

Percutaneous Endoscopic Gastrostomy: Opinions, Attitudes and Experiences of Patients, Care Takers and Health Workers at a Sub-Saharan Hospital

Victoria Nkore¹, Francis Basimbe², Othiniel Musana³ and Gorreti Nassali³

¹Department of Surgery, St Francis Hospital Nsambya, Uganda Martyrs University, Nkozi, Uganda

²Gastrointestinal Surgery, St Francis Hospital Nsambya, Uganda Martyrs University, Nkozi, Uganda

³Department of Oncology, St Francis Hospital Nsambya, Uganda Martyrs University, Nkozi, Uganda

Abstract

Dysphagia has a high burden of disease with a global prevalence estimated to be at 43.8% and the highest prevalence rate was estimated in Africa at 64.2%. Many medical conditions have been associated with dysphagia including; stroke, Parkinson's disease, dementia and traumatic brain injury. Dysphagia is associated with malnutrition and carries a significant risk of mortality in many patients. To ensure adequate nutritional intake, enteral nutrition is usually the method of choice in patients with a normally functioning gastrointestinal system. The (European Society on Parenteral Nutrition) ESPEN guidelines recommend Nasogastric tube feeding for short term enteral feeding and Percutaneous Endoscopic Gastrostomy (PEG) for long term feeding (>4 weeks). Despite this recommendation the uptake of PEG Tube feeding has been very low in our setting we therefore set out to explore the opinions, attitudes and experiences of patients, caretakers and health workers towards PEG Tube feeding.

Methods: This was a cross-sectional, exploratory qualitative study design conducted using semi-structured in-depth interviews to enable participant's air out their opinions and describe their experiences. Opinions attitudes and experiences of patients, caretakers, health workers that manage patients with PEGs and interact with patients who may require PEG Tube feeding were explored

Results: Three major themes emerged from interviews with health worker and these were: positive experience; negative experiences and community care. "So the PEG has really improved their life in terms of weight gain. We used to rush to hospital because of aspiration pneumonia, but now we stopped and these events reduced in the frequency." – Nurse

The three main theses that emerged from the care takers and patients were, Need for PEG, Benefits of PEG and the challenges they have faced while with a PEG Tube for feeding and Coping mechanisms "When we went home, we were feeding the tube and the porridge is so good for him. You could see that he had become healthy and the skin at come back soon as and so smooth" – caregiver.

Conclusion: Our study found that the need for PEG was significant due to the increasing burden of dysphagia and its associated complications. It also noted that PEG has shown to have improved care and better patient outcomes in terms of health and nutrition. . However multiple challenges and set backs were noted and these included cost, lack of knowledge and resistance from patients and families.

Introduction

Dysphagia has a high burden of disease with a global prevalence estimated to be at 43.8% and the highest prevalence rate was estimated in Africa at 64.2%. Many medical and surgical conditions have been known to cause dysphagia include; stroke, Parkinson disease, dementia and traumatic brain injury. Dysphagia is associated with malnutrition and carries a significant risk of mortality. To ensure adequate nutritional intake, enteral nutrition is usually the method of choice in patients with a normally functioning gastrointestinal system. The ESPEN guidelines recommend NG tube feeding for short term enteral

feeding and PEG (Percutaneous Endoscopic Gastrostomy) for long term feeding (>4 weeks) [1]. PEG has been available as an option of enteric feeding for a while. It was introduced in 1979 by Michael Gauderer, a pediatrician and Jeffrey Ponsky an Endoscopist at university of Cleveland to establish an alternative route for enteral feeding without need for a laparotomy [2-6].

Since then, the procedure has undergone a lot of modifications and improvements. It is currently the recommended and preferred choice for medium- and long-term enteral nutrition in the Western world with an estimated 100000-125000 PEG tube insertions are performed annually in the United states and a total number of 90185 PEG tubes inserted during a ten-year period in Poland [3]. A retrospective study done in the middle east showed 113 paediatric patients who had PEG tube insertion from 2011-2021 [4]. While in Sub-Saharan Africa, only one study done in Benin to determine clinical and nutritional benefits of early PEG placement in patients with locally advanced squamous cell carcinoma of head and neck could be identified [5]. PEG has been shown to be a simple, safe and low cost procedure that has been associated with better superior outcomes with regards complication and mortality rates and also has better outcomes compared to other artificial methods of Enteric nutrition i.e. NGT, Radiological and surgical Gastrostomies [7]. PEG has also been shown to have low complication rate and excellent safety profile even in the elderly and those on anticoagulation [8]. It is also associated with superior outcomes in terms of quality of life, nutritional status and lower rate of complications.

Despite the evidence supporting the role of PEG feeding, the popularity

***Address for Correspondence:** Francis Basimbe, Gastrointestinal Surgery, St Francis Hospital Nsambya, Kampala, Uganda, Tel: +256782506721, E-mail: basimbef@yahoo.co.uk

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and acceptability of PEG varies across different settings and continents. In the western world, PEG as a method of long-term enteral feeding is now widespread while the uptake is low in Asia and almost non-existent in Sub-Saharan Africa. A studies done in Asia have shown very dismal uptake of PEG Tube feeding. In One only 0.62 % of patients underwent PEG after prolonged NGT placement [9]. Some Qualitative data from Asia has identified some Barriers towards use of PEG feeding. Among Heath care Professionals and these s included; lack of knowledge about the PEG, Poor communication between fellow HCPs, patients and the family, lack of understanding of PEG among patients and their families and cost and unavailability. (PEG 6). After five years of PEG Tube insertion in our Hospital we noticed a fairly low uptake with 45 PEG Tube Insertions despite many patients in our setting as potential beneficiaries of this intervention. We therefore set out to determine the attitudes, opinions and experiences of patients, Caregivers and Heath care Professionals s towards PEG insertion which may be contributing to its low uptake in a sub-Saharan setting [10].

Patients involved and methods used: This case-control observational study included 60 adults over the age of 18 with GC and AG. Clinical and endoscopic evidence supported the diagnosis, which was then supported by a histological review of gastric biopsies. Patients were chosen from outpatient clinics and were scheduled for upper GIT Endoscopy in Endoscopy unit in Gastroenterology Unit in Internal Medicine Department, Alexandria University Hospital. After clearly informing all patients, their written consent was obtained. There were two groups of patients: group 1, which contained 30 AG diagnosed patients, and group 2, which had 30 patients with GC. 30 healthy people were enlisted as a control group. Patients who had undergone partial or total gastrectomy, patients who were undergoing chemotherapy or radiotherapy, patients with gastric polyps, patients suffering gastric lymphoma, and patients suffering gastric carcinoid were all excluded from the study. Patients who had taken inhibitors of proton pump or nonsteroidal anti-inflammatory medicines within the earlier six weeks before enrolment were also excluded.

Each patient underwent a full medical history review as well as a regional and local clinical abdominal examination. All patients underwent upper gastrointestinal endoscopy using traditional and narrow band imaging endoscopy with biopsy. Biopsy samples were collected using the most recent Sydney system

of classification. Five biopsy samples were obtained: Two were taken from the antrum, which is 2 to 3 cm from the pylorus; one was taken from the lesser distal curvature, and the other from the greater distal curvature; two were taken from the corpus, which is 8 cm away from the cardia; one was taken from the lesser curvature; and one was taken from the incisura angularis classification of AG using the Sydney system of grading. Serum Pg 1 and Pg 2 assay was estimated by Enzyme-linked immunosorbent assay (ELIZA) and Pg 1/2 was calculated. Finally, Pylori Antibodies IgG in blood and Pylori Ag in the stool were assessed.

Methods

We conducted a cross-sectional, exploratory qualitative study using semi-structured in-depth interviews to enable participant's air out their opinions and describe their experiences. The study was conducted at St. Francis hospital Nsambya Gastrointestinal Surgery Unit. The Gastrointestinal services offered include gastrointestinal endoscopy which performs on average 3000 diagnostic and interventional endoscopies annually including percutaneous Endoscopic Gastrostomies. Patients requiring PEGs were referred from the neurosurgeon, physicians in Medical ward, Intensive Care Unit and children from the paediatric neurologist. These patients have a wide range of medical conditions that require parenteral feeding including, cerebral vascular accidents, oral tumors, severe Parkinsonism, severe dementia, cerebral palsy and many others. All patients who underwent PEG Tube placement at St Francis Hospital Nsambya were included in the study , the caretakers of their patients were also included in this study as well the health care professionals working closely with patients who require PEG Tube Placement and those who have had PEG Tubes placed (Table 1).

Patients and caretakers: Records of patients who underwent PEG since 2018 were retrieved from Gastrointestinal Endoscopy Unit and Hospital identification numbers obtained. Records were accessed and Patients and caregivers were contacted, and an appointment set up at the time and place convenient for the participants (Table 2). Health workers who work closely with patients who are on PEG those in charge of initiating PEG feeding as well as those who take care of them long term were contacted to participate in the study.

Table 1. Demographics of care takers interviewed.

Code no	Age	Gender	Relationship to Patient	Level of Education	Marital Status
P1	51	F	Daughter	Bachelor	Married
P2	50	F	Daughter	P7	Married
P3	49	F	Niece	P7	single
P4	25	F	Nanny	Bachelor	Single
P5	39	F	Mother	Bachelor	Married
P6	33	M	Son	Bachelor	Single
P7	27	F	Foster mum	Bachelor	Married
P8	23	F	Grand daughter	Bachelors	Single
P9	32	M	Father	S4	Married
P10	27	F	Mother	S4	Married
P11	51	F	Father	S.4	Married
P12	27	F	Nanny	Certificate	Married
P13	26	F	Nanny	S.4	married
P14	29	F	Nanny	S,4	Married
P15	35	F	Nanny	S.6	Married
P16	59	M	Brother	Masters	Married
P 17	43	F	Leader of Nursing home	Bachelors	married

Table 2. Demographic characteristics of health care professionals interviewed

Code No	Age	Gender	Occupation	Experience of PEG
HCP 1	40	M	Gastrointestinal surgeon	7 years
HCP 2	61	M	Physician	5 years
HCP 3	40	M	Paediatric neurologist	5 years
HCP 4	31	M	Medical officer (ICU)	5 years
HCP 5	35	M	Medical officer	6 years
HCP 6	45	F	ICU nurse	2 years
HCP 7	28	F	Nurse(Nursing home A)	7 years
HCP 8	27	M	Nurse (lead nurse Nursing home A)	5 years

Eight HCPs participated in the study and these included five doctors and three nurses (one ICU nurse and two from the nursing homes). Cadres of the doctors included; one endoscopic surgeon, two medical officers with one working in ICU, one physician and a paediatric neurologist. A nutritionist was also contacted but had never interacted with a patient using a PEG tube for feeding.

Study procedure: Informed consent was obtained from participants who agreed to participate in the study. Face to face semi-structured interviews were then conducted by the principal investigator using interview guides that had been developed from results and findings of prior literature. Interviews of caretakers took place in their area of convenience, either home or work. Privacy was ensured to permit participants to talk freely about their experiences without worry or interruption. Interviews lasted from 6 minutes to 28 minutes. Average time of the interviews was 12 minutes and were audio recorded using a phone recorder. Notes were taken during the interview and clarification was sought where necessary. Recorded interviews were transcribed verbatim. Data was then analyzed in stages using latent content analysis with an inductive approach. Data was also inserted into a software called N-vivo 12 with the help of the qualitative researcher which were then assessed and condensed to generate codes. Codes were compared, grouped together into subthemes which were then used to generate themes.

Results

This study set out to assess the opinions, attitudes and experiences healthcare workers, caretakers and patients to PEG use. Eight healthcare workers, one patient and 13 caretakers in total were interviewed.

Healthcare workers opinions, attitudes and experiences

Three major themes emerged from interviews with health worker and these were: positive experience; negative experiences and community care. Under positive experience, the following subthemes emerged.

Ease of use: All the health workers agreed on the PEG being easier to use than the alternatives. It is easy to insert, has less requirements once inserted and makes feeding the patient and administering medications a lot easier for the nurses and caretakers. "...the beauty about it is the procedure of putting a peg is simple; both endoscopically and surgically." – doctor 3 "They're easy to use and for a doctor can easily manage and monitor the patient. Apart from that, as long as you get the peg in situ, it doesn't require a lot after. You only come for a checkup." – doctor 2 "Even giving medication is easier now. Because we don't have to deal with dislodged Ng tubes anymore For example. If you would find a Nasogastric tube has dislodged, you it would take about 30 minutes to insert another one. And yet I have many children to give medication to." – nurse 1.

Better tolerance: Many health workers reported that the PEG was better tolerated by their patients than the NG tubes. The health workers no longer have to worry about irritations to the oesophagus, choking. "There is less vomiting and regurgitation. They tolerate feeds better." – doctor 5. The Nasogastric tube renders the lower oesophageal sphincter incompetent, so there is still a risk of reflux and aspiration." – doctor 3 "I noticed then was that most of these patients would have Nasogastric tubes irritating their nose so they would come out even when we would be doing the scopes the whole oesophagus would have wounds because of prolonged Nasogastric tube. Sometimes during its use during feeding, you find you patients end up choking" – doctor 1.

Convenience: The PEG comes with more convenience for the patients and their caregivers. "It provides more comfort for the patient and it's easier to take care of." – doctor 5. "It is easy for someone to walk around with a PEG tube and no one will know. But you cannot move around with a Nasogastric tube." – nurse 3. "When we switch it, sometimes to a button, it is even cosmetic. So someone is even able to be rehabilitated better because they don't have a tube sticking out of them, and it can only be connected when they are feeding it" – doctor 1.

Improved care: Majority of the health workers reported that the care given to patient improved with the introduction of the PEG Tubes. The Nasogastric tube is changed every month well as the PEG Tube can take 3 to 6 months without changing. Patients are also able to feed better reducing the requirement for hospital monitoring. "But" – doctor 2 "It's big enough and you're able to give the patient enough food. It helps you avoid malnutrition. Basically, it affords comfort to the patient and you prevent the problems that usually get when you use the Nasogastric tube such as infection and maintenance blockage." – nurse

3. "Because of the PEG, you know that your patient will be able to feed, you don't have to keep the patient in the hospital all the time as long as you impart them with knowledge. And skills they can do it so they can only come back for a few issues." – doctor 2.

Better patient outcomes: Patients who were switched to PEG showed marked improvement in their health. The health workers reported that this was due to improvement in feeding, reduced risk for pneumonia and other infections. "So the PEG has really improved their life in terms of weight gain, improved health, and reduced aspiration. We used to rush to hospital because of aspiration pneumonia, but now we stopped." – Nurse 1 "Some have gained weight compared to before because they used to vomit without pegs. Some of them used to feed from the Nasogastric tube, but right now they are no longer vomiting and are gaining some weight. And some of them are no longer coughing the way they used to. They used to get pneumonia but this time, no more coughing." – Nurse 2. "Now the children are doing very well; the weight gain, the smile and eventually helps the parents who were hiding their children and are now getting the children out, even exposing them. Initially, they were clothing them and hiding because they're very malnourished and these mothers were ashamed of their children." – Doctor 4. The negative experiences reported by the health workers were falling in the following subthemes.

Cost: Cost of PEG is a big barrier to its utilization as not very many patients are able to afford. "As an intervention, the PEG kit itself is a bit costly. It is still a challenge, even up to now because the average cost of a PEG Kit and procedure for placement is 1.6 million Uganda shillings (400USD)." – Doctor 1. "I think when the costs go down then they can go to the outskirts of Kampala because they are just in Kampala." – Doctor 2. "It is expensive and not many people are doing it. So because not many people are doing it, you end up having the Cost becomes that very high. People have not embraced it and it's expensive." – Doctor 4. "Even if you tell them what they need, most times they cannot afford. Because the patient will tell you, yes, musawo I know I need it, but how much does it cost? How will I cater for it after? And even the maintenance because they will have to replace it every three or six months or four months. And most of them cannot afford." – Nurse 3.

Inadequate knowledge: The health workers sited that not very many of their colleagues are knowledgeable about the procedure which limits its recommendation to the patients. "Many times, the attendants and the doctors and the health workers taking care of these patients do not have the knowledge. So have not been counseling and picking the patients appropriately who need the intervention" – Doctor 1. "The people who are responsible for prescribing it and they talk to their parents, do not know about it, they even fear it, the doctors themselves." – Doctor 4. "Both of them, both the caretakers and the health workers, need to be taught about the PEG tube because most of the health workers are still not familiar with it. So that has been my biggest challenge." – Nurse 3.

Low adoption from health workers: Health workers in many setting have been slow in adopting PEG Tube for feeding. It has also not been taught in many of the universities the health workers trained from. The other opportunity for learning about the procedure is in Continuous Professional Development (CPD) sessions but even these are not satisfactorily attended. "So it is probably an issue of adoption to newer and better ways of doing things" – doctor 1. "Even at the university we don't study it." – Doctor 2.

Low acceptance from patients: Some health workers have faced resistance from patients and their caregivers on the use of PEG Tubes. This they believe is because the procedure is relatively new.

"The other challenge that we face is resistance to accept a tube on the abdomen. They find it as something very strange which is still a bit of a challenge" – doctor 3.

"Sometimes even convincing the relatives to put an Nasogastric tube is hard. So a PEG Tube is even harder to convince them" – Doctor 3.

"Acceptance of a PEG Tube in our setting it is not something that is very common, that has been used commonly given that even many doctors do not know about these PEG tubes." – Doctor 4.

Community care

Under the theme of community care, health workers felt that patients do not yet have many places they can go to if they get issues while in the community.

"I feel there is not enough (in terms of taking care of a PEG in the community) because people do not know about the PEG. Few centers are doing a PEG Tube placements. Usually you have to have a PEG Care nurse and a PEG Follow up clinic where people come and tell you this is what we did and everything, this is where we are so far but we don't have." – doctor 4

These gaps are being filled by doctors having to go into the community to follow-up on their patients or collaborating with health workers with in the community.

"I have managed patients with issues of PEG at home." – Doctor 1.

"I have had to correspond with health workers at nearby centers where these patients are taken when they notice a challenge" – doctor 1.

Though not adequate, some health workers believe that the community offers some support for patients with PEG.

"There are people in the community, the Village Health Teams and those other health workers that are available to lend a hand whenever they need help." – doctor 5

"The bed side nursing services are on the increase." – Doctor 3.

Patient opinion, attitude and experience: The patient attitudes and experiences were categorized into 4 themes.

Need for PEG: The patient reported to have had a tumor that affected his swallowing. The PEG was recommended because he was not eating food. "I was unable to swallow the food I that was eating" – Patient.

Benefits of the PEG: The tube improves his health. He reported being able to feed and gaining weight. "It has helped me a lot in terms of feeding, since I used not to eat anything. But now, at least I have some energy." – Patient. "Yes, I am much better now, I can walk. I can even travel alone to the village." – Patient.

Challenges: Use of the tube came with a few challenges. He some experiences blockage of the tube, infection around the tube, pain and too much saliva from the throat. "So whenever I get infections around the tube, I produce a lot of saliva, and start feeling a lot of pain around the tube." – Patient. He also complains that the food he has to consume is not very ideal for his daily requirements. "Because of the food being dilute, it cannot build me up the same way as someone who eats solid food." – Patient.

Coping: The patient has lived with the PEG for six months now and has learnt to use and take care of the tube. He reports feeding 5 to 6 times daily and maintaining the tube himself. "But they showed me how to use it and I went on learning slowly by slowly. I am now very used to the tube.What I usually do is clean around the tube with warm, salty water and then smear Vaseline after." – Patient. Even when the tube gets blocked, he has found ways of solving his issues without going to the hospital. "The tube had started blocking, but I devised means and got a new spare part of a bicycle that I always use and fix in the tube and it starts working" – patient.

Caregivers' opinions, attitudes and experiences: In exploring caregivers' opinions, attitudes and experiences, 5 themes emerged.

Reasons for PEG: "He had gotten two strokes; one in the brain, the other one had affected the right side. And then he had taken about 5 months without eating because as if he wanted to die" – Caregiver 11. "He was not eating enough and would refuse the food" – Caregiver 11. "Elizabeth has been getting a lot of congestion so during the feeding process if she begins coughing most definitely she will vomit out the food." – Caregiver 12. "According to me, I think they realized maybe the feeding wasn't that proper and adequate." – Caregiver 12. "Because of the on and off congestion, so when she starts choking like that, You have to definitely stop the feeding so she gets less food than what she is supposed to get." – Caregiver 11. "We had a problem of allergy When the weather is cold, He scratches all the body and started spitting out the food" – Caregiver 13. "When it is very cold, he has to spit it out whether drinking porridge or drinking juice." – Caregiver 11

"Of course and he was not putting on weight so the doctor said that maybe because of the allergy and the spitting he was not getting satisfied" – Caregiver 13. "He cannot swallow well the food and it chokes him" – Caregiver 14. "So mum had a problem with esophageal cancer" – Caregiver 6. "She had lost a lot of weight" – Caregiver 6. "She was just trying to force food through the throat, the food was not moving was very difficult and would vomit most of the time." – Caregiver 6.

Benefits: "When we went home, we were feeding the tube and the porridge is so good for him. You could see that he had become healthy and the skin at come back soon as and so smooth" – caregiver 11. "It has even been working better for her than the Nasogastric tube because she doesn't have congestion or secretions like previously." – Caregiver 12. "The vomiting is not there" – caregiver 12. "He even stops that thing of over vomiting cause here at first when you would feed him speedily, he would vomit a lot." – Caregiver 14. "She has Gain weight" – caregiver 6. "Yeah, that's improved really because at some point but it's too bad. She couldn't even walk. She was literally starving to death." – Caregiver 6.

Challenges: Caregivers sited some challenges they faced with the PEG which ranged from cost of the procedure, blockage of the tube. "So when we accepted they told us it is 1.6 million" (400USD) – caregiver 11. "At first it was a challenging thing because it blocked the first day in hospital and had to call someone to help us and the nurse helped us" – caregiver 11. "She has discomfort with sitting she doesn't like being on the chair." – Caregiver 12. "It has been good but we still have the same problem because when you feed him and the weather is cold, he stretches in a funny way and the food does not move in the tube. It comes back up" – caregiver 13. "I don't know where it is still the same problem or there is another problem because sometimes even when it is not cold, he still does the same thing." – Caregiver 13. "Through the tube so we are still experiencing the same problem as when we were feeding by mouth" – caregiver 13. "And the challenge I faced was that it could take long to feeding him because, you give him. You stop and the way you wait for some minutes until he relaxes and then you add him more food. So it could just take long while feeding him So this one this one, it takes long specifically than the shorter one" – caregiver 14. "But also we use a lot of warm water If we have to because sometimes, if you put food it sticks around it, you Have to flush a lot." – Caregiver 6. "So sometimes, she says, there is some pain and she uses a warm cloth sometimes and it gets okay." – Caregiver 9. "You know, is there some point which is a bit narrow and sometimes you put food which is A bit thick and that's what causes the blockage." – Caregiver 8. "They're supposed to change it but I'm still waiting for money because it's also quite expensive." – Caregiver 10.

Coping: Some caretakers reported that the patients received help from the family member which helped them cope with the PEG. "Sometimes it was challenging but we had the children also helping us since we could do in intervals." Patients got self-reliant where they no longer need to go a health facility for issues faced with the PEG tube. "She got something so she could use whenever it blocks. So it's a part of a bicycle, shaped as a small wire. So she inserts it and tries to unblock." – Caregiver 12. "You know because even initially it was that blocking we went to a nearby clinic and they helped us but over time, we learnt because we couldn't be going all the time." – Caregiver 13.

Discussion

The following themes emerged from in-depth interviews with Heath care professionals (HCP); positive experiences, negative experiences and community care. Attitudes and experiences of the patient were grouped into four themes namely; need for PEG, benefits of PEG, challenges of PEG and coping. Themes compiled from the caretakers were seven in number and this was attributed to the fact that they were more in number and caretakers of both children and adults were interviewed making their experiences and attitudes vast and diverse. These included; reason for tube, anxiety before procedure, benefits of PEG, challenges of PEG, peoples' reactions, coping and unpleasant experiences. A popular theoretical framework that describes how people's attitudes, beliefs, and experiences can influence their health behaviours called the Health Belief Model (HBM) was used in our study. It focuses on the following; perceived susceptibility, perceived severity, perceived benefits, perceived barriers, modifying variables, cues to action and self-efficacy.

In our study, perceived susceptibility and severity were seen in terms of degree and complications of dysphagia which were associated with acceptance of the PEG namely; inability to chew or swallow any food which resulted into vomiting, choking, aspiration and the recurrent hospital admissions due to chest infections and malnutrition. These prompted the caretakers and HCPs to get PEG tubes. In addition, the irritation, discomfort and numerous dislodgements of the Nasogastric Tubes also made them consider the PEG tubes. Caretakers and patients reported that they would choose the PEG again if given the option again because they perceived benefits of PEG in terms of improved nutrition and weight gain for their patients due to improved feeding. They also noted improved health outcomes since the patients were now able to take medicine and the

rate of aspiration pneumonia and hospital admissions had reduced. However; one caretaker reported that she would recommend PEG insertion but only for patients who are strong enough to withstand the procedure since her mother died immediately after PEG insertion.

The cost, lack of knowledge and low adoption identified from the HCPs could be understood through the Health Belief Model as a lack of cues to action leading to confusion, misunderstanding and resistance among patients and caretakers. This is because health workers will not properly recommend what they don't know. Furthermore, they cannot recommend an expensive procedure to someone who cannot afford which could be contributing to the low adoption. The resistance/poor acceptance by the patients and caretakers is mainly attributed to the cost, poor counselling and contradicting information from the health workers. It can also further be explained through the Health Belief Model as part of the modifying variables which include the psychosocial and demographic characteristics of the patients, caretakers and the rest of the community. These include the socio-economic, stigma and negative comments uttered by family members and the community identified from the study.

In terms of positive experiences, health workers reported that the PEG was easier to use and had less requirements once inserted. They also noted better and improved outcomes for their patients in terms of nutrition, health and hospital requirements since the PEG was better tolerated and more convenient for the patients, caretakers and even health workers themselves. Patients and caretakers also reported great improvement in feeding and taking medication which led to weight gain and improved health. This can be explained through the HBM as perceived benefits since both health workers and caretakers would both recommend the PEG due to its numerous advantages. This is similar to a systematic review done in Turkey in which five of the studies reviewed showed that gastrostomy feeding improved the quality of life of patients and their caretakers [11]. A study done in Thailand; caregivers mostly agreed that their child had improved nutritional status, overall health and quality of life [12].

However, negative experiences were also noted; cost was one of the major barriers noted among the health workers and caretakers towards use of the PEG. This was attributed to multiple factors; for the health workers, high cost was attributed to the low expertise, few centres doing the procedure as well as the fact that PEG is not readily available in Uganda. For the patients and caretakers; cost was attributed to the low socio-economic status to facilitate insertion of the PEG, replacement and even to acquire the types of feeds required for the PEG. A systematic review on attitudes and barriers to PEG feeding found that health systems and resource allocation influenced decision to use a PEG tube. It showed that in Asia and some parts of Europe there was no reimbursement to PEG and long-term enteral feeding yet in USA and countries like Germany, medical insurance covered enteral feeding [13]. Another study carried out in Pakistan, many of the respondents positively agreed that the PEG prolonged survival and was more convenient to use than the Nasogastric tube however 49% reported financial constraints in terms of replacement procedures and use of commercially available feeds [14].

The other negative challenge cited among health workers was inadequate knowledge and low adoption of PEG among other health workers which limits its recommendation to the patients. This is because they cannot recommend what they don't know. The lack of knowledge is attributed to its absence in the undergraduate curriculum and poor reading behaviour of the health workers. According to a systematic review of PEG barriers, HCPs' expertise and familiarity with PEG will help patients and caregivers who are unsure about the procedure develop confidence [13]. HCPs also noted that Nasogastric tube feeding was their first choice of recommendation regardless of clinical condition since it was readily available and convenient and it was perceived as a reversible process hence giving hope to the patients [15]. According to a Malaysian study, the lack of emphasis on enteral nutrition training in medical and allied health professions' undergraduate and diploma curriculum appears to be the cause of knowledge gaps [16].

They also cited a challenge of resistance and low acceptance from the patients and caretakers to PEG. This is because the procedure is relatively new and most people find it strange to feed from a tube in the abdomen. This could also be explained by the reactions reported by the caretakers that family and community members viewed PEG as scary, unnatural and painful to the patient. These reactions are bound to increase resistance among patients and caretakers. A study done on PEG in cystic fibrosis patients cited that patients without PEG were apathetic towards the procedure and were more concerned that it would interfere with sports, look bad and be painful [17]. Some caretakers

allowed to use the PEG but were however anxious before the procedure and for some it took months of counselling for them to agree to the procedure. This was mainly attributed to fear of surgery and the invasiveness of the procedure.

A study done in Thailand showed that 39% of the caregivers still had a hard time accepting the PEG despite adequate information. The main reason stated was the child's pain [12]. Instances of unpleasant experiences were also noted and these were due to multiple reasons; loss of a loved one immediately after the procedure, health workers who didn't know how to use the tube. Most of these however can be attributed to multiple factors that have been talked about in the study namely, knowledge, poor counselling and family influences. The other theme identified from the data was coping by both the patient and caretakers implying that they were able to get along and manage the PEG tube. This made life bearable for the patients and caretakers since they were able to deal with any issues concerning the tube.

Limitations

We were only able to interview one adult patient since most patients were unable to communicate, however since most of the procedures were done in children, the input of the caretakers and nurses was quite valuable.

Conclusion

Our study found that the need for PEG was significant due to the increasing burden of dysphagia and its associated complications. It also noted that PEG has shown to have improved care and better patient outcomes in terms of health and nutrition. This is because it is easier to use, convenient and is well tolerated by the patients, caretakers and HCPs. However multiple challenges and set backs were noted and these included cost, lack of knowledge and resistance from patients and families.

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