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Identifying Current Decision-Making Processes when Considering the Insertion of Gastrostomy Tubes in Children within a Public Hospital Setting

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Declaration

I, Louise Reed, declare that this Research Report is my own, unaided work. It is being submitted for the Degree of Master of Science in Medicine, Child Health, Neurodevelopment at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other university.



21 August 2018

To Keegan and Scott, my family, friends and loved ones.

Abstract

Purpose: The purpose of this study was to identify the current decision-making processes that are in place when inserting gastrostomy tubes in children within a public hospital setting.

Design: The study adopted a quantitative approach where a descriptive design was employed based on information obtained from questionnaires.

Participants: Professionals were selected from three public hospitals who are involved in the decision-making process when considering the insertion of gastrostomy tubes in children.

Implications: This study determined if there was a common decision-making process between professionals when inserting gastrostomy tubes in children as well as ascertained whether the implementation of guidelines would be beneficial to assist with the process.

Results: The study showed that there is a multidisciplinary team involved in the decision-making process. Professionals reported that the main reason for the insertion of a gastrostomy tube was because of neurological disorders. Some assessments are being conducted prior to the insertion. The study showed that there is a confusion around the assessments used to investigate gastroesophageal reflux. Counselling the families surrounding the gastrostomy tube was contacted mostly by the speech-language therapists and dieticians, to ensure they know how to feed and troubleshoot any problems arising from the gastrostomy tube. Complications such as tube dislodgement, leaking tubes and infections of the stoma are reportedly common within the hospitals studied.

Conclusion: A checklist was compiled to assist professionals with the decision-making for the insertion of gastrostomy tubes as well as the follow up plan surrounding the care.

Key Words: Gastrostomy tubes, decision-making, professionals in a public hospital setting.

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1. Introduction

The topic surrounding gastrostomy tube feeding has been of considerable interest in the medical literature. There are many studies[1–4] that have reported on the indications and limitations as well as the ethical factors that need to be considered prior to the insertion of a gastrostomy tube. There is however, very little discussion regarding the roles of the professionals involved as well as the procedures that are required prior to the placement of a gastrostomy tube. Angus and Burakoff[4] reported poorly defined roles of the individual health care professionals who take part in the decision-making team. The European Society for Pediatric Gastroenterology, Hepatology, and Nutrition (ESPGHAN) position paper on the management of gastrostomy tubes in children and adolescents was released early in 2015, which began to allude to the importance of the roles that certain health care professionals play when making a decision regarding the insertion of a gastrostomy tube.[5] The authors also report that the decision-making process needs to be based on each individual child and it is therefore difficult to create a standardised protocol around the insertion of a gastrostomy tube.[5] In order to completely understand the decision-making process involved when considering a gastrostomy tube in the paediatric population, it is important to have an understanding of gastrostomy tube feeding, why it is necessary, and what type of population usually requires it.

A gastrostomy is the term used when an opening in the anterior abdominal wall is surgically made and a tube is inserted directly into this opening, which is used for feeding.[6] The procedure for a gastrostomy can now be performed in the following ways: surgically, radiologically, laparoscopically or endoscopically.[6] For the purpose of this study, the term gastrostomy tube will be used to refer to all types of feeding tubes placed in the stomach. A gastrostomy tube is usually inserted when a child has inadequate nutrition and/or has

difficulties with his/her swallowing mechanism. El-Matary[6] described the following groups of children who may require the insertion of a feeding tube:

1. "Failure of adequate intake due to impossible or inadequate oral intake."
2. "Neurological disorders with inability to swallow or dysphagia."
3. "Craniofacial abnormalities."
4. "Oncology problems with malnutrition."
5. "Other clinical conditions such as cystic fibrosis and Crohn's disease."[6]

The insertion of a gastrostomy tube in children is increasing, especially in those with disabilities.[6] Furthermore, it has become an integral part of the management of children with feeding and/or nutritional problems.[5]

It must be mentioned that these gastrostomy tubes can be placed in children, adolescents and adults. For the purposes of this study, children and adolescents who fall within the range of 0–18 years will be the focus. As aforementioned, the decision-making process around inserting a gastrostomy tube is complicated and not very well expressed in the literature, especially in South Africa. This study will therefore focus on the decision-making processes that occur prior to the insertion of the gastrostomy tube within a public health care setting.

2. Literature Review

A very important aspect to mention when considering the insertion of a gastrostomy tube is the multidisciplinary team behind the decision. This is evident as Heuschkel et al[5] states that the management of the child should begin before the insertion of a gastrostomy tube as it has implications for all aspects of the child's life. A multidisciplinary team can be defined as "a group of professionals working toward a common purpose, in which a variety of disciplines may be represented".[7] Professionals within each discipline need to be flexible and willing to provide their expertise as well as their knowledge.[7] Healthcare providers of varying professions should therefore be required to contribute to the decision-making process prior to the insertion of the gastrostomy tube. Complications such as: leakage, tube dislodgement, granulation tissue, perforation of colon/viscera, infections that either require oral antibiotics or hospitalisation, and/or aspiration, can occur post the insertion of a gastrostomy tube. [8] Complications are reported to occur in 5% of patients in the United States of America.[9] It is unclear as to the number of complications that occur in SA, however, the potential complications suggest that more than one professional should be involved in the decision-making. This would be to ensure that all risks are considered, and a follow-up plan is discussed for the management after the insertion of the gastrostomy tube.

The Society of Interventional Radiology (SIR) Executive Council committee recently endorsed a documentation in order to implement possible guidelines for paediatric gastrostomy placements.[9] This guideline was based on international standards. It states that the following need to be considered prior to the insertion of the gastrostomy tube:

(i) patient selection,

(ii) techniques of tube placement

(iii) monitoring of the patient.[9]

This guideline does not mention the assessments that should be performed prior to the insertion of the gastrostomy tube as well as the counselling processes that should take place. Normal gastric and small bowel motility as well as adequate gastric anatomy needs to be assessed to determine whether it is possible and feasible to insert a gastrostomy tube.

One of the most important factors that should be considered is the family; whether they have received adequate counselling and whether they have had adequate time to consider the effects that the gastrostomy tube may have on the child's life.[9] Educating the parent is a crucial aspect before and after the insertion of the gastrostomy tube as it will decrease the rate as well as the severity of post-procedure complications.[8] According to the standards of practice,[9-10] the following pre-procedure assessments should occur when inserting a gastrostomy tube, to assist in decreasing these abovementioned complications:

1. Fluoroscopy: making sure the radiation exposure is low. This procedure allows for one to see a continuous x-ray image displayed on a monitor.[11] A contrast agent is given to the child which moves through the body and the movement can be tracked on the monitor.[11] The type of fluoroscopy that is used specifically for swallowing is called the videofluoroscopy or modified barium swallow. This test is used to visualise structures of the upper airway and digestive tract and to determine if a child has a normal swallowing mechanism.[12] The American Speech-Language Association stipulates the following rationale for performing a videofluoroscopy[13]:

(i) "To identify normal and abnormal anatomy and physiology of the swallow."

(ii) "To evaluate integrity of airway protection before, during, and after swallowing."

(iii) "To evaluate the effectiveness of postures, manoeuvres, bolus modifications, and sensory enhancements in improving swallowing safety and efficiency."

(iv) "To provide recommendations regarding the optimum delivery of nutrition and hydration (e.g., oral versus non-oral, method of delivery, positioning, therapeutic interventions)."

(v) "To obtain information in order to collaborate with and educate other team members, referral sources, caregivers, and patients regarding recommendations for optimum swallow safety and efficiency."[13]

2. Sedation and anesthesia needs to be assessed. The anesthesiologist will need to determine the following risk factors prior to the insertion: (i) respiratory difficulties; (ii) cardiovascular disease; (iii) craniofacial malformations; (iv) neuromuscular diseases; and (v) gastroesophageal reflux (GOR) or delayed gastric emptying.[9]

Itkin et al.[10] further explain that the maintenance of care needs to continue post insertion of the gastrostomy tube, which highlights the importance of counselling the family. Post-operative care and counselling includes:

1. Tube Dressing and Positioning: It is important to counsel the parents on cleaning the wound around the gastrostomy tube and that the external bumper is flush on the skin.[10]

2. Initiation of Feeding: Previously, feeding was initiated after 24 hours, but recent studies[14–16] have found that feeding immediately after the insertion is safe.[10]

3. Routine Tube Flushing to Prevent Blocking: Blocking of the gastrostomy tubes occur 20-45% of the time.[10] It has been shown that water, carbonated liquids and cranberry juice are the most successful in preventing blockages.[10]

4. Gastrostomy Tube Change: All gastrostomy tubes will eventually require replacement and should only remain in place for 1-2 years.[10]

Based on the assessments and care mentioned above, it is clear that the decision to insert a gastrostomy tube should be a multidisciplinary approach as valuable skills from each healthcare professional are required. Heuschkel et al[5] support this idea as they state that "it is mandatory for children requiring a gastrostomy tube to be assessed and monitored by appropriately trained health care professionals." Heuschkel et al[5] further suggest that the multidisciplinary team should manage the type of feed and the feeding regime, specific feeding therapy techniques, swallow assessments, education around care for the gastrostomy tube as well as provide access to psychological support. The ideal team members who should therefore be involved are: paediatric gastroenterologists, paediatric surgeons, psychologists, dieticians, nutrition nurses, speech-language therapists, and stoma sisters.[5] Careful preparation and planning should be done prior to the insertion of the gastrostomy tube. This includes identifying relevant co morbidities, discussing ethical issues and establishing ongoing and future strategies to maintain oral feeding skills and planning the gastrostomy tube weaning process where appropriate.[5]

As previously mentioned, it is not easy to implement a standardised protocol that should be followed prior to the insertion of a gastrostomy tube, however, it is necessary to understand which procedures should be performed and when. Heuschkel et al[5] reported that there is no evidence that gastrostomy tube insertion causes GOR and therefore it is not necessary to perform a routine assessment to rule out GOR prior to the insertion of the gastrostomy tube. Thomson, Rao, Rawat and Wenzl[17] found significant evidence that the insertion of a gastrostomy tube increases GOR episodes in neurologically impaired children. The study noted that the percentage of the GOR events reaching up to the pharyngeal space increased from 56 to 82% after an insertion of a gastrostomy tube.[17] Thomson et al. state that GOR should only be investigated when a gastrostomy tube is being inserted in a child who has neurological impairment. Vandenplas et al. also mention that studies suggest the placement of

a gastrostomy tube in children with neurological impairment increases the risk of GOR, although it is more common when inserting the gastrostomy tube via open surgical procedures.[18] The ESPGHAN paper does not specify specific details as to which population or surgery influences the presence of GOR, it purely states that the insertion of a gastrostomy tube does not increase GOR. It would therefore appear that there is an inconsistency in the literature surrounding the importance of assessing for GOR in specific populations and surgical options prior to the insertion of the gastrostomy tube.

It is important to take this information into consideration when deciding on the insertion of a gastrostomy tube in children who have neurological impairments. Again, this brings the statement that each case is individual to light, and must therefore be approached differently, thus making specific protocols difficult to follow. A guideline, however, may be appropriate to aid in a thorough assessment of the child prior to the gastrostomy tube placement. For a guideline to be devised as appropriate and easy to follow; the current practices regarding decision-making processes for gastrostomy tube insertion in children needs to be explored.

The public healthcare sector serves the population who are unable to fund their own healthcare or contribute to a medical aid scheme. The resources in the public healthcare sector are limited and therefore are at risk for delivering inadequate healthcare services.[19] South Africa is faced with a quadruple burden of disease, namely HIV/AIDS, tuberculosis (TB), poverty and unemployment.[19] The public healthcare sector in South Africa covers 83% of the population which is usually those who are faced with the quadruple burden of disease. Blecher et al.[19] further report that only 17% of the South African population is covered by medical aid schemes. It is for that reason that the public healthcare sector was chosen as it services more of the population.

3. Methodology

3.1. Aims of the Study

3.1.1. Main Aim

The primary aim of this study was to determine what current decision-making processes are in place prior to the insertion of a gastrostomy tube in a child within a public hospital setting.

3.1.2. Objectives of the Study

1. To identify which professionals are part of the decision-making process when inserting a gastrostomy tube in children.
2. To determine if medical, radiological or imaging assessments are being conducted prior to the insertion of the gastrostomy tube.
3. To determine if the patients are being referred to other healthcare professionals prior to the insertion of the gastrostomy tube.
4. To identify specific reasons, if any as to why the assessments are in place or not in place.

3.2. Design of the Study

The prospective study employed a quantitative, descriptive design. The researcher used a questionnaire to obtain the data. Nykiel[20] suggested that a descriptive study would assist with gaining information regarding particular characteristics in a particular field of study. The descriptive study further investigated suspected similarities and/or differences between populations in terms of the specific variables of interest.[21] This therefore allowed the researcher to gain information regarding the specific decision-making processes that were used prior to the insertion of a feeding tube placement in a child.

The study adopted a quantitative approach. There are advantages to a quantitative study as it can determine whether one concept or idea is better than the alternatives as well as project data to the population.[20]

3.3. Participants

The participants of this study were professionals who were part of the decision-making team prior to the insertion of a gastrostomy tube in children within a public hospital setting. These professionals included but were not limited to: dieticians, paediatricians, paediatric gastroenterologists, paediatric surgeons, psychologists, speech-language therapists and stoma nurses. The participants were recruited from three academic public hospitals.

3.3.1. Participation Recruitment

This study implemented non-probability purposive sampling, as the participants were specifically chosen from pre-selected hospitals. The hospitals included were: Charlotte Maxeke Johannesburg Academic Hospital; Rahima Moosa Mother and Child Hospital and Chris Hani Baragwanath Academic Hospital from the public sector. A variety of professionals who are involved in the decision-making prior to the insertion of a gastrostomy tube in children within a public hospital setting, were identified and located by the researcher. The participants selected were spread as evenly as possible over the variety of professionals targeted. This assisted with an even number of professionals across the board. This type of sampling was therefore non-random sampling as the researcher chose the participants with specific characteristics to participate in this study.[22]

3.3.2. Inclusion Criteria

1. All professionals involved in children who require feeding tubes.

   These professionals include but were not limited to:

a. Dieticians

b. Paediatricians

c. Paediatric gastroenterologists

d. Paediatric surgeons

e. Psychologists

f. Speech-language therapists

g. Stoma nurses.

2. These professionals had to be involved in a public hospital setting.

3.3.3. Exclusion Criteria

1. Professionals who have not worked with the insertion of gastrostomy tubes in children within the last two years.

3.4. Context

The study was conducted at three different public hospitals in Gauteng, South Africa. The public hospital setting was chosen as a convenience. This is a setting in which more than one professional will collaborate in order to make a decision regarding a child's healthcare.

3.5. Data Collection Procedures

3.5.1. Measures

A questionnaire (see appendix A) was used to obtain the relevant data. These questionnaires were given to all the professionals who make decisions regarding an insertion of gastrostomy tubes in children. The questionnaire was a combination of closed and open-ended questions and participants could select more than one answer in a question.

Study data was collected and managed using REDCap (Research Electronic Data Capture) hosted at the University of the Witwatersrand. REDCap is a secure, web-based application designed to support data capture for research studies. The questionnaire was converted to an online survey using REDCap to increase the sample size.

3.6. Consent and Permission

Ethical clearance was obtained from the Human Research Ethics Committee (Medical) (see Appendix B). Permission by the CEO's of each of the three public hospitals was also granted, (Appendices C-E). Permission was further granted by the Head of Department of Paediatrics' for two of the three public hospitals (see Appendices F-G). A permission letter was sent to Chris Hani Baragwanath Academic Hospital (see Appendix H), however a formal letter was not received as approval by the CEO was already obtained. A participant information sheet was given to each participant (see Appendix I). Informed consent from each participant was obtained (see Appendix J).

This study aimed to maintain the anonymity and confidentiality of the participants, as the questionnaires did not require any personal details. The researcher will keep the data for a period of five years for possible publication. The results will be reported in hard copies and electronically and can therefore be reviewed by students at the University of Witwatersrand. These results will also be shared with the CEO's of the hospitals who were involved.

3.7. Validity and Reliability

A limitation to using questionnaires in the study was low compliance. A hard copy of the questionnaires was therefore given out to the professionals by hand and asked the participants to complete them while the researcher waited. This worked well with two of the public hospitals but was unsuccessful with one. An online questionnaire using REDCap was then sent out to increase the sample size and obtain participants for the third hospital.

3.8. Data Analysis

The data was analysed using descriptive statistics. This allowed the researcher to summarise the data collected to describe the important characteristics of a set of measurements.[23-24] Descriptive statistics further allowed patterns in the data to be depicted as well as outlined common tendencies within the data collected.[25] The data collected was categorical which represented counts or number of observations within each question.[26] Percentages and frequencies were calculated to determine common tendencies and variabilities to describe what was happening prior to the decision to insert gastrostomy tubes in children.[25] It also described the complications that are occurring.

3.9. Implications of the Study

This study aimed to provide information regarding the types of decisions that were made prior to the insertion of gastrostomy tubes in children. It also aimed to provide information as to why certain procedures are conducted and not conducted. The study further determined which professionals were involved in this decision-making process. In addition, it has assisted to promote a multidisciplinary team approach.

3.10. Funding

The expense of the research was covered by the researcher.

4. Results

A total number of 63 questionnaires were returned. Four were excluded as three professionals had no experience with the insertion of gastrostomy tubes and another did not work at one of the three public hospitals targeted. The study was therefore made up of 59 participants consisting of the following professionals:

- Paediatricians (n = 26),
- Speech-language therapists (n = 16),
- Paediatric surgeons (n = 7),
- Dieticians (n = 6),
- Paediatric gastroenterologists (n = 2), and
- Paediatric cardiologists (n = 2).

The results of the study are presented in the following order:

4.1. Professionals involved in the decision-making process

4.2. Reason for inserting a gastrostomy tube

4.3. Prior assessments performed

4.4. Prior information obtained

4.5. The professional making the final decision

4.6. The professional performing the surgery

4.7. Areas in which the families receive pre/post-operative counselling

4.8. Professionals providing the counselling

4.9. Complications experienced post-operative

4.10. Follow-up plans for the children post-operatively

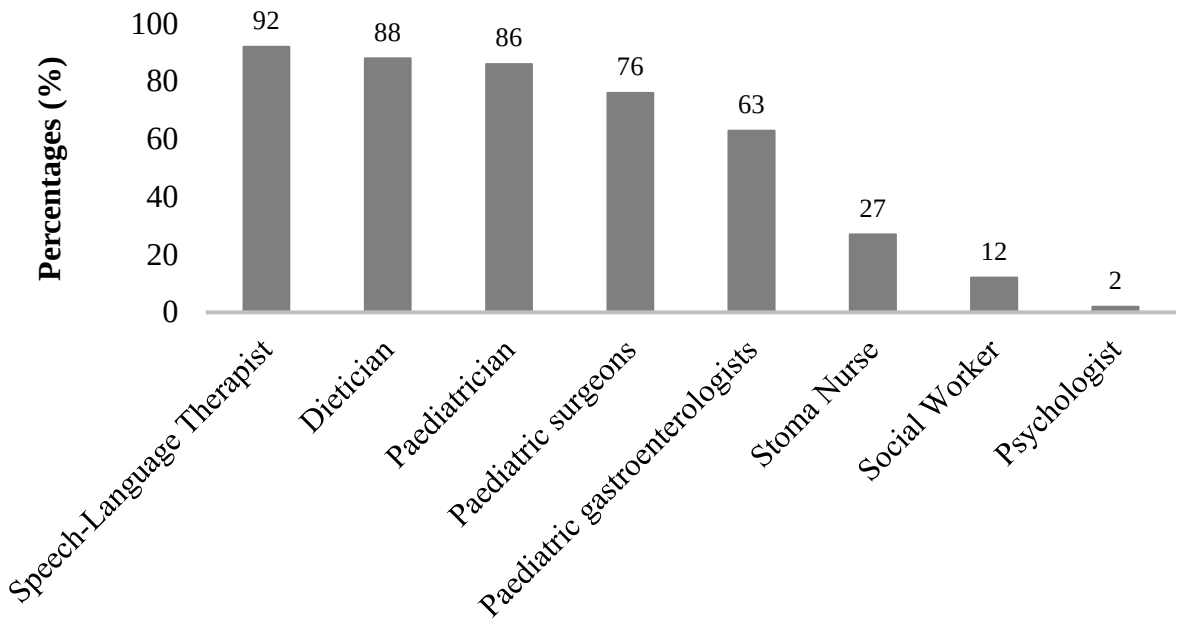

Figure 4.1 *Professionals involved in the decision-making process when considering the insertion of a gastrostomy tube (N=59).*

Figure 4.1 shows that a multi-disciplinary team is involved when deciding to insert a gastrostomy tube. This usually consists of speech-language therapists, dieticians, paediatricians, paediatric surgeons and paediatric gastroenterologists. The professionals least involved in the decision-making process are stoma nurses, social workers and psychologists.

Table 4.1 *Reasons for inserting a gastrostomy tube (N=59).*

Reason	**N=59**	**Percentage (%)**
Neurological disorders causing dysphagia	59	100
Failure of adequate intake	38	64
Craniofacial abnormalities	12	20
Oncology problems with malnutrition	5	8
Other	6	10

Table 4.1 illustrates the reasoning behind the insertion of the gastrostomy tubes. All of the professionals surveyed stated that a gastrostomy tube is inserted secondary to neurological disorders causing dysphagia. The professionals that stated ‘other’ mentioned that a gastrostomy tube is inserted owing to caustic ingestion; neonatal encephalopathy; quality of life for the families and “other anatomical abnormalities”.

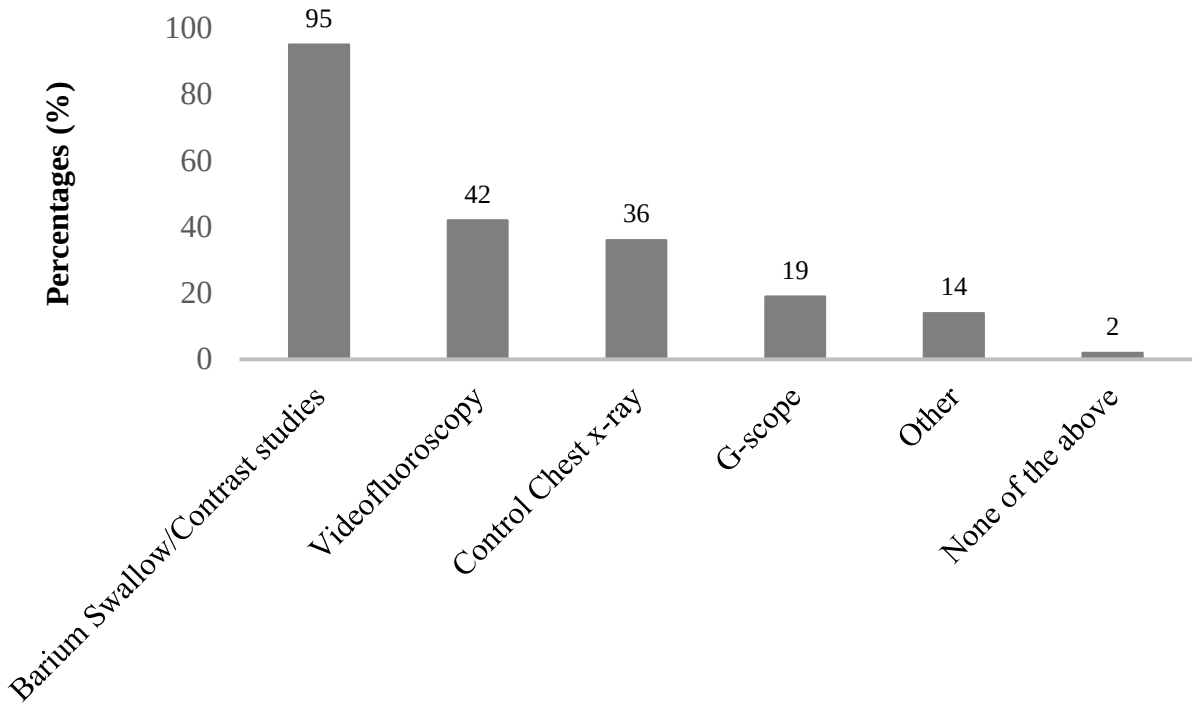

Figure 4.2 *Assessments performed prior to the insertion of a gastrostomy tube (N=59).*

Figure 4.2 shows the most common assessment, of the professionals surveyed, is the barium swallow with 95% (n = 56) of the professionals claiming to use it. Eight professionals noted other types of assessment, of which five mentioned a milk scan was performed in addition to the barium swallow prior to the insertion of the gastrostomy tube.

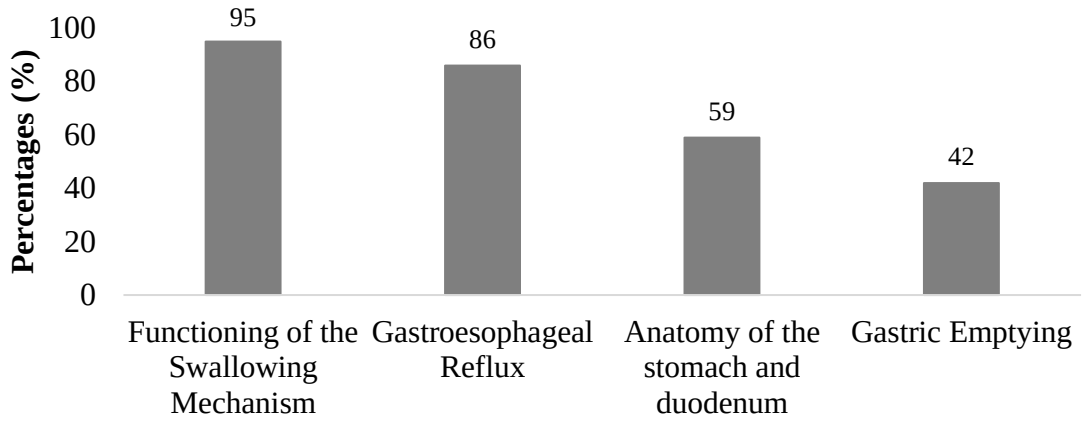

Figure 4.3 *Information obtained prior to the insertion of the gastrostomy tube (N=59).*

Figure 4.3 shows the most common information obtained by the professionals surveyed, is the evaluation of the swallowing mechanism and the presence of gastroesophageal reflux. The information that is required the least is gastric emptying.

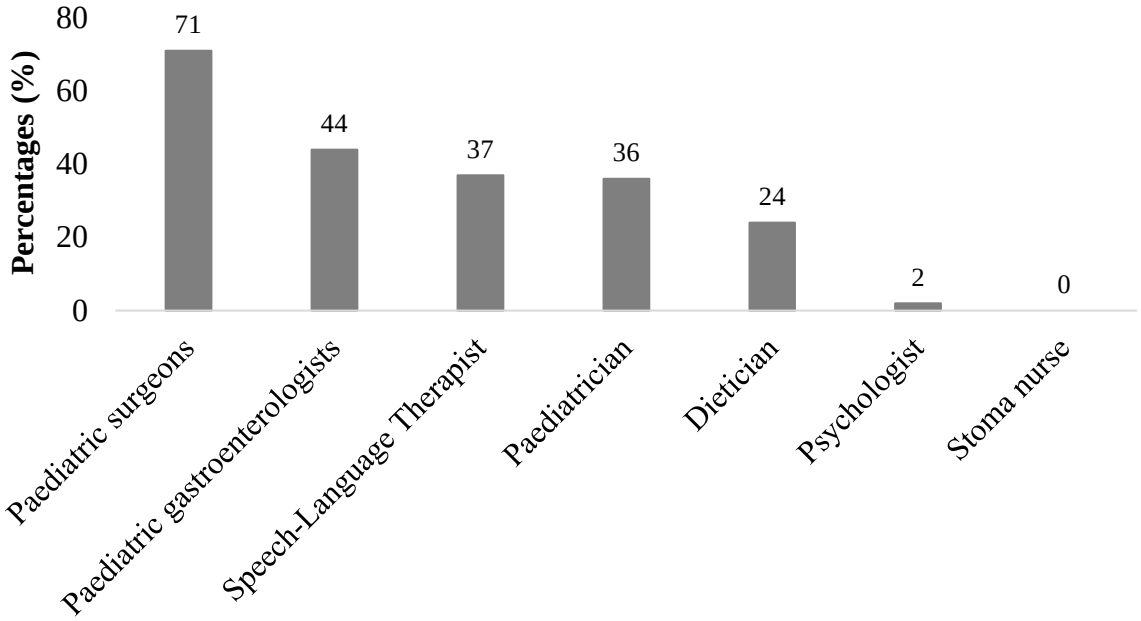

Figure 4.4 *The professional making the final decision to insert the gastrostomy tube (N=59).*

Figure 4.4 shows that 71% (n = 42), of the professionals surveyed state that the paediatric surgeons are making the final decisions to insert the gastrostomy tubes.

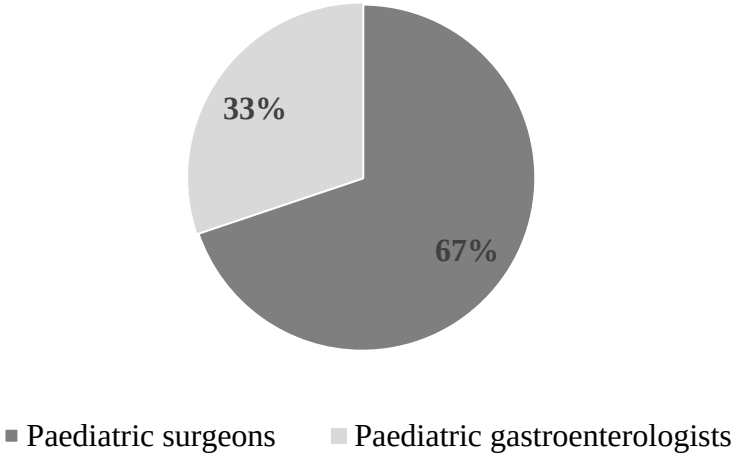

Figure 4.5 *The professional performing the surgery (N=59).*

Figure 4.5 illustrates that the paediatric surgeons are performing the surgery when a gastrostomy tube is required.

Table 4.2 *Areas in which the family receive pre- and/or post-operative counselling (N=59).*

Area's Counselled	**N=59**	**Percentages (%)**
How to feed using the tube	56	95
Details of the surgery	52	88
How to flush the tube	52	88
What type of food to feed through the tube	51	86
Cleaning the stoma	49	83
How to troubleshoot if the tube leaks, gets blocked or becomes dislodged	42	71
How to change the gastrostomy tube	37	63
Positioning of the external bumper on the skin	32	54

Families recieve a range of pre- and post-operative counselling information. Table 4.2 shows that families receive informaiton on how to feed via the gastrostomy tube; details of the surgery and how to flush the tube after gastrostomy as stated by the professionals surveyed. The least common information given, is where to correctly postion the external bumper on the skin.

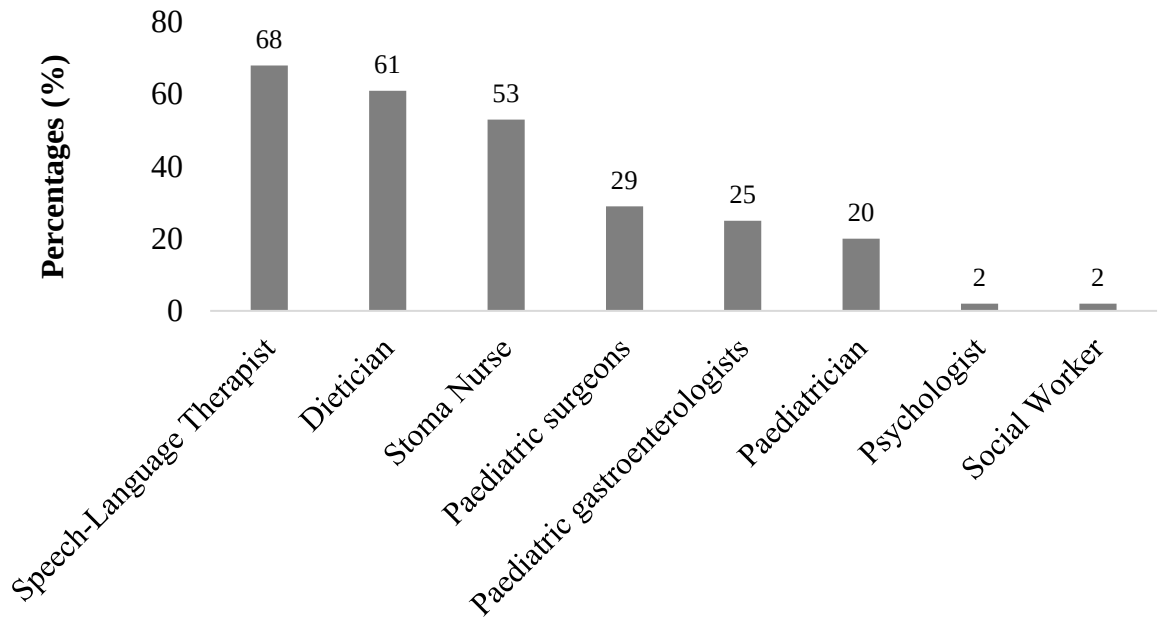

Figure 4.6 *The health care professional providing the counselling around the gastrostomy tube (N=59).*

Figure 4.6 shows the speech-language therapists (n = 40) and the dieticians (n = 36) are the professionals that are providing the counselling to the patient's families.

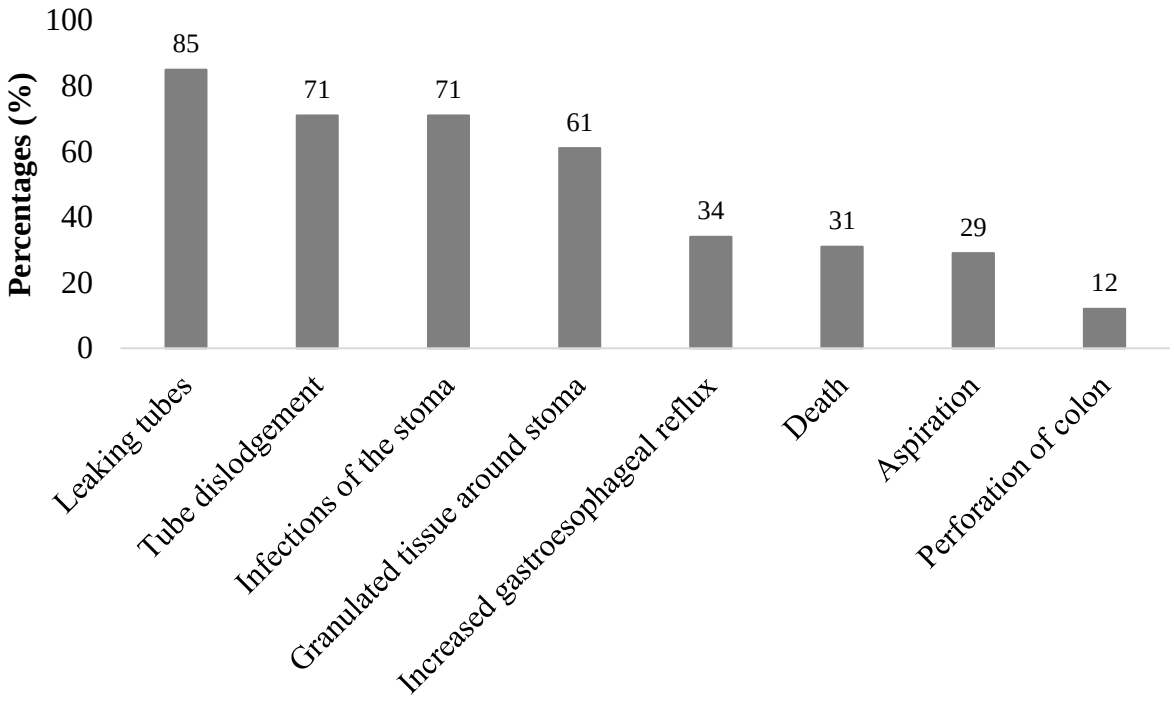

Figure 4.7 *Complications experienced after the insertion of the gastrostomy tube.*

Figure 4.7 shows that the most common complications reported by the professionals are leaking gastrostomy tubes (n = 50), tube dislodgement (n = 42) and infections of the stoma (n = 42). Perforation of the colon (n = 7) was reported to be the least common complication observed by the professionals in the survey.

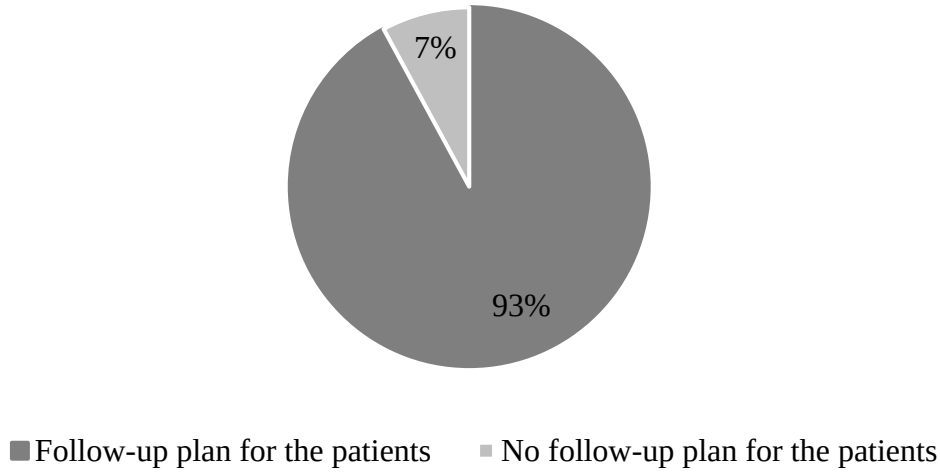

Figure 4.8 *Patients receiving a follow-up plan after the insertion of the gastrostomy tube.*

Figure 4.8 demonstrates that 93% (n = 55) of the professionals surveyed stated that there is a follow-up plan for their patients after the insertion of the gastrostomy tube.

5. Discussion and Future Work

The study set out to determine the decision-making processes prior to the insertion of a gastrostomy tube. Looking at the data from the survey, a multidisciplinary team approach within the three public hospitals is being implemented when it comes to the decision-making. This team approach assists with providing a variation of skills needed to make an appropriate decision regarding the children and their families. The survey did not discuss the importance of each professional's role in the decision, however, it was found that the speech-language therapist is the most involved professional in the team, this is depicted in Figure 4.1. The professionals that closely follow the speech-language therapists are the dieticians, paediatricians, paediatric surgeons and paediatric gastroenterologists.

Neurological disorders causing dysphagia are the most common reason for the insertion of a gastrostomy tube as reported by the health professionals, outlined in Table 4.1. It is known that neurological disorders cause difficulties with the functioning of the swallowing mechanism and therefore this would need to be assessed.[9] Figure 4.2 shows that a barium swallow is the most common type of assessment completed. A modified barium swallow or videofluoroscopy is usually used to determine the functioning of the swallowing mechanism, but it is a poor diagnostic test for GOR.[18] Five out of eight professionals who ticked 'other' mentioned that a milk scan was used as one of their assessments, which is represented in Figure 4.2. A milk scan is usually used to assess gastric emptying, however, it is also a poor diagnostic test for GOR.[27] Gastric emptying is the least common information obtained amongst the professionals surveyed. Three out of those five professionals, indicating a milk scan is performed, indicated that information about the children's gastric emptying as well as GOR is obtained prior to the insertion of the gastrostomy tube. The results from the survey suggest that there is a confusion between what the barium swallow and milk scan assess and what assessment should ultimately be used. The gold standard for assessing GOR would be a

24 hour esophageal pH monitoring impedance study, but this equipment is not readily available in the public health care sector.[18] The lack of consistency in the investigations for GOR reflects in the disagreement in the literature regarding the needs to perform investigations prior to the insertion of a gastrostomy tube.

The final decision to insert the gastrostomy tube in children amongst the hospitals surveyed is done by the paediatric surgeons, which is shown in Figure 4.4. This directly relates to the professional performing the surgery in the hospitals surveyed. The paediatric surgeons are usually performing the surgery for the gastrostomy tubes, as demonstrated in Figure 4.5. In the literature, it reports that either the gastroenterologists or the paediatric surgeons are the professionals performing the procedure, as it depends on the hospital.[28]

From the results of the survey, the families are receiving a range of pre- and post-operative information as shown in Table 4.2. This includes the details of the surgey, how to feed via the gastrostomy tube and how to flush it. Counselling the family before and after the insertion of the gastrostomy tube is one of the most important areas that need to be covered.[8] This should assist in decreasing the complications as well as the severity thereof.[8] Figure 4.6 shows that the speech-language therapists, dieticians and stoma nurses are the professionals who are most involved with this counselling process. The least common information given is where to correctly postion the external bumper on the skin with 27 out of 59 professionals stating that the correct position of the external bumper is not shown. Out of those 28 professionals, 22 reported that leaking tubes is one of the complications that occurred after the insertion of the gastrostomy tube. Delegge[29] reported that the placement of the external bumper, if placed against the skin too tightly, could lead to “poor tissue blood flow, wound breakdown, and peristomal leakage”. Studies around each professional’s role in the decision-making process may be interesting to obtain in order to correctly identify if the families are receiving adequate and appropriate information before, and after, the insertion of a gastrostomy tube.

Giving the parents information about potential complications and the maintenance of the gastrostomy tube can assist in early identification of problems allowing for appropriate treatment in a timely manner.[30]

It would be useful to look at a direct correlation between areas that are counselled and what complications occur, if any, over a longer period after the insertion of the gastrostomy tube. Correct positioning of the external bumper could have a positive impact on decreasing the number of leaking tubes.[29] Infections of the stoma and tube dislodgements are among the most common complications reported by the professionals in this study. Tube dislodgements have been reported in the USA to be around 12.8%.[27] Seventy-one percent of the professionals in the survey, as shown in Table 4.2, stated that the patients are provided with counselling around troubleshooting the gastrostomy tube if it leaks, gets blocked or becomes dislodged. It is not unusual that the importance of education around the gastrostomy tube is only recognised after complications have occurred.[8] Education around gastrostomy tube care would therefore be important to include in a guideline to assist with decreasing the complications seen.[8] Schweitzer, et al.[8] mention that a standardised evidence-based education protocol for gastrostomy tubes should be devised. Based on the findings of this study, and supporting literature[8], a checklist was created to ensure participation from multidiscipline professionals and to guarantee proper counselling for parents and/or families when considering the insertion of a gastrostomy tube. This checklist can be found in Table 5.1.

Table 5.1 *Checklist for professionals to follow when considering the insertion of a gastrostomy tube in children.*

Professionals involved in the presenting case:	✓
Dietician	
Paediatrician	
Paediatric Surgeon	
Paediatric Gastroenterologist	
Speech and Language Therapist	
Stoma Nurse	
Information to obtain prior to the insertion:	✓
Functioning of the swallowing mechanism	
Gastroesophageal reflux (if the child has a neurological impairment or previous history of reflux)	
Area's the family need to be counselled in before and/or after the surgery	✓
Details of the surgery (*Doctor performing the surgery*)	
Cleaning the stoma (*Dieticians, SLTs and Stoma Nurse*)	
Flushing the tube (*Dieticians, SLTs and Stoma Nurse*)	
Using the tube to feed (*Dieticians, SLTs and Stoma Nurse*)	
Types of food to feed and how to prepare it (*Dietician*)	
Troubleshoot if the tube leaks (*Doctors, Dieticians, SLTs and Stoma Nurse*)	
Troubleshoot if the tube gets blocked (*Doctors, Dieticians, SLTs and Stoma Nurse*)	
Troubleshoot if the tube becomes dislodged (*Doctors, Dieticians, SLTs and Stoma Nurse*)	
Correct position of the external bumper on the skin making sure it is flush against the skin, not too tight (*Doctors, Dieticians, SLTs and Stoma Nurse*)	
Follow-up Plan	✓
To be seen at the Feeding/Stoma Clinic	
To be seen at individual departments	

Ninety-three percent of the professionals stated that there is a follow-up plan with the children after the insertion of the gastrostomy tube. However, there were inconsistencies in the details of the follow-up plan not only between the three public hospitals but also between professionals within the same hospital. It would appear from the study that each professional is involved in the follow-up plan, but it is unclear if it is still a multi-disciplinary team approach post-operatively. Two out of the three hospitals in the study have a specific feeding clinic, although, it did not appear that the different professionals knew about this multidisciplinary service. "It remains important that the decision to place an endoscopic gastrostomy is made by an appropriate multidisciplinary team, which then provides active follow-up and care for the child and device."[5]. It would be beneficial to obtain information on the process detailing follow-up plans and educational support within the specific public hospitals.

6. Conclusion

Professionals working within the three public hospitals targeted in the study have shown that their decision-making process prior to the insertion of a gastrostomy tube is made within a multidisciplinary setting. Assessments and information obtained beforehand are in line with recent literature. Based on the number of professionals reporting neurological disorders, as the main reason for the insertion of a gastrostomy tube, some authors would recommend that GOR is investigated before. In a setting without access to esophageal pH monitoring impedance studies, a detailed evaluation of the clinical history and associated symptoms is recommended to assess for GOR. In cases with severe GOR, concomitant anti-reflux surgery may be indicated.[5] This would need to be addressed in the follow up plan. The families are receiving counselling by a variety of professionals, namely the speech-language therapists, dieticians and stoma sisters, to ensure they know how to feed and troubleshoot any problems arising from the gastrostomy tube. Complications, such as tube dislodgement, leaking tubes, and infections of the stoma, are reportedly common within the hospitals studied.

A checklist was compiled to assist professionals with decision-making for the insertion of gastrostomy tubes. Identification of GOR in children with neurological impairments as well as outlining specific areas of counselling, which must be performed by certain professionals involved, as well as a brief follow up plan, was included in this checklist.

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Appendices

Appendix A: Questionnaire for Data Collection

UNVERSITY OF THE WITWATERSRAND

FACULTY OF HEALTH SCIENCE

POST GRADUATE RESEARCH

011 717 2075

Questionnaire

1. What is your profession?	☐ Dietician ☐ Paediatrician ☐ Paediatric gastroenterologists ☐ Paediatric surgeons ☐ Psychologist ☐ Speech-Language Therapist ☐ Stoma nurse ☐ Other: _____
2. Do you see children who require gastrostomy tubes?	☐ Yes ☐ No (if no, you do not need to continue with the questionnaire)
3. How long have you been working with children who require gastrostomy tubes?	☐ 0 – 5 years ☐ 6 – 10 years ☐ 11 – 15 years ☐ More than 15 years
4. As a general guideline, how many children have you recommended/referred for a gastrostomy tube?	☐ 0 – 10 children ☐ 11 – 20 children ☐ 21 – 30 children ☐ 31 – 40 children ☐ More than 40 children

5. What is usually the reason behind inserting gastrostomy tubes? (*if appropriate, tick more than one*)	☐ Craniofacial abnormalities ☐ Failure of adequate intake ☐ Neurological disorders causing dysphagia ☐ Oncology problems with malnutrition ☐ Other: _____
6. Please indicate which professional/s are involved in the decision-making process when considering the insertion of a gastrostomy tube? (*if appropriate, tick more than one*)	☐ Dietician ☐ Paediatrician ☐ Paediatric gastroenterologists ☐ Paediatric surgeons ☐ Psychologist ☐ Social Worker ☐ Speech-Language Therapist ☐ Stoma nurse ☐ Other: _____
7. Which professional/s in your hospital make the final decision to insert a gastrostomy tube? (*if appropriate, tick more than one*)	☐ Dietician ☐ Paediatrician ☐ Paediatric gastroenterologists ☐ Paediatric surgeons ☐ Psychologist ☐ Speech-Language Therapist ☐ Stoma nurse ☐ Other: _____
8. Please indicate if any of the following assessments are performed prior to the insertion of a gastrostomy tube? (*if appropriate, tick more than one*)	☐ Control Chest x-ray ☐ Barium Swallow/Contrast studies ☐ G-scope ☐ Videofluoroscopy ☐ None of the above ☐ Other: _____ If none, please provide a reason: _____ _____ _____ _____ _____

9. Please indicate if the following information is required prior to the insertion of the gastrostomy tube, in your hospital? (*if appropriate, tick more than one*)	☐ Anatomy of the stomach and duodenum ☐ Functioning of the Swallowing Mechanism ☐ Gastroesophageal Reflux ☐ Gastric Emptying
10. Does the family receive pre- and/or post- op counseling in the following areas? (*if appropriate, tick more than one*)	☐ Details of the surgery ☐ Cleaning the stoma ☐ How to change the gastrostomy tube ☐ How to feed using the tube ☐ How to flush the tube ☐ How to troubleshoot if the tube leaks, gets blocked or becomes dislodged ☐ Positioning of the external bumper on the skin ☐ What type of food to feed through the tube ☐ Other: _____
11. Which health care professional usually provides the counseling? (If it is offered) (*if appropriate, tick more than one*)	☐ Dietician ☐ Paediatrician ☐ Paediatric gastroenterologists ☐ Paediatric surgeons ☐ Psychologist ☐ Social Worker ☐ Speech-Language Therapist ☐ Stoma nurse ☐ Other: _____
12. Which doctor performs the surgery in your hospital?	☐ Paediatric gastroenterologists ☐ Paediatric surgeons ☐ Other, please specify: _____ ☐ Unsure
13. Is there a follow up plan once the gastrostomy tube is inserted?	☐ Yes ☐ No If yes, please specify what the follow up entails: _____ _____

	_____ _____ _____ _____ _____ _____ _____
14. Please indicate, if any, the type of complications that you have experienced in your hospital after the insertion of a gastrostomy tube. (*if appropriate, tick more than one*)	☐ Aspiration ☐ Death ☐ Granulated tissue around stoma ☐ Increased gastroesophageal reflux ☐ Infections of the stoma ☐ Leaking tubes ☐ Perforation of colon ☐ Tube dislodgement ☐ Other, please specify: _____

Appendix B: Ethical Clearance Certificate

R14/49 Miss Louise Reed

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160362

NAME: (Principal Investigator)	Miss Louise Reed
DEPARTMENT:	Paediatrics Charlotte Maxeke Johannesburg Academic Hospital Rahima Moosa Mother and Child Hospital Chris Hani Baragwanath Academic Hospital
PROJECT TITLE:	Identifying Current Decision-Making Processes when Considering the Insertion of Gastrostomy Tubes in Children within a Public Hospital Setting
DATE CONSIDERED:	01/04/2016
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Andrea Fourie and Tim De Maayer
APPROVED BY:	Prof C Feldman, Co-Chairperson, HREC (Medical)
DATE OF APPROVAL:	20/12/2016

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 301, Third floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in March and will therefore be due in the month of March each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

Date 10·01·2017

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix C: Permission Letter from CEO (CMJAH)

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Mr. J. Maepa
Office of the Clinical Director
Tell: (011) 488-3365
Email:johannes.maepa@gauteng.gov.za
08 April 2016

Dear Ms L. Reed

Study Title: Identifying current decision-making processes when considering the insertion of gastrostomy tubes in children within a hospital setting.

Permission to conduct the above mentioned study is provisionally approved. Your study can only commence once Ethics approval is obtained. Please forward a copy of your ethics clearance certificate as soon as the study is approved by the Ethics committee for the CEO's to give you the final approval to conduct the study.

Approved / ~~not approved~~

Dr. M. Mofokeng
Clinical Director
DATE: 8/4/2016

Appendix D: Permission Letter from CEO (RMMCH)

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

RAHIMA MOOSA MOTHER AND CHILD HOSPITAL

Enquiries : Dr Edward Hank
Tel : (011) 470 9030/1
Fax : (011) 477 4117
Email : Edward.Hank@gauteng.gov.za

Department of Speech Pathology
University of the Witwatersrand

Dear Louise,

RE: IDENTIFYING CURRENT DECISION-MAKING PROCESSES WHEN CONSIDERING THE INSERTION OF GASTRNOMY TUBES IN CHILDREN WITIN A HOSPITAL SETTING

Permission is granted for you to conduct the research as indicated in the title above.

The terms under which this permission is granted is contained in the Researcher Declaration form that you have signed. Failure to comply with these conditions will result in the withdrawal of such permission.

It is crucial for you to inform the Research Coordinator, Karen Marshall of the actual start and end dates of your study. This could be done by e-mail.

Should the study commence more than 12 months after receipt of this approval letter you will have to go through the process of applying again.

You are strongly advised to keep a signed copy of the declaration form so as to ensure that the terms of this agreement are complied with at all times.

Yours sincerely,

DR EDWARD HANK
Clinical Manager
2016.03.07

ADDRESS: Cnr FUEL & OUDSTHOORN STREET CORONATIONVILLE 2093 / PRIVATE BAG X20 NEWCLARE 2112 JHB

Appendix E: Permission Letter from CEO (CHBAH)

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE
CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 26 Feb 2016

TITLE OF PROJECT: Identifying current decision-making processes when considering the insertion of gastrostomy tubes in children within a hospital setting

UNIVERSITY: Witwatersrand

Principal Investigator: L Reed

Department: Paediatrics and Child Health

Supervisor (If relevant): A Fourie

Permission Head Department (where research conducted): No

Date of start of proposed study: Feb 2016
Date of completion of data collection: Dec 2017

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Hospital. The CEO /management of Chris Hani Baragwanath Hospital is accordingly informed and the study is subject to:-

- Permission having been granted by the Human Research Ethics Committee of the University of the Witwatersrand.
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.

.....
Recommended
(On behalf of the MAC)
Date: 26 February 2016

.....
Approved/Not Approved
Hospital Management
Date: 02/03/16

Appendix F: Permission Letter from HOD of Paediatrics (CMJAH)

TPH 49

DEPARTMENT OF HEALTH
C M Johannesburg Academic Hospital
Department of Paediatrics and Child Health
Private Bag X39
JOHANNESBURG
2000
Tel: 011 488-4246

22 February 2016

The CEO
CMJAH

Dear Ms. Bogoshi

Research Project: Identifying current decision making processes when considering the insertion of gastrostomy tubes in children within an acute hospital setting.
Degree: Master of Science in Medicine (Neurodevelopment)
Candidate: Louise Reed

I hereby consent to Louise Reed collecting data and conducting the above research project in the Department of Paediatrics at CMJAH.

Yours sincerely

Professor V A Davies
Acting Head: Department of Paediatrics

Appendix G: Permission Letter from HOD of Paediatrics (RMMCH)

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

DEPARTMENT OF PAEDIATRICS & CHILD HEALTH
RAHIMA MOOSA MOTHER AND CHILD HOSPITAL

PrivateBag X20, Newclare 2112, South Africa Telephone: +27 11 470-9100/470-9284· Fax: +27 11 470-9169

TO WHOM IT MAY CONCERN

RE: MS LOUISE REED – SPEECH THERAPIST AND AUDIOLOGIST

In my capacity as Head of the Department of Paediatrics and Child Health, I hereby provide my approval and support for the proposed research project "IDENTIFYING CURRENT DECISION-MAKING PROCESSESS WHEN CONSIDERING THE INSERTION OF GASTRONOMY TUBES IN CHILDREN WITHIN A HOSPITAL SETTING" at Rahima Moosa Mother and Child Hospital.

Sincerely

Adjunct Professor Ashraf Hassen Coovadia
Head of Department: Paediatrics and Child Health
Rahima Moosa Mother and Child Hospital
University of the Witwatersrand
2016.05.16

Appendix H: Permission Request Letter to HOD of Paediatrics (CHBAH)

UNVERSITY OF THE WITWATERSRAND
FACULTY OF HEALTH SCIENCE
POST GRADUATE RESEARCH
011 717 2075

Research Title: Identifying current decision-making processes when considering the insertion of gastrostomy tubes in children within a hospital setting.

Dear Head of Department of Paediatrics at CHBAH,

My name is Louise Reed. I am a Speech Therapist and Audiologist who is interested in alternative feeding practices. I am currently completing my Masters in Child Health - Neurodevelopment (Msc) at the University of Witwatersrand. As part of the degree, a research study is required. I am therefore conducting research to determine the decision-making processes prior to the insertion of gastrostomy tubes in children. In this study I am wanting to learn which healthcare professionals are involved in this decision-making process and what type (if any) assessments are done prior to the insertion of the gastrostomy tubes.

In order to gather the information for the study, a questionnaire (see Appendix attached), will be given to professionals within your hospital who are part of the decision-making process prior to the insertion of a gastrostomy tube. The questionnaire will be hand delivered to the professionals and collected after two weeks. It should only take around 20 minutes to complete. It will not affect the workload of the staff or continuance of patient care.

I, _____ (HOD of Paediatrics) of Chris Hani Baragwanath Academic Hospital, hereby grant Louise Reed permission to conduct her data collection at Chris Hani Baragwaneth Academic Hospital in the Department of Paediatrics, in order to determine the decision-making processes prior to the insertion of gastrostomy tubes in children.

If you would like any further information on this research, please contact me on: liz.louisereed@gmail.com or my supervisor, Andrea Fourie, on andrea.l.fourie@gmail.com.

Thank you for your time.

Warm Regards,



Louise Reed

Speech Therapist & Audiologist

Appendix I: Participant Information Sheet

UNVERSITY OF THE WITWATERSRAND

FACULTY OF HEALTH SCIENCE

POST GRADUATE RESEARCH

011 717 2075

Research Title: Identifying current decision-making processes when considering the insertion of gastrostomy tubes in children within a hospital setting.

Dear Colleague,

I am currently conducting research to determine the decision-making processes prior to the insertion of gastrostomy tubes in children. I want to learn which healthcare professionals are involved in this decision-making process and what (if any) assessments are performed prior to the insertion of the gastrostomy tubes.

I would like to invite you to be a part of this study by completing a questionnaire that will take approximately 10 minutes to complete. You will remain anonymous as your name is not required on the questionnaire and your name will not be released in the final results. Your profession however, will be required on the questionnaire and will be documented in the research. Participation in this study is completely voluntary, and if you decide not to participate, there will be no consequences.

If you would like to take part in this study, please complete the consent form attached (appendix E). For any further information based on this research or if you would like to receive a copy of the results, you can contact me on: liz.louisereed@gmail.com or 072 260 5585 or my supervisor Andrea Fourie on: andrea.l.fourie@gmail.com

Thank you very much for your time.

Warm Regards,



Louise Reed
Speech Therapist & Audiologist

Appendix J: Consent Form

UNVERSITY OF THE WITWATERSRAND
FACULTY OF HEALTH SCIENCE
POST GRADUATE RESEARCH
011 717 2075

Research Title: Identifying current decision-making processes when considering the insertion of gastrostomy tubes in children within a hospital setting.

I, _____ (professional) hereby consent to participating in the research study conducted by Louise Reed by completing the relevant questionnaire.

I understand that participating in this study is voluntary and I can remove myself from the study at any stage during the research process.

Kind Regards,



Louise Reed
Speech Therapist & Audiologist