it’s just a matter of what other people think.” D 1

Mothers avoid feeding their children in public because of the stigma related to the gastrostomy. Health care practitioners understood that some mothers did not want community members to see the gastrostomy and that they were sensitive to the opinions of others regarding their child’s gastrostomy. As a result, the mother is forced to stay at home with her child, particularly during feeds.

2.3 The cosmetic implications of living with a gastrostomy

Health care practitioners were of the opinion that the gastrostomy had both cosmetic advantages and disadvantages which impacted on the quality of life of the child.

“The long gastrostomy tube is cosmetically not attractive, but once they’ve got the Mickey in, they generally accept it very well.” GIT 2

“The Mickey is a button that’s flush with skin. So, there will not be anything bulging out from underneath the t-shirt. So, it won’t be obvious to other people that they have a gastrostomy tube.” GIT 1

“I think the main thing is body image. Your friends making fun of you because you have a tube. You know it influences the use of the gastrostomy.” GIT 1

The placement of the Mic-key was perceived to be less obvious and could be hidden easily. The GIT suggested that the gastrostomy could negatively influence the body image in older children.

4.3 Theme three: The gastrostomy process: just as you think things are going right then something goes wrong

This theme reflects the experiences and practices of the health care practitioners when engaging with caregivers of children with gastrostomies. The health care practitioners understand and appreciate that the process of the gastrostomy begins with the caregivers. They perceive this

experience as being one of decision-making, education and acceptance. The health care practitioners have described their practices and common experiences that they have put in place when guiding caregivers along the gastrostomy process.

The subthemes describe each aspect of the perceived process that the caregivers and families undertake as well as the practices and experiences of the health care team at various stages of the caregivers’ gastrostomy process. The four subthemes are: *The process begins with the caregivers, the caregivers’ concerns and fears observed by the health care practitioners, health care practitioners’ practices with education and support, perceptions and experiences of the health care practitioners relating to caregivers’ satisfaction with the gastrostomy.*

Table 4: The gastrostomy process: just as you think things are going right then something goes wrong

THEME 3	SUBTHEME	QUOTES
The gastrostomy process: just as you think things are going right then something goes wrong	3.1 The process begins with the caregivers	"It starts with the caregivers." ST 5

3.2 Caregivers' concerns and fears as observed by the health care practitioners

"They ask me will my child ever feed orally again." ST 2

"They fear that they are being judged as a failure, fear that the child has to undergo a surgical procedure, fear that they not going to be able to handle the actual business of it [gastrostomy]." PN 1

3.3 Health care practitioners' practices with caregiver education and support

"During the process, we want moms to be in the wards to help clean the gastrostomy from the beginning and also want her to be changing tubes on her own so that she can be in full control of whatever's happening ... You train them." ST 1

"Um with the gastrostomy things do go wrong ... Everywhere you go people can't help you. We

have an open-door policy to try to make it as easy as possible.”

SS 1

3.4 Health care

practitioners’ experiences of caregivers’ satisfaction with the gastrostomy

“After the gastrostomy procedure, our caregivers come back and tell us “why didn’t we do this long ago” it has made life so much easier for them. So yes, resistance at first, and across the board, sort of real happiness afterwards.” PN 3

3.1 The process starts with the caregivers

The health care practitioners reported that gastrostomy placement began with the caregivers; helping caregivers understand why it was needed and agreeing to have the gastrostomy placed.

“You know I think you really need to get them [caregivers] on board from the start; let them understand what the problem is, so while they describe what the symptoms are, you almost have to explain the implications of those symptoms” ST 5

“The family has to be on board with it [gastrostomy] so they have to feel happy that they are prepared to try it because otherwise you are just not gonna get anywhere with it.” PN 1

The team members stressed the importance of having the caregivers accept and agree to the procedure, as this was the first step in the process of gastrostomy placement. Leading up to the decision-making process, the speech therapist felt it important that caregivers understood the effects of the dysphagia and what the implications were for their child’s health and why enteral feeding was essential.

The common practice followed by the health care practitioners was to offer caregivers support by having them meet and observe other caregivers of children already living with gastrostomies.

“We arrange for caregivers to see it [gastrostomy], so it’s not always as scary as it is in their minds.” PN 4

“You have to put them in contact with patients who are comfortable, who have been through the problems and are now coping well.” PN 2

“The ones [children referred for gastrostomy placement] we happen to hear about beforehand, that’s really nice because we’ve got really nice educational things we can explain to them; they get to ask questions and are actually in control right from the beginning which makes a huge difference ... We very much try to encourage moms and

dads. We try to bring them here to practice on our dolls and most of them seem to link up with other moms which is quite a useful thing.” SS 1

“I usually introduce them to other moms in the hospital whose children have a gastrostomy and let them talk to them, also I take them to the clinic to see what we do there, she can then find out the positives and the negatives.” ST 1

Health care practitioners found that exposure to the appearance and mechanics of the gastrostomy helped create a realistic image of what it entailed. This introduction to the feeding tube contributed to the alleviation of gastrostomy related preconceptions the caregivers might have. While caregivers’ counselling and information sharing before gastrostomy placement and during the decision-making process was recognized as standard practice, it was not always achieved.

“And mostly we don’t hear about it [gastrostomy placement] as early as we would like. Sometimes we hear about them [children undergoing gastrostomy placement] on the day of surgery which is a problem because the mom is already upside down and upset and then you kind of end up rushing and getting her a pamphlet to read because you don’t want to overwhelm her.” SS 1

“Look, from my own experience I am not convinced that they understand the full process [placement and life with the gastrostomy]; this is when I sit with them after the procedure has been done.” ST 5

The stoma sister had experienced cases where caregivers had not been referred to their department for pre-gastrostomy counselling. Meeting the caregiver on the day of the surgery was reported as being a rushed experience; information was offered in the form of a pamphlet as to not overwhelm an already distressed caregiver. The speech therapist reported that she had experienced

caregivers not fully understanding what the gastrostomy entailed, suggesting that more information should have been provided during the decision-making process.

3.2 The caregivers' concerns and fears observed by the health care practitioners

The health care practitioners all reported that caregivers shared fears about the gastrostomy. Concerns regarding the permanency of the gastrostomy were often raised during the decision-making process.

“I think it’s the permanent thing. I think they always want to know that if their child improves, there’s an option that it can be reversed. That will always be the first thing they will say to me.” ST 5

“They [caregivers] ask is this child going to have this gastrostomy for the rest of their lives.” PN 4

“They ask me will my child ever feed orally again.” ST 2

Health care practitioners experienced caregiver concerns regarding the permanency of the gastrostomy and if it signified that the children would never be able to feed orally again.

The surgical aspect of gastrostomy placement was another concern that caregivers often shared with the health care practitioners.

“Um they are concerned that it is an operation; that their child might die during the operation. It goes against the grain to open the body and put in a gastrostomy”. PN2

“And then you get other mothers that even though they come in with this continuous or recurrent admission [to hospital] um they still don’t like the idea of a gastrostomy and I think it is just the idea of putting a tube in that, makes them a bit uneasy.” D 2

The paediatric neurologist reported that caregivers expressed concern about a foreign object, like the gastrostomy, being placed in their child’s body as well as the surgery itself and the implications thereof, including death of the child. In some cases, caregivers’ fear of gastrostomy placement contributed to the persistence of swallowing problems and frequent hospitalizations.

The health care practitioners experienced caregiver concerns regarding the child’s weight.

“Um will the child be able to grow and if they do grow will they get fat because then they [the caregivers] won’t be able to pick them [the child] up anymore. They don’t want a fat child.” ST 1

The speech therapist reported that caregivers feared an overweight child, and the implications thereof. Lifting and transferring of a heavier child would be difficult for the caregivers.

Health care practitioners reported that caregivers often expressed a fear of being judged or perceived as a failure because on an inability to orally feed their child.

“They fear that they are being judged as a failure.” PN 1

“I am sure it has all kinds of cultural ramifications making a mother feel she’s failed at being able to feed her child and keep her child alive and I think that’s quite a primal thing for caregivers’, um a primal need.” PN 2

“One tries not to; one mustn’t be judgmental, if you want to get people on board you have to try and get them to trust you, when they mention their fears then try to explain that there are other ways of looking at it and to not hurry them.” PN 1

Health care practitioners reflected on their awareness that mothers were often concerned about being perceived to have failed at feeding their child by their communities. The participants understood that the mother would feel that she had failed because she would not be able to feed her child orally. Health care practitioners, such as the paediatric neurologist, were careful not to appear judgmental when addressing the caregivers’ concerns and fears in order to achieve the trust of the caregivers and stressed that the caregivers should not be hurried during the decision-making process.

The gastrostomy placement process does not continue if caregivers are not in agreement with the concept of enteral feeding.

“... and only then, when they want it [the gastrostomy], can we move onto the part, where it is actually placed, surgically.” PN 1

As soon as the caregivers had agreed to the insertion of the gastrostomy, the surgical procedure took place and the gastrostomy process progressed onto a new phase.

3.3 Health care practitioners’ practices concerning caregiver education and support

Once the gastrostomy has been placed, it was common practice amongst the health care practitioners that mothers stay in the wards with their child. They are shown how to feed with the

gastrostomy. Health care practitioners schedule a series of follow up appointments in which they educate and train caregivers on how to manage and care for the gastrostomy.

“During the process, we want moms to be in the wards to help clean the gastrostomy from the beginning and also want her to be changing tubes on her own so that she can be in full control of whatever’s happening ... You train them.” ST 1

“There are no [support] groups but lots of one on one counselling from doctors and from the nursing staff, just general education, about how to look after the gastrostomy. And we do a regular follow up with our kids” PN 3

The health care practitioners create opportunities for the caregivers to be educated and trained on how to manage the mechanics of the gastrostomy as well as supervise them while they do so. At the time of the participant interviews, the health care practitioners reported that there were no existing support groups offered for caregivers and children with gastrostomies; caregivers were counselled during their scheduled appointments.

Health care practitioners recognized that there would be limited learning opportunities and support for the management of the gastrostomy once the children have been discharged from the hospital post-surgery. Therefore, they facilitated the provision of easy access for caregivers when needed.

“Everywhere you [caregivers] go people can’t help you. We have an open door policy to try to make it easy as possible.” SS 1

“Um I think with me they have a walk-in policy, so if anything goes wrong I can help them with that.” ST 1

“I think our stoma sister does it [supports and counsels] but I feel we could do better. I feel that the caregivers must not be left unsupported especially in the in early stages, um they must have access to a unit where there is suitably qualified staff member who is available.” PN2

Some health care practitioners facilitated access to gastrostomy related assistance by allowing caregivers to visit them without appointments because the necessary help was not readily available at primary health care facilities. While follow up appointments and ongoing counseling was provided by the health care practitioners, they reported that caregivers required additional support such as reinforcement of information shared, counselling and assistance with the management of gastrostomy related complications.

The basic education (given to caregivers) was insufficient for preparing caregivers to deal with the gastrostomy related complications.

“Um with the gastrostomy things do go wrong, just as you think it’s going right then something goes wrong.” SS 1

“The mothers then have to be taught to put the tube back in, so that when they come back to hospital the hole is not completely closed because they close quite quickly. We actually had a patient, that was one of our long-term patients that went home with a gastrostomy and the tube came out and she didn’t know what to do. Then they brought the child in and by the time the child came back to our ward um the hole had been closed. So, they had to redo the gastrostomy which they were reluctant to do and the doctors were upset that the mother hadn’t been taught how to re -enter the tube.” D 1

In the case mentioned above, the child had to have the surgical procedure repeated due to inadequate training provided by the hospital staff or because of poor understanding by the caregivers on tube reinsertion (despite being trained).

“Then there’s also poor compliance with caregivers; maybe caregivers are not being compliant with our instructions. Um sometimes it’s a bit too much for them, maybe the mathematics, volume of the amounts, and the times when feeds need to be given is too much for them [caregivers] to understand.” D 2

The other thing that I feel is one child ripped out his gastrostomy, and the caregiver was beside herself. She hadn’t been properly trained on the ramification of pulling out the gastrostomy and how to put it back in. I feel that the training of the caregiver is essential.” PN 2

“A lot of moms find it difficult to carry out the instructions as specified. Um I had children coming here with their tubes blocked, tubes that have not been used since I don’t know when.” ST 3

There was a common perception amongst the health care practitioners that poor compliance and follow through of instructions by caregivers contributed to the presence of gastrostomy related complications. The dietician reported that in her experience, the issues with compliancy could have been linked to a lack of understanding on the caregiver’s behalf, or that too much information had been given to the caregivers. Some health care practitioners referred to caregivers not having received suitable or sufficient training and how essential this was in preventing gastrostomy related complications.

3.4 Health care practitioner experiences of caregivers’ satisfaction with the gastrostomy

The health care practitioners reflected on their experiences of the varied caregivers' satisfaction with the gastrostomy.

“The first few weeks they find quite difficult. It’s a new thing they have to get used to. It’s a shock for the caregivers to see this hole in the baby’s stomach with this tube coming out of it.” GIT 2

The health care practitioners report that at first, caregivers struggle with the idea of the gastrostomy, they find it difficult to manage; but then comes acceptance.

“A couple of weeks or months later they actually normally have totally integrated it so that it doesn’t seem to be as much of an issue. They accept it remarkably well, a lot of them do.” GIT 3

“But then often two three weeks down the line they are very happy, in most cases.” GIT 2

“All the mothers have come back to me and said we are happier now, it had made a big difference.” P 1

A few weeks after gastrostomy placement, the health care practitioners perceived caregivers to have accepted the gastrostomy. It had become part of their daily routine and had contributed to an improvement in the quality of life of these families. This acceptance was observed to contribute to caregivers returning to the hospital feeling satisfied with the gastrostomy, and that it had made a positive difference in their lives and in the management of feeding.

They do however mention the importance of creating awareness of the possible surgical complications. When caregivers knew what to expect, they were able to manage the complications much easier as opposed to not knowing that there would be gastrostomy related complications.

“And the caregivers in retrospect are glad that they got the gastrostomy but I think you have to warn the patients very carefully that there can be surgical problems.” PN 2

“So, ja, one has to make sure that they’re aware of the complications. I think they certainly get used to it.” GIT 3

After the gastrostomy procedure, our caregivers come back and tell us - “why didn’t we do this long ago” it has made life so much easier for them. So, ja, resistance at first, and across the board, sort of real happiness afterwards.” PN 3

At first, the health care practitioners experienced some resistance to and difficulties with the gastrostomy from the caregivers, but afterwards, once the surgical complications had passed and were perceived as being manageable, they believed that the quality of life for the caregivers had improved. The health care practitioners stressed the importance of preparing caregivers for the complications and that the awareness and insight into the expected gastrostomy difficulties influenced the caregivers’ ability to cope with the gastrostomy.

4.4 Theme four: Experiencing multidisciplinary team work; and its influences on the management of patients with gastrostomies.

Management of paediatric gastrostomies requires a team of health care practitioners. This theme reflects the experiences the health care practitioners shared with regards to team work when managing children and gastrostomies. This theme also addresses the experiences relating to the team dynamics and the impact this has on service provision. The participants shared experiences that were specific to their working context. Subthemes describe the health care practitioners’

experiences as being part of the team, as well as the advantages and disadvantages associated with the team.

Table 5: Experiencing multidisciplinary team work; and its influences on the management of patients with gastrostomies

THEME 4	SUBTHEME	QUOTES
Experiencing multidisciplinary team work; and its influences on the management of patients with gastrostomies.	4.1 It is a team effort.	“It’s a multi-disciplinary decision” PN1
	4.2 When the team works together it’s great, but...	“I think the outpatient department like referrals between me, Dr A (GIT), Dr B (PN) and the dieticians is quite good, we know exactly when we can refer. Inpatients ... no, not at all. I can tell you exactly what the problem is- the doctors change, interns change they don’t have a clue what to do ... but they never refer straight to me.” ST 1

4.1 It is a team effort

All of the health care practitioners interviewed for this research study reported that the multidisciplinary team approach was common practice when managing children with gastrostomies.

“It’s a multidisciplinary decision.” PN 1

“It’s a team effort.” D 1

It's the speech therapist, dietician, um surgeon, stoma sister, GIT, and then myself (paediatric neurologist) of course." PN 4

"Right um GIT, surgeons, dieticians, speech therapists, CP [cerebral palsy] clinic, and the stoma sister, occupational therapists and physiotherapists, it depends on the child's diagnosis." ST 2

There was consensus amongst the health care practitioners, in all working contexts (outpatient clinics and inpatients), that the decision regarding suitability of gastrostomy placement in children was a decision made within the team and that management of such cases was a combined team effort. All participants acknowledged the same core group of health care practitioners as forming part of their team.

Some health care practitioners perceived caregivers to be an important part of the team.

"I'd say they[caregivers] are pretty essential members of the team. I mean they should be involved in the pre-planning and getting to know that, and they should really speak to all of those members of the team before." GIT 3.

"Well they have to be in the decision-making process ... we discuss it with the caregivers, the final decision is definitely theirs." PN 1

"Caregivers should be involved afterwards [after gastrostomy placement] as well, in terms of what the long-term plans are, and that's probably not done as comprehensively as it should be". GIT 2

Caregivers were acknowledged as forming an important part of the gastrostomy management team. They were involved in the decision-making process, where they should have

been granted the opportunity to discuss the gastrostomy with all members of the team, yet this was not always achieved. The health care practitioners recognized that final decision to have the gastrostomy placed or not was made by the caregivers.

4.2 When the team works together it's great, but...

At both tertiary hospitals, the health practitioners managed their gastrostomy patients either in the wards or at outpatient clinics. Experiences reported by the health care practitioners were specific to the clinical context they saw the child in.

Suitable referrals made between the team members were essential in ensuring that the child was getting the best management for his/her gastrostomy.

“I think in the outpatient department, like referrals between me, Dr A, Dr B and the dieticians is quite good, we know exactly when we can refer.” ST 1

Health care practitioners reported that the team worked well when referrals were made appropriately and when they had a good understanding of each other's roles within the team.

Most of the health care practitioners interviewed, acknowledged that the speech therapist had an important role regarding oral feeding, before and after gastrostomy placement.

“All the team members in the hospital knows what the speech therapist's role is. Especially in terms of swallowing assessments; they are always referred [for gastrostomy placement] via me.” ST 2

“I refer them first to our speech therapist, who has specialized training in feeding.” PN 1

“Well in my experience they [speech therapists] are pivotal because we’ve always had a speech therapist at hospital 1 who is well versed in the disabled child and the mechanism of swallowing, assessing it, making recommendations like barium swallows. I tend to send my kids back to them after a while, once the kid has stabilized and has settled so we can review for oral feeding so they have to be involved all the time in my view. I don’t know how many people know that but it is important.” P 1

The speech therapist was acknowledged to have specialized knowledge and training with regards to oral feeding. The doctor reported that he/she made referrals to the speech therapist to re-evaluate the safety of the swallow, and the possible return to oral feeds for the child even while the child has a gastrostomy in place.

The speech therapist (ST1) stated that referrals made regarding gastrostomy inpatients were not always made correctly. The speech therapist was not always involved in the management of children who required speech therapy intervention.

“Inpatients, like from the wards side no [they do not work], not at all. I can tell you exactly what the problem is- the doctors change, interns change. They don’t have a clue what to do, physios get referrals for oral stimulation, some phone me to bring a dummy which I am not prepared to do, um they phone the dietician to ask her like can the child have solids um so then she will obviously call me but they never refer straight to me.”

ST 1

“I think it’s difficult for them to understand. Doctors don’t understand that there are things that can be done to work on feeding and chewing. They just accept that if the child can’t chew, it means gastrostomy.” ST 4

“I think the general thing from most medical professors working with inpatients is that if the child has a gastrostomy he’s sorted. He doesn’t need anything else.” ST 1

ST 1 reported that referrals from the inpatient setting (ward) did not always come directly to him/her. In his/her experience, the interns and doctors in the wards did not always know what the procedure was regarding oral feeds once the gastrostomy had been placed. Both speech therapists’ experiences speak to a lack of awareness and knowledge of team members’ roles relating to gastrostomy management, and specifically their role with feeding post gastrostomy placement. Change of staff in the wards was a contributor to inconsistent provision of health care. As there was no standard protocol regarding gastrostomies at the hospitals (at the time of the interviews), new staff that were not aware of the procedures after the gastrostomy placement, i.e. that referrals to the speech therapist had to be made for the assessment of the swallow and related feeding needs. ST 1 and ST 2 shared different experiences regarding the understanding of their roles within their respective multidisciplinary teams; these two speech therapists work at different hospitals and form part of different teams.

The stoma sister and paediatric neurologist experienced that the communication between team members was lacking and that there was a need for improved team engagement.

“To be honest I’ve hardly met them [the speech therapists] on this side, I have no contact with them. The communication between us is not really what it’s meant to be.” SS 1

“Maybe a little bit more communication on a more formal level between speech and neurology so that we can learn from them and they can learn a little bit from us as well.”

PN 3

The health care practitioners admitted that there was a need for consistent contact between team members. The perception was that improved communication would provide an opportunity for staff members to learn from one another and allow practitioners to understand one another's roles better.

When team decision-making, consultations and referrals did not take place, the child may not have been receiving suitable treatment in his/her best interest. For example:

“Where a lot of the time gastrostomies have been put in, I have been called afterwards to assess. Then the child never had any aspiration, it was just poorly fed by the mother. Then the child starts feeding and then the doctor comes to me and says but why are you feeding the child, then I say because the child can feed and then they angry because the child just had a gastrostomy done and didn't need it. I think if we can stop things like that.” ST 1

In the case presented by ST 1, a speech therapy consultation was not requested during the decision-making process before the gastrostomy was placed. This resulted in the child undergoing an unnecessary surgical procedure. Poor decision-making and lack of appropriate referrals as seen above can have adverse implications for the health and well-being of patient; the child in this case did not receive the best care due to team inefficiencies.

A dietician reported cases where the gastrostomy tube had been removed prematurely and patients were discharged from the ward without consulting all the relevant team members.

“Dr's are quick to send the patients home ... I also find that some doctors tend to feel if they [the child] eating orally that's also an indication for removing the gastrostomy, and ja that's one of the problems I come across, because their intake will be poor. They might

take in one, two, three teaspoons but nobody has been there to assess full intake, consistencies, amounts, are they coughing, aspirating that type of thing. So ja we do have a problem when the gastrostomy is removed and that kinda affects their nutritional status also.” D 2

The dietician’s quote reflects two separate issues. There was no post gastrostomy placement referral to other team members which influenced the quality of the service provided; children were prematurely discharged from the hospital or discharged without a suitable follow up plan. The second issue raised by the health care practitioner was that the gastrostomy was removed without consultations with a dietician and speech therapist. Removal of the gastrostomy without the input of these team members had consequences for the child’s health and nutritional status. Children were then reliant on oral feeds to sustain nutritional needs in cases where oral feeding was not the best option.

It was evident that based on the experiences shared by the health care practitioners, that team dynamics and understanding of the team members’ roles within the team was essential to ensuring the child and family received the best, most suitable care related to the gastrostomy. Poor communication and inappropriate or inadequate referrals resulted in less than optimal care and poor service delivery.

5. Discussion

This study used semi-structured interviews to explore the health practitioners' practices, perceptions and experiences when working with children with gastrostomies in a paediatric setting. The four themes that have emerged from this study are the experience of better patient health evolving post gastrostomy despite complications, health care practitioners' perceived change to a family's quality of life, the gastrostomy process: just as you think it's going right then something goes wrong and experiencing multidisciplinary team work; and its influences on the management of patients with gastrostomies.

Experience of better patient health evolving post gastrostomy despite complications

The health care practitioners are aware that many of the medical issues children experienced before gastrostomy placement, had bettered significantly, similar to that reported in the literature (Craig, 2013; Craig et al., 2006; El-Matary, 2008; Hannah & John, 2013; Marchand et al., 2006; Martinez-Costa et al., 2011; Nelson & Mahant, 2014; Sevilla & McElhanon, 2016; Sullivan, 2013; Sullivan et al., 2005; Sullivan et al., 2004; Sumritsopak et al., 2014; Townsend et al., 2008). They saw improvements in the children's general health, weight and nutritional status, and a decrease in recurrent chest infections and fewer hospital admissions.

Health care practitioners are mindful of the complications associated with gastrostomy placement (Morrow et al., 2006) which are similar to that reported in the literature (Craig et al., 2006; Cunningham & Best, 2013; El-Matary, 2008; Fröhlich et al., 2010; Hannah & John, 2013; Martinez-Costa et al., 2011; McSweeney & Smithers, 2016; Naiditch et al., 2010; Nelson & Mahant, 2014; Schweitzer et al., 2014; Sullivan, 2013; Thomas et al., 2016). Although the

advantages are seen to outweigh the potential for negative outcomes and in this way, the study participants reflect international practice whereby despite these associated complications, there is a steady increase in the placement of gastrostomies worldwide (Naiditch et al., 2010). There is agreement that gastrostomies in the paediatric population is a widely accepted, common procedure and has become the preferred method for long term enteral access, especially in cases where children are struggling to safely and sufficiently meet their nutritional requirements orally (Fröhlich et al., 2010; Norman et al., 2011; Richards et al., 2016; Sullivan, 2013; Thomas et al., 2016). The insertion of a gastrostomy demonstrates its value in a variety of patient populations who have multifaceted health needs (McSweeney & Smithers, 2016).

Children show better health post gastrostomy placement (Fröhlich et al., 2010; Norman et al., 2011) and it is therefore likely that the health care practitioners will continue to use gastrostomies as a means to achieving better health outcomes for their patients. The gastrostomy process indicates that while better health outcomes is the goal for health care practitioners, the child's improved health post gastrostomy placement coincides with changes to the quality of life of the families and must be considered and regarded as important, when managing children with gastrostomies.

Health care practitioners' perceived change to a family's quality of life

Studies relating to the quality of life and gastrostomies have shown that desirable and undesirable experiences are not mutually exclusive but can coexist (Hewetson & Singh, 2009; Mahant et al., 2011). The clinical benefits of the gastrostomy are well recognized as leading to improved quality of life (Brotherton & Abbott, 2012; Craig et al., 2006; Fröhlich et al., 2010; Sumritsopak et al., 2014). The perceived benefits a gastrostomy has on the quality of life of

caregivers that has emerged from this study are well documented (Brotherton et al., 2007a; Craig, 2013; Fröhlich et al., 2010; Morrow et al., 2006; Nelson & Mahant, 2014; Sullivan et al., 2004; Townsend et al., 2008). Feeding becomes a less stressful experience for the caregivers and child; it is described as being quick and easy, caregivers are not as anxious as they were before the gastrostomy was placed and they are satisfied knowing their child is consuming the right amount of calories.

The health care practitioners' understanding of the negative impact the gastrostomy has on the lives of caregivers is consistent with existing literature. Studies that reported quality of life from both the health practitioners and caregivers point of views, reported the struggles caregivers experience with finding suitable help and assistance for their children with gastrostomies (Brotherton et al., 2007a; Craig & Scrambler, 2005; Fröhlich et al., 2010; Hewetson & Singh, 2009; Morrow et al., 2006; Nelson & Mahant, 2014). Health care practitioners were aware of the lack of access to help and support for caregivers outside the tertiary hospital context and the adverse effects this has on the quality of life (Hewetson & Singh, 2009; Morrow et al., 2006; Townsend et al., 2008). Medical services related to gastrostomy care are not readily available at all levels of health care in South Africa therefore leaving caregivers with no choice but to attend tertiary hospitals when in need of medical care.

The health practitioners showed an awareness of the stigma associated with the gastrostomy (Brotherton et al., 2007a; Craig, 2013; Craig & Scrambler, 2005; Fröhlich et al., 2010; Hannah & John, 2013; Morrow et al., 2006; Nelson & Mahant, 2014). The healthcare team, in accordance with WHO (2007), should therefore consider and guide caregivers as to how the gastrostomy affects the child and family's activity and participation within the ICF-CY framework throughout the process, i.e. considering the functioning of the child as a member of society and

the environmental factors affecting these experiences and whether these factors are facilitators or barriers.

The findings of this study suggest that health care practitioners working with children with gastrostomies had insights into the experiences and challenges of the caregivers which is different from that reported in the literature (Morrow et al, 2006; Brotherton et al. (2007a). Different perceptions impact on the relationship and quality of communication between health care practitioners and caregivers, (Morrow et al, 2006), which should have boded well for improved relations between health care practitioners and caregivers, but this was not always the case because awareness did not change practice (i.e. “we know we should be doing it but we are not”).

Despite the challenges gastrostomy placement imposes on the quality of life of families throughout the process, the health care practitioners are likely to continue placing gastrostomies because of better health outcomes for the child. With the awareness that the families experience both positive and negative changes in their quality of life, practices in place do not always reflect enough support provided for caregivers to address the challenges gastrostomy placement can create.

The gastrostomy process: just as you think things are going right then something goes wrong

The health care practitioners from this study engaged in a series of gastrostomy related practices, before and after surgery. These practices are in agreement with authors in national and international literature. The health practitioners recognize that the gastrostomy process starts with the caregivers (Brotherton & Abbott, 2012; Fox et al., 2012; Fröhlich et al., 2010; Mahant et al., 2011; Marchand et al., 2006). When gastrostomy placement is medically indicated, the caregivers are introduced to the concept and are encouraged to meet other caregivers of children with

gastrostomies (Hewetson & Singh, 2009; Jackson et al., 2008; Martinez-Costa et al., 2011), but this practice is not always experienced by all caregivers (Craig & Scrambler, 2005; Mahant et al., 2011)

Most of the health care practitioners identified that the standard practice is to refer caregivers to the stoma sisters for preoperative counselling and information sharing (Edwards et al., 2016); the stoma sisters in this study were not always consulted in time. These findings are consistent with the results from Norman et al, (2011), and Hannah & John, (2013).

The health care practitioners are aware of the common concerns and fears raised by caregivers during the decision-making process (Mahant et al., 2011; Sullivan et al., 2004; Thorne et al., 1997; Wilson et al., 2009); yet do not always engage enough with these concerns during the preoperative phase (Hewetson & Singh, 2009; Mahant et al., 2011). Shared decision-making is beneficial as it improves health outcomes and patient and caregiver satisfaction (Aarthun & Akerjordet, 2012; Brotherton et al., 2007a; Brotherton et al., 2007b; Craig, 2013; Hannah & John, 2013; Mahant et al., 2011).

Gastrostomy related support is needed during all phases of the process (Aarthun & Akerjordet, 2012; Brotherton et al., 2007b; Fröhlich et al., 2010; Hannah & John, 2013; Hewetson & Singh, 2009; Mahant et al., 2011; Marchand et al., 2006; Sevilla & McElhanon, 2016), including post placement when complications often present. It is known that support is needed but it is not necessarily provided when required. The incidence of gastrostomy complications in children is known to be 73% to 83% (Craig et al., 2006; Naiditch et al., 2010; Nelson & Mahant, 2014; Schweitzer et al., 2014). It could therefore be anticipated that caregivers would need to seek medical attention post discharge. The health care practitioners in this study were aware that

ongoing support for caregivers was essential and that caregivers had limited options for help outside the tertiary hospital setting (Hewetson & Singh, 2009; Kirk et al., 2014; Norman et al., 2011).

The gastrostomy related education provided by health practitioners to caregivers impacted on the caregivers' experience. The participants provided gastrostomy related education, but were aware that it was insufficient for caregivers to manage the gastrostomy and potential complications. Inadequate caregiver education is consistent with research findings (Mahant et al., 2011). Schweitzer et al. (2014) and can lead to poor health outcomes for the child with the gastrostomy (Schweitzer et al., 2014).

Perceptions of poor caregiver compliance and adverse outcomes were understood to be related to poor education, and a lack of understanding of the information and instructions given (Evans et al., 2012). Poor education provided to the caregivers regarding the gastrostomy resulted in an increased number of reported complications (Schweitzer et al., 2014), and increased the frequency of emergency department visits for tube related issues (Schweitzer et al., 2014; Sevilla & McElhanon, 2016). There are consequent adverse effects on the health, and well-being of child and the quality of life of both the child and the family (Schweitzer et al., 2014; Sevilla & McElhanon, 2016). Provision of good quality education to the caregivers facilitates less stress and anxiety for them, with better health outcomes observed (for the child) (Clancy, 2009; Hannah & John, 2013; Schweitzer et al., 2014; Sjöberg et al., 2017).

Guidelines on how best to share information with caregivers, ensuring positive health outcomes for the child, are available in literature (Brotherton et al., 2007b; Mahant et al., 2011; Schweitzer et al., 2014). Caregivers benefit from hearing information from the health care

practitioner more than once (Hewetson & Singh, 2009; Jackson et al., 2008; Mahant et al., 2011; Sjöberg et al., 2017) as they require additional time to process what is shared, throughout the process, (Aarthun & Akerjordet, 2012; Hewetson & Singh, 2009; Mahant et al., 2011). Efforts should be made by the health care practitioners to allow time for information sharing into standard health care practice. The ethical principal of autonomy must be considered; are caregivers making informed choices if they are not efficiently educated prior to gastrostomy placement and signing of consent (Guerriere et al., 2003)? In the South African context where gastrostomies are placed at tertiary level access to healthcare services by trained health care professionals is a challenge.

Well after the gastrostomy has been placed, the health care practitioners experienced most caregivers as being relieved and satisfied with the feeding tube similar to available research (Fröhlich et al., 2010; Hewetson & Singh, 2009; Martinez-Costa et al., 2011; Sullivan et al., 2004; Wilson et al., 2009). These findings are significant because they validate the benefits of the gastrostomy despite the associated complications and challenges experienced by caregivers.

The health care practitioners are aware that their role with the caregivers on the gastrostomy process is ongoing. The caregivers require effective gastrostomy related education and support throughout the process. The findings of this study help outline the course this process takes as the health care practitioners were mindful of the needs and concerns of the caregivers at the different stages of the process, although awareness did not necessarily change practice.

Experiencing multidisciplinary team work; and its influences on the management of patients with gastrostomies

Working with a multidisciplinary team is standard practice for the management of a gastrostomy (Edwards et al., 2016; Hannah & John, 2013; Marchand et al., 2006; Norman et al., 2011; Richards et al., 2016), with the caregivers being included as part of the team (Doyle, 2008; Mahant et al., 2011).

Team members reported positive experiences when referrals were made appropriately, and adverse experiences when they were not. Factors contributing to incorrect referrals included lack of awareness of the professional roles of the different members of the team, team dynamics, referral protocols and systems in place at the institutions (Doyle, 2008; Seedat et al., 2011). Systemic issues were exemplified by the differences between well-coordinated referrals for outpatients but not for inpatients – where there were frequent changes of staff in the wards similar to that reported by Seedat et al., (2011). Increased workload, limited time and resources as well as lack of appropriately trained staff, and poor understanding of the roles of team members are known to challenge the effectiveness of a multidisciplinary team (Doyle, 2008; Seedat et al., 2011), realities known to the South African context.

The health care practitioners in this study were aware of the role of the speech therapist in managing feeding and swallowing, both before and after gastrostomy placement. Some speech therapists and dieticians reported dissatisfaction with the lack of referrals from team members suggesting a dissonance between awareness of roles and referral practices. Poor referral practices resulted in gastrostomies being placed when there was no feeding and swallowing difficulty; of discharge with a newly placed gastrostomy without the speech therapist being consulted; and

removal of the gastrostomy where there was inadequate consumption of the required calories. Norman et al., (2011) noted a significant drop in the percentage of patients seen by the speech therapist after the gastrostomy was placed versus those had been seen before placement, even though the speech therapists were the predominant referral source for gastrostomies. It is important that these team members be included as post gastrostomy there is a need to monitor weight, provide therapy to improve feeding ability and in some instances, wean the child off the gastrostomy (Arvedson & Brodsky, 2002; Norman et al., 2011). There is a need for speech therapists working in an institution where gastrostomies are placed to promote their services, provide in-service training on their role in the decision-making process as well as the reintroduction of oral feeding post gastrostomy placement (Arvedson & Brodsky, 2002; Norman et al., 2011). While in most cases speech therapists were consulted, perhaps they should not wait to deliver input only when asked but be part of the decision-making process from the onset as well as during the patient discharge procedure (Norman et al., 2011) in an attempt to avoid being left out of the various phases of gastrostomy management. The speech therapist must be proactive in working with the team to develop a protocol that contributes to the process of gastrostomy decision-making and management and reflects the inclusion of the speech therapist's services before and after placement. The protocol or standard guidelines then needs to be workshopped and in-service training must be provided given the high turnover rate of hospital staff (Seedat et al., 2011).

The health care practitioners believed that more contact was needed between team members and identified a need for improved communication. Poor referrals have significant implications for the health outcomes of patients. Failure to communicate and work together results in care being duplicated, omitted or poorly managed (Doyle, 2008). Multidisciplinary team work is not only necessary, but it is critical if the all-inclusive needs of the patients are to be met (Doyle, 2008).

6. Conclusion

The health practitioners' practices perceptions, and experiences with children with gastrostomies shared in this study are similar to and complementary of the existing literature. The team showed awareness of standard gastrostomy related practices but these were not always realized. The results of this study reflect a process, with somewhat of a predictable course that health care practitioners, caregivers and their children with gastrostomies experience. The gastrostomy is of great benefit to children who require enteral feeding, improving the health and quality of life; the positives of gastrostomy placement is perceived to outweigh the complications and adversities associated with tube feeding. The education and support provided by the health care practitioners affected the health outcomes of children in their care. Multidisciplinary team work is a necessity when working with children with gastrostomies, inadequacies experienced within the team lead to undesirable health outcomes. The question raised is if the majority of the health care professionals are doing what they should be doing and are well trained, then why is there an apparent gap between how families feel versus the health care professional? This must be addressed in future research.

Limitations

This study would have benefitted from the input of the nurses working in the wards. They are responsible for a large amount of the caregiver education and training that takes place postoperatively. The private sector, in which gastrostomies are placed in the paediatric population was not included in the study. Involving members of the team working in this sector could have

enriched the data collected. Caregivers are considered an important part of the multidisciplinary team, particularly in the decision-making process. They were not included in this study as the purpose was to understand the health care practitioners' experiences, practices and perceptions of gastrostomies in the paediatric population.

Implications for clinical practice

The findings from this study provide insight into the gastrostomy process and experience and can therefore be used by health care practitioners as a guide when working with children with gastrostomies. The common practices and experiences described throughout the different phases of the process have led to positive and negative outcomes for the child's health, and the quality of life for the families involved and should be considered when developing a standardized protocol which can be used in gastrostomy practice. This guide can be used by even a novice health care practitioner working with gastrostomies as it describes their common practices, experiences and perceptions before and after placement. Awareness of the importance of the health care practitioner's role in the decision-making process, sharing of information, provision of ongoing support and multidisciplinary team dynamics could result in improved practice, service delivery and ultimately better health outcomes for the patient.

Recommendations for future research

Access to medical assistance with gastrostomy related issues at primary levels of health care is an area that would be of value to the gastrostomy knowledge base, especially in South Africa. Many children with cerebral palsy live in rural areas and have to travel to cities for health care, especially for gastrostomy management. Studies that look into access to medical help for

gastrostomies at primary levels of care would be beneficial to the knowledge base of gastrostomy management, for both adults and children.

The need for a clear set of guidelines for the management of gastrostomy in the two tertiary hospitals in Cape Town, South Africa was evident in this study. The set of best practice guidelines could be researched further and a standardized protocol for gastrostomy management should be developed and implemented. This would improve the experience of the gastrostomy for the children, caregivers and health care practitioners involved. A protocol should provide the clear steps of the gastrostomy process from the early identification of feeding and swallowing problems, decision-making process, caregiver education needs before and after placement, as well as the support offered upon discharge from the hospitals and the follow ups that take place after that (Correa et al., 2014; Cunningham & Best, 2013; Majika et al., 2014; Richards et al., 2016; Schweitzer et al., 2014). Having a protocol in place would furthermore assist with eliminating issues such as the lack of referrals, communication issues within a team and the high turnover rate of staff. While protocols exist in other countries, none are specific to the South African context. This protocol should also consider issues specific to the South African health care system as well as the country's diverse cultures and languages.

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8. Appendices

Appendix A: Ethics approval letter



UNIVERSITY OF CAPE TOWN

**Health Sciences Faculty
Research Ethics Committee**
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: lamees.emjedi@uct.ac.za

01 September 2009

REC REF: 339/2009

Ms S Coetzee
Health & Rehab
F Floor
OMB

Dear Ms Coetzee

PROJECT TITLE: PROFESSIONAL FACTORS INFLUENCING GASTROSTOMY PLACEMENT IN A PAEDIATRIC POPULATION

Thank you for submitting your study to the Research Ethics Committee for review.

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

Approval is granted for one year till 06 September 2010.

Please send us an annual progress report if your research continues beyond the approval period. Alternatively, please send us a brief summary of your findings so that we can close the research file.

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

Please quote the REC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSE HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.

emjedi

Appendix B: Permission letter to medical superintendent



UNIVERSITY OF CAPE TOWN

School of
Health & Rehabilitation Sciences

Faculty of Health Sciences

Divisions of Communication Sciences & Disorders · Nursing & Midwifery ·
Occupational Therapy · Physiotherapy

Old Main Building · Groote Schuur Hospital · Observatory · 7925

Telephone: + 27 21 406 6401

Fax: + 27 21 406 6323

Research Reference: 339/2009

Dear Superintendent

Re: Participating in research project at the University of Cape Town

I am a Master's student in the Department of Communication Sciences and Disorders at the University of Cape Town. In order for me to complete my degree, it is required that I conduct a research report. The research topic of interest aims to describe the health care practitioners' practices, perceptions and experiences regarding gastrostomy placement in a paediatric setting.

I hereby wish to ask permission to enter the hospital and invite the health care practitioners currently working with children who may require a gastrostomy to participate in the study. They will be granted the opportunity to share their views, experiences and practices regarding gastrostomy in the paediatric setting.

There are no risks associated with this research project. The results of this study may contribute to and expand existing knowledge regarding the gastrostomy placement. Information obtained will provide meaningful answers to questions regarding the current practice of gastrostomy in paediatrics and will provide the basis and support for further research. Findings may improve the services delivered to children and families living with gastrostomy and improve quality of life.

The interviews will take place at a time and venue judged to be appropriate for the participants. This entire process is not expected to take more than 1 hour. A copy of the final research report will be available should you be interested to read it.

The hospital may withdraw from this study at any time, without having to give a reason for doing so.

I thank you for your time and your consideration of this matter.

Yours faithfully,

Samantha Coetzee

Should you have any questions, please do not hesitate to contact me on 0832797967 or my supervisors:

Prof. Shajila Singh: Shajila.Singh@uct.ac.za (w) 021 4066041

Vivienne Norman: Vivienne.Norman@uct.ac.za / (w) 021 4066317

Attached is the permission form should you allow the study to take place at the hospital.

PERMISSION TO CONDUCT RESEARCH AT THE TERTIARY INSTITUTION

(Hospital superintendent)

Title of Project: Health practitioners' practices, perceptions and experiences regarding gastrostomy placement in a paediatric setting.

Researcher & Samantha Coetzee

Contact Details 0832797967/ samanthacoetzee@gmail.com

Research Supervisors: Prof. Shajila Singh

& contact details Head of Division of Communication Sciences and Disorders:

Shajila.Singh@uct.ac.za (w) 021 4066041

Vivienne Norman

Division of Communication Sciences and

Disorders: Lecturer

Vivienne.Norman@uct.ac.za / (w) 021 4066317

I _____ (name of superintendent) hereby give permission that the project mentioned above may be conducted at _____ (name of hospital) during the time frame indicated by the researcher. My signature certifies that I have read and understood the information that was presented. My signature also certifies that I have had adequate opportunity to discuss this study with the researcher and have had all my questions answered to my satisfaction. I understand that I will be given a copy of this form to keep. I, the undersigned (superintendent) _____

Please PRINT

of (hospital name and address) _____

Postal Code: _____ Contact Tel Numbers: _____

give my permission for any results from the study to be used in reports or research papers after completion of the project, on the understanding that identifying information will not be disclosed. I understand that as superintendent, I have the right to disallow the continuation of the study at any stage of the process. If the hospital chooses to withdraw from the study after entering voluntarily, I undertake to inform the researcher at the earliest opportunity.

Signature: _____

Date: _____

Superintendent



Departement van Gesondheid
Department of Health
iSebe lezeMpilo

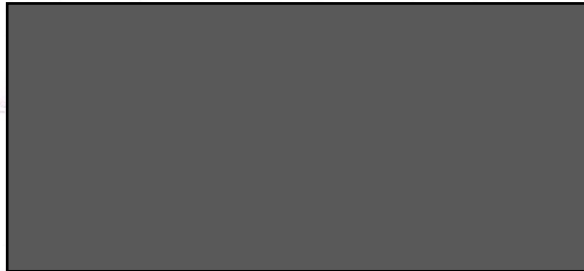


Navrae
Enquiries
Imibuzo
Telefoon
Telephone
Ifowuni
Datum
Date
Umhla

Dr M A Mukosi

021 938-5966

23rd October 2009





Your Research / Clinical Trial: Ethics No: 339/2009:

Professional factors influencing gastrostomy placement in a paediatric population.

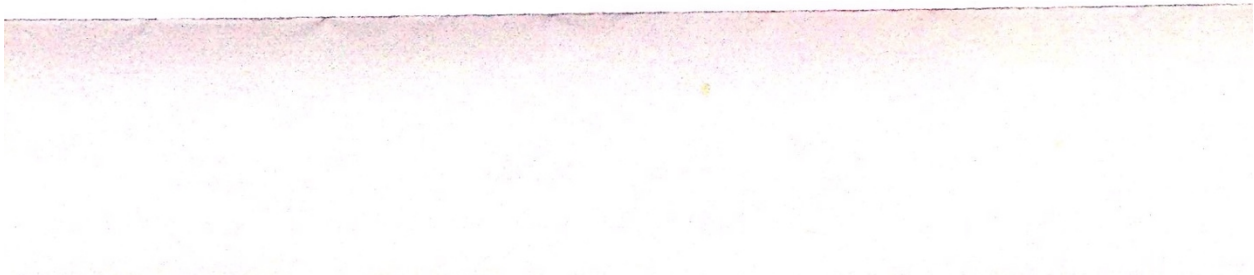
Dear Ms Samantha Coetzee

PERMISSION TO CONDUCT YOUR RESEARCH / CLINICAL TRIAL AT 

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





Appendix C: Information and consent form for health care practitioners



UNIVERSITY OF CAPE TOWN

School of
Health & Rehabilitation Sciences

Faculty of Health Sciences

Divisions of Communication Sciences & Disorders · Nursing & Midwifery ·
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Old Main Building · Groote Schuur Hospital · Observatory · 7925

Telephone: + 27 21 406 6401

Fax: + 27 21 406 6323

Research Reference: 339/2009

Dear Sir/Madam,

Re: Participating in research project at the University of Cape Town

I am a Master's student in the Department of Communication Sciences and Disorders at the University of Cape Town. In order for me to complete my degree, it is required that I conduct a research report. The research topic of interest aims to describe the health care practitioners' practices, perceptions and experiences regarding gastrostomy placement in a paediatric setting.

Should you wish to participate in this study, you will have the opportunity to share your views, experiences and practices regarding gastrostomy in the paediatric setting.

The results of this study may contribute to and expand existing knowledge regarding gastrostomy placement. Information obtained will provide meaningful answers to questions regarding the current practice of gastrostomy in paediatrics and will provide the basis and support for further research. Findings may improve services delivered to children and families living with gastrostomy and improve quality of life. An increased awareness of the need for further research in the field could be highlighted, which will initiate a move towards improved service delivery and quality of life for children and their families living with gastrostomy. Participation in the current study will not cause you discomfort or harm in anyway.

The interview will take place at a time and venue that is suitable for you. In order to record exactly what is discussed in the interview, a tape recorder will be used. This tape will only be listened to by the research team. Your details will be kept confidential at all times.

Areas covered in the interview will include the rationale for recommending a gastrostomy, other considerations or factors that influence health care practitioners when deciding to recommend a gastrostomy or not, health care practitioners' experiences regarding gastrostomy, options for long term management of feeding in children with gastrostomies, the team involved in the management of gastrostomies, and health care practitioners' experiences of caregivers' responses to gastrostomy placement.

There is no remuneration for participation in this study.

This entire process is not expected to take more than 1 hour. After the interview is completed, transcripts of your interview will be returned to you for verification of accurate interpretation of what was shared. A copy of the final research report will be available should you be interested to read it.

You may withdraw from participating in this study at any time, without having to give a reason for doing so.

I thank you for your time and your consideration of this matter.

Yours faithfully,

Samantha Coetzee

Should you have any questions, please do not hesitate to contact me on 0832797967 or samanthacoetzee@gmail.com or my supervisors:

Prof. Shajila Singh: Shajila.Singh@uct.ac.za (w) 021 4066041

Vivienne Norman: Vivienne.Norman@uct.ac.za / (w) 021 4066317

Prof. Marc Blockman (Chairperson of Research Ethics Committee): (w) 021 4066496

Please find attached the written consent letter should you wish to participate in the study.

WRITTEN CONSENT FORM FOR PARTICIPARION IN THE STUDY

Biographical Details *(for purpose of overview of participants' profiles)*

Name:

Occupation & Place of practice:

Qualification:

Years of practice in public tertiary healthcare

Contact details:

I, _____ *(full name in print)* understand my rights as a research participant and I voluntarily consent to participating in this study. I understand the nature of and rational for this study. I understand what my participation in this study entails and I have had all my questions answered. I do not feel that I am forced to take part in this study and I am doing so of my own free will. I am aware that I may withdraw from the study at any time if I so wish and that it will have no negative implications for me. I have received a copy of this consent form.

Signature of participant

Date

Signature of researcher

Date

Should you have any questions, please do not hesitate to contact me, Samantha (researcher) on 0832797967 or my supervisors:

Prof. Shajila Singh: Shajila.Singh@uct.ac.za (w) 021 4066041

Vivienne Norman: Vivienne.Norman@uct.ac.za / (w) 021 4066317

Appendix D: Interview Guide

Interview guide

1. What are reasons for the placement of gastrostomies in children?
 - What informs the indicators used?
 - Are there protocols in place at the hospital?
 - What are the protocols based on? (literature? Evidence based practice?)

2. What other considerations/ factors influence your decision on whether or not to recommend a gastrostomy
 - Family concerns
 - Quality of life
 - Family lifestyle
 - Living environment

3. What are your experiences with gastrostomy placement?
 - a. Complications experienced
 - b. Concerns regarding gastrostomy placement
 - c. Concerns regarding life with a gastrostomy
 - d. Advantages of gastrostomy
 - e. Disadvantages of gastrostomy

4. In your experience, what are the options for long term management of feeding in children with gastrostomies?
 - a. Once it has been placed, can it be removed?
 - b. What are your experiences of children with gastrostomies feeding orally

5. Who would you work with when managing children with gastrostomies?
 - a. During the decision-making process
 - b. During management including once the child has been discharged
 - c. Are caregivers included as part of the management team?
 - d. Nature of caregiver involvement, from the decision-making right through to discharge plans.
 - e. What role, if any, does the speech therapist play in children with gastrostomies?

6. Describe your experiences of caregivers and care givers reactions and responses to gastrostomy placement?
 - a. How do you deal with these reactions?
 - b. Is there pre-and post-operation counseling?
 - c. If so is it effective?
 - d. What concerns do caregivers raise regarding gastrostomies?
 - e. Are there systems in place to support caregivers and children with gastrostomies?