

**PERCUTANEOUS ENDOSCOPIC GASTROSTOMY  
FEEDING IN DYSPHAGIC HOSPITALISED OLDER  
PEOPLE: CLINICAL OUTCOMES AND HEALTHCARE  
PROFESSIONALS' ATTITUDES**

**MOHAMAD HASIF BIN JAAFAR**

**FACULTY OF MEDICINE  
UNIVERSITY OF MALAYA  
KUALA LUMPUR**

**2017**

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**MOHAMAD HASIF BIN JAAFAR**

**THESIS SUBMITTED IN FULFILMENT OF THE  
REQUIREMENTS FOR THE DEGREE OF DOCTOR OF  
PHILOSOPHY**

**FACULTY OF MEDICINE  
UNIVERSITY OF MALAYA  
KUALA LUMPUR**

**2017**

**UNIVERSITY OF MALAYA**  
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Registration/Matric No: MHA 140033

Name of Degree: Doctor of Philosophy

Title of Project Paper/Research Report/Dissertation/Thesis ("this Work"):  
Percutaneous Endoscopic Gastrostomy Feeding in Dysphagic Hospitalised Older  
People: Clinical Outcomes and Healthcare Professionals' Attitudes

Field of Study: Medicine

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## ABSTRACT

The purpose of this doctoral thesis was to explore issues surrounding the use of percutaneous endoscopic gastrostomy (PEG) feeding in dysphagic, older people requiring artificial feeding for a variety of medical conditions in an Asian population. Systematic reviews and observational and interventional studies were conducted to explore the perceptions of healthcare professionals (HCPs), and clinical benefits associated with enteral feeding through the PEG route compared to the nasogastric (NG) route. The two systematic reviews conducted evaluated (i) intervention studies evaluating PEG versus NG feeding in older adults with non-stroke dysphagia, and (ii) quantitative and qualitative studies evaluated attitudes and perceptions of HCP towards PEG feeding. Our mixed methods approach therefore included a quantitative assessment using a survey questionnaire, a qualitative analysis of HCPs' practice and perception of their knowledge, responsibility and documentation followed by a comparative, non-randomized study in relation to NG tube and PEG tube feeding. Our first systematic review highlighted that few studies have compared PEG to NG in non-stroke dysphagia, and meta-analysis did not show any significant benefits of PEG over NG. Following that, our second systematic review highlighted regional variations in acceptability of PEG, which appears to vary according to legal provisions for decision making and funding streams for PEG. Our quantitative survey highlighted that most HCPs would agree to PEG as the preferred route for long-term enteral feeding. However, for those who would not recommend a PEG, they were most likely to perceive reluctance of family members, concerns with procedural risk and cost of PEG insertion as reasons for refusal. The qualitative study supported this finding by revealing several universal barriers, including education, knowledge, communication and team work. A few unique cultural and political barriers had also emerged including the deeply hierarchical work cultures, autocratic approaches to leadership, and lack of funding structures. The impact

of enteral feeding on patients' nutritional status, morbidity, and mortality rates was explored. There was a significant reduction in the composite outcome of complication-free survival with PEG feeding compared to NG feeding. Nutritional improvement was seen in both NG and PEG groups, while greater improvement in mid-arm circumference was observed in the PEG group rather than NG group after controlling for potential confounders. Through this we have identified approaches and areas worthy of further study. Our results suggest that there is a need for clinical audit to continue to view and monitor the service delivery process at the local level. Moreover, this research further suggests that there is a need for up-skilling in knowledge and practice among HCPs in order to provide support to patients with PEG and their caregivers. The present research has also supported the development of local multi-agency guidelines on enteral feeding so that more PEG tube use can be promoted and a common approach exists in clinical practice.

## ABSTRAK

Tujuan tesis Doktor Falsafah ini ditulis adalah untuk menerokai isu-isu sekeliling yang berkaitan dengan penggunaan tiub *percutaneous endoscopic gastrostomy* (PEG) di kalangan warga emas populasi Asia yang memerlukan bantuan tiub pemakanan. Dapatan kajian lepas yang dilakukan secara bersistematik, dan kajian yang melibatkan pemerhatian dan intervensi telah dilakukan untuk meneliti persepsi warga kerja kesihatan, dan faedah klinikal yang berkaitan dengan tiub pemakanan PEG dan tiub *nasogastric* (NG). Dua dapatan kajian lepas yang dibuat adalah menjurus kepada (i) kajian intervensi melibatkan penggunaan PEG dan NG di kalangan warga emas yang tidak strok tetapi mempunyai masalah menelan makanan, dan (ii) kajian kualitatif dan kuantitatif yang meninjau sikap dan persepsi warga kerja kesihatan terhadap tiub PEG. Pendekatan kaedah campuran termasuklah kajian menggunakan soalan kaji selidik, analisis kualitatif amalan dan persepsi warga kerja kesihatan berkaitan pengetahuan, dan tanggungjawab diikuti dengan kajian perbandingan yang melibatkan tiub NG dan PEG. Dapatan kajian lepas yang pertama menunjukkan bahawa hanya segelintir kajian yang membandingkan tiub NG dan PEG di kalangan warga emas yang tidak strok tetapi mempunyai masalah menelan makanan, dan analisis-meta tidak dapat membuktikan bahawa tiub PEG lebih baik daripada tiub NG. Justeru, dapatan kajian lepas yang kedua mempamerkan faktor tempat mempengaruhi penerimaan tiub PEG iaitu perbezaan undang-undang dan isu pendanaan terhadap tiub PEG. Kajian penilaian kuantitatif menunjukkan kebanyakan warga kerja kesihatan bersetuju untuk menggunakan tiub PEG terhadap pesakit yang memerlukan bantuan tiub pemakanan untuk jangka masa yang panjang. Walaubagaimanapun, mereka yang tidak bersetuju berpendapat bahawa halangan utama adalah keengganan keluarga, bimbang terhadap risiko prosedur dan kos untuk memasukkan tiub PEG. Kajian kualitatif menyokong keputusan kajian ini dengan mendedahkan beberapa halangan umum, termasuklah pendidikan, pengetahuan,

komunikasi dan kerjasama. Beberapa halangan budaya dan politik juga didapati yang lebih menjurus kepada budaya hierarki tempat kerja, pendekatan kepimpinan autokratik, dan kekurangan struktur dana pembiayaan. Keseluruhan kajian ini memfokuskan kesan tiub pemakanan terhadap nutrisi pesakit, komplikasi, dan kadar kematian. Hasil analisis 'hidup tanpa sebarang komplikasi' menunjukkan tiub PEG lebih baik daripada tiub NG. Pertambahan nutrisi dilihat baik pada kedua-dua kumpulan manakala pertambahan ukuran lengan adalah lebih baik pada kumpulan PEG. Melalui pemfokusan ini, kajian ini telah mengenalpasti pendekatan dan bidang yang berbaloi untuk dikaji dan diterokai pada masa akan datang. Keputusan kajian mencadangkan perlunya audit klinikal untuk meneruskan pemantauan proses penyampaian maklumat dan isu-isu berkaitan di peringkat tempatan. Tambahan lagi, kajian ini berpendapat bahawa perlunya penambahan pengetahuan dan amalan di kalangan warga kerja kesihatan dalam usaha untuk memberikan sokongan kepada pesakit dan penjaga mereka. Kajian ini juga menyokong penggubalan garis panduan tempatan terhadap tiub pemakanan supaya tiub PEG boleh digunapakai secara meluas dan menjadi amalan dalam perubatan.

## ACKNOWLEDGEMENTS

First and foremost I would like to thank my Mentors and Supervisors, Associate Professor Dr. Tan Maw Pin and Professor Sanjiv Mahadeva for the successful completion of this thesis. I want to express my deep sense of gratitude to them for their tireless efforts and guidance in making me an independent researcher and to survive in this field of research as well as giving many fruitful discussions, which greatly contributed to my scientific works.

Thanks also to the UMMC staffs who cooperated to suggest several suitable patients to participate in this study. To the participants in the study, I would like to extend my thanks for your valuable time and support to the work in this thesis. Many thanks to Associate Professor Dr. Karen Morgan, and Dr Pathmawathi Subramanian for sharing their expertise in the area of systematic reviews and qualitative methods.

My appreciation also goes to the members of the Ageing Research Group especially Sumaiyah Mat, Pey June Tan, Nemala Nalathambi, Puvanesswaray Ramakrishnan, Roshaslina Rosli, Kah Yan, Goh Choon Hian, Dr. Izzati, and Dr. Khor Hui Min. You have made the office most enjoyable to work even though many challenges we have to put up with.

To my parents Jaafar Bin Ali and Saudah Binti Abdullah, thank you for your encouragement and your prayers. I would like to express my deepest appreciation to Siti Norbaya, Muhammad Hakim and Nur Syuhaidah for all their support and for cheering me up to endure this long journey. Without your unconditional support, love and patience, I could not have survived.

This study was supported by the University of Malaya, Malaysia. I am indebted to them for this.



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## **LIST OF SYMBOLS AND ABBREVIATIONS**

ADL	:	Activities of Daily Living
ASPEN	:	American Society for Parenteral and Enteral Nutrition
BAPEN	:	British Association of Parenteral and Enteral Nutrition
BI	:	Barthel Index
BMI	:	Body Mass Index
CC	:	Calf Circumference
CI	:	Confidence Intervals
ESPEN	:	European Society for Clinical Nutrition and Metabolism
GDP	:	Gross Domestic Product
HCP	:	Healthcare Professional
HyVet	:	Hypertension in the Very Elderly Trial
ICU	:	Intensive Care Units
MeSH	:	Medical Subject Heading
MNA	:	Mini Nutritional Assessment
mRS	:	modified Rankin Scale
NG	:	Nasogastric
NICE	:	National Institute for Health and Care Excellence
NPSA	:	National Patient Safety Agency
OR	:	Odds Ratios
PEG	:	Percutaneous Endoscopic Gastrostomy
PICO	:	Problem, Intervention, Comparison, and Outcomes
PRISMA	:	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PSDA	:	Patient Self Determination Act
QUOROM	:	Quality of Reporting of Meta-analyses

RCT	:	Randomized Controlled Trial
SD	:	Standard Deviation
UK	:	United Kingdom
UMMC	:	University of Malaya Medical Centre
US	:	United States
WGM	:	Workers in Geriatrics Medicine

University of Malaya

## **LIST OF APPENDICES**

Appendix A: Research Instruments

Appendix B: Publications

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## CHAPTER 1: INTRODUCTION

### 1.1 General

The 2010 Malaysian census showed that the total Malaysian population was 28.6 million. Among this, 1.4 million were considered older people using the age cut-off of 65 years and above, which was the definition used by the National Statistics department at the time (Department of Statistics 2011). Malaysia will see a rising tide in terms of the total number of older people living our country due to increased life expectancy, changing demographics and family structures. The percentage of the older population is expected to reach 9.8% by year 2020, with the absolute number increasing from 1.4 million to 3.3 million (from year 1990 to 2020) (Ekberg *et al.* 2002). As individuals get older, their susceptibility to illness increases due to reduced immune response and deteriorating body systems. Diseases which commonly affect the older population include Alzheimer's dementia, stroke, heart disease, diabetes mellitus, hypertension, cancer and osteoarthritis (Sazlina *et al.* 2012, Zainuddin *et al.* 2011).

As the result of some of the conditions mentioned above, the swallowing mechanism can become compromised in the elderly. Nutritional intake in these individuals will therefore need to be maintained with artificial feeding. In the short-term, nasogastric (NG) feeding is used to bypass the swallowing mechanism and deliver meal replacements in terms of liquid feed directly into the stomach. However, numerous problems are associated with NG feeding which makes long-term use difficult, leading to the development of other alternative feeding methods. This dissertation is concerned with the potential use of percutaneous endoscopic gastrostomy (PEG) feeding in dysphagic older people requiring artificial feeding for a variety of medical conditions in an Asian population. Attitudes towards PEG tube feeding based on healthcare

professionals' (HCPs) perspectives will be studied. Furthermore, this body of work will measure morbidity and nutritional outcomes of both long-term NG tube and PEG tube. The results of this body of work will be relevant to Asian countries in terms of its cultural context as well as other nations with significant Asian populations worldwide.

## **1.2 Dysphagia in Older People**

Some older people may develop difficulty in swallowing due to illnesses associated with ageing. Difficulty swallowing is also known as dysphagia. In dysphagia, the oesophagus has problems transporting food and liquids to the stomach. The signs and symptoms of dysphagia are coughing, choking, drooling, breathlessness and gurgling during meals (Wieseke *et al.* 2008). Dysphagia seen in people in 13% to 15% of patients with pneumonia (Department of Statistics 2010, Stroud *et al.* 2003), 35% to 69% of stroke patients (Agency 2005, Hinds & Wiles 1998, Zaherah Mohamed Shah *et al.* 2012) and 11% to 14% of community dwelling older people (Spieker 2000, Xue *et al.* 2008, Zaherah Mohamed Shah *et al.* 2012). Furthermore, it can lead to serious complications like aspiration pneumonia (Department of Statistics 2010), malnutrition (Sobotka *et al.* 2009) and death (Hamidon *et al.* 2006) if not diagnosed early.

Cabre *et al.* (2010) reported that 55% of community-dwelling older adults diagnosed with pneumonia presented with clinical signs of oropharyngeal dysphagia (Cabre *et al.* 2010). On top of that, participants had greater decline in functional status and exhibited a higher prevalence of malnutrition. A study performed among an older Malaysian population evaluated the relationship between dysphagia and the risk for malnutrition. The authors reported that 51% of stroke patients had dysphagia and among this, 71% did not achieve the required calories needed (Zaherah Mohamed Shah *et al.* 2012). These findings highlight the potential relationships among dysphagia, pneumonia and nutritional status among older adults.

### **1.3 Decisions for Enteral Tube Feeding in Older People**

The need for enteral tube feeding in older people can arise suddenly or gradually in individuals with various conditions. In conditions such as stroke the loss of swallowing occurs suddenly, and the decisions for enteral feeding is usually straight forward. The decision to start enteral tube feeding is emotive, controversial and influenced by complex ethical issues (The *et al.* 2002). The decision to intervene differs with clinical need, local practice and physician and caregiver preference, and whether there is an advance directive or advance care plan in place. Common justifications given may include the prolongation of life by correcting malnutrition, reducing the risk of aspiration and pressure ulcers, pneumonia and other infections and/or the optimizing of quality of life by promoting physical comfort (Sampson *et al.* 2009).

#### **1.3.1 Overview of the nutritional needs in dysphagic older people**

Patients with oropharyngeal dysphagia frequently experience a functional disorder of deglutition which affects oropharyngeal swallow response caused by aging, stroke, or associated with systematic or neurological diseases (Rofes *et al.* 2011). Older patients have prolonged reaction time in the submental muscles (Nagaya & Sumi 2002) and can be associated with an impairment of sensations (Teismann *et al.* 2009). Other conditions such as delirium, confusion and dementia, and the effects of sedative, neuroleptic, or antidepressant drugs can also be attributed to impaired swallow response in frail older patients (Turley & Cohen 2009).

#### **1.3.2 Significance of enteral feeding in older people**

The European Society for Clinical Nutrition and Metabolism (ESPEN) have recommended using enteral nutrition within three days for patients who are expected to have dysphagia (Abellan Van Kan & Vellas 2011). Early tube feeding can increase daily caloric intake (Grahm *et al.* 1989, Hasse *et al.* 1995) while delaying it reduces

small intestine glucose absorption (Nguyen *et al.* 2012). Decisions on route, content and management of nutritional support are best made by multidisciplinary teams.

### **1.3.3 Types of enteral feeding formulae**

Modifying the consistency of solid food and/or liquid is important for patients with dysphagia. Diet modification is crucial to improve the safety and ease of oral consumption and thus maintain safe and adequate oral intake of food or liquid. Nevertheless, low acceptability and poor adherence with modified food or liquid may increase risk of inadequate nutrition in elderly patients with dysphagia (Sura *et al.* 2012).

The type of formulae is chosen based on the formula contents and the ability of the patients to digest and absorb nutrients. It also depends on the disease and condition of the patients. In order to have the best possible outcome, it is important to select the most standard formulas which comprise the enteral product category most often used in patients that require tube feeding. Their nutrient composition should be matched that recommended for healthy individuals (Malone 2005).

Caloric density is an important consideration for patients that have volume restrictions. The formulas are always used for overnight feedings or bolus feedings where they can give the patient large amount of calories in a short amount of time (Collins 2011). Another aspect to look into is fiber content. If a patient is suffering from diarrhea or constipation, it is best to look at the fiber content of the formula (Malone 2005).

**Table 1.1: Levels of Modified Diet**

Level	Description	Examples of recommended foods
<b>Four Levels in the National dysphagia diet</b>		
Level 1: dysphagia pureed	Homogenous, cohesive, and pudding like.  No chewing required, only bolus control	Smooth, homogenous cooked cereals  Pureed: meats, starches (like mashed potatoes) and vegetables with smooth sauces without lumps  Pureed/strained soups  Pudding, soufflé, yogurt
Level 2: dysphagia mechanically altered	Moist, semi-solid foods, cohesive.  Requires chewing ability	Cooked cereals with little texture  Moistened ground or cooked meat  Moistened, soft, easy to chew canned fruit and vegetables
Level 3: dysphagia advanced	Soft solids. Require more chewing ability	Well moistened breads, rice and other starches  Canned or cooked fruit and vegetables  Thin sliced, tender meats/poultry
Level 4: regular	No modifications, all foods allowed	No restrictions

Adapted from Groher ME, Crary MA. Dysphagia: Clinical management in adults and children. Maryland Heights, MO. Mosby, Elsevier; 2010.



### **1.3.4 Routes and methods of administration**

There are various methods of administering enteral feeding. The most common ones are by delivering food directly into the stomach via NG or PEG feeding. A number of studies have been performed on the effectiveness of NG and PEG feeding.

#### **1.3.4.1 Nasogastric tube feeding**

NG tube is the most commonly used method to deliver substances directly into the stomach. It can also be used to remove substances from the stomach and test stomach function or contents. The tube is simple to insert but can be displaced easily. However, it can be dangerous if a clinical practitioner accidentally places the tube in the lung instead of the stomach. It may cause harm or even death from unintentional introduction of feeds into the lungs and subsequent infection.

The National Patient Safety Agency (NPSA) provides a better guideline in order to reduce the occurrence of tube misplacements. This includes not to use 'whoosh' test and blue litmus paper to test acidity. The guidelines also highlighted not to observe for signs of respiratory distress and bubbling at the proximal end of the tube (Agency 2005). Only fine bore (5-8 French gauge) NG tubes should not be used for enteral feeding unless there is a need for repeated gastric aspiration or administration of high viscosity feeds or drugs via the tube. Feeding tubes should only be inserted by experienced medical or nursing staff. The tubes should be changed every 4-6 weeks (Stroud *et al.* 2003).

#### **1.3.4.2 Percutaneous endoscopic gastrostomy tube feeding**

Percutaneous endoscopic gastrostomy was introduced in 1979. Now, indications have expanded to allow temporary nutritional support in patients with oropharyngeal tumors, facial trauma, inflammatory bowel disease, chronic intestinal obstruction secondary to carcinomatosis or radiation enteritis (Gauderer *et al.* 1998). The British

Association of Parenteral and Enteral Nutrition (BAPEN) suggests that PEG or gastrostomy feeding should be considered if the patients are likely to receive enteral feeding for more than 4-6 weeks (Stroud *et al.* 2003). PEG tubes can be inserted by 3 methods: endoscopic; radiological; or surgical. Once placed, a PEG tube is left in situ until it is can no longer be used. Damaged tubes can be easily replaced at the bedside, in the nursing home or at home (Opilla 2003).

### **1.3.5 Complications of enteral tube feeding**

Tube feeding has been recognised to have several complications. A study among hospitalized patients receiving NG tube feeding reported the most common problems were tube dislodgement, electrolytic alterations, hyperglycaemia, diarrhoea, constipation, vomiting, tube clogging and lung aspiration (Pancorbo-Hidalgo *et al.* 2001). Other study had shown that patients with dementia fed with NG tubes were likely to acquire pneumonia (Alvarez-Fernandez *et al.* 2005). Moreover, some studies including a Cochrane systematic review study suggested that NG feeding did not improve survival rate in advanced dementia patients (Azzopardi & Ellul 2013, Finucane *et al.* 1999, Sampson *et al.* 2009, Tuna *et al.* 2013).

Although PEG is generally considered to be a safe procedure, there is always the potential for both minor and major complications. The main complication of the PEG tube insertion is infection but it is nearly always mild and can be treated with antibiotics (DeMeo & Bruninga 2002). Other complications would be site infection (DeMeo & Bruninga 2002, Wilson *et al.* 2002), leakage (Quinn *et al.* 2008), bleeding (Canal *et al.* 1987) and post-procedural pain. These complications are not frequent.

Complications also occur with PEG feeding. This includes aspirations, self-extubation (Dwolatzky *et al.* 2001) and a lower rate of tube-related mechanical complications (Magne *et al.* 2001). Some studies demonstrated that early PEG feeding

could significantly increase functional oral intake (Drakulovic *et al.* 1999, Schulz *et al.* 2009) and reduce hospitalizations for nutritional deficits (Drakulovic *et al.* 1999).

However, PEG tube may not be suitable for all patients requiring long-term nutritional support. There are several contraindications to PEG tube insertion. For example, patients who are unfit for endoscopy; inability to pass the endoscope; failure to transilluminate; and patients having ascites (Opilla 2003).

#### **1.4 Objectives of the Study**

The overall objective was to evaluate the usage of PEG feeding by the healthcare professionals on the effectiveness in reducing mortality and morbidity associated with PEG, and improving nutritional status.

The specific objectives were:

- i. To determine the perception of Malaysian HCPs towards PEG feeding
- ii. To determine potential differences in perception according to clinical experience, profession and specialty
- iii. To explore their perceptions of the use of PEG feeding
- iv. To identify barriers to the acceptance of PEG tube feeding from the HCP perspectives
- v. To determine the effectiveness of PEG feeding in reducing enteral feeding related morbidity and improving nutritional status in dysphagic older people compared to NG tube feeding'

#### **1.5 Study Questions**

To achieve the objectives, several study questions were identified:

- i. What is the perception of Malaysian HCPs towards PEG feeding?

- ii. Is difference in perception of HCPs associated with clinical experience, profession and specialty?
- iii. How do HCPs perceive knowledge of their role in terms of responsibility, knowledge and documentation regarding PEG tube feeding?
- iv. Is PEG feeding superior to NG feeding for patients requiring long-term enteral feeding in terms of reducing morbidity and improving nutritional status?

## **1.6 Research Justification**

While PEG tube feeding is now commonly used among those requiring long-term enteral feeding, especially in Western Europe and the United States of America, large numbers of patients in Asian countries appear to remain on long-term NG feeding. In Taiwan, 80% of patients with dysphagia were found to be on long-term NG feeding. Numerous studies have evaluated potential difficulties in the practice of long-term enteral feeding. The work behind this thesis was initiated in order to obtain a better understanding of the variations in practice and acceptability of PEG tube feeding in the Asian region. The results of this study will confirm or refute the net benefit of PEG tube feeding in our older Asian population compared to previous studies published in Western countries. The barriers behind the acceptance and utility of PEG tube feeding among patients and HCPs will be explored in order to identify modifiable factors to improve the use of PEG feeding. The rationale behind the investigatory approach will be further expounded in Chapter 2.

## **1.7 Organization of the Thesis**

The thesis is divided into six chapters, each of which is then subdivided into sections and subsections. The chapters are arranged in the following sequences:

Chapter 1 presents a brief introduction to the long-term enteral tube feeding in older people with dysphagia. Later, it describes the background of the work undertaken within the study and its main objectives.

Chapter 2 provides a systematic review of the outcomes between of NG tube versus PEG tube in non-stroke patients, followed by another systematic review of the attitudes and perceptions of HCPs regarding barriers to the acceptance of PEG tube feeding.

Chapter 3 offers a quantitative survey of the attitudes of HCPs and obstacles of advocating PEG tube feeding in Malaysia. Important parameters are discussed.

Chapter 4 explores the views and opinions of HCPs regarding the use of PEG feeding in elderly patients with dysphagia. The experience and issues of HCPs in managing the long-term PEG feeding is addressed.

Chapter 5 comprises a clinical study comparing the efficacy of nutritional support and complication rates between PEG and long-term NG feeding in older Malaysians with dysphagia.

Chapter 6 concludes the overall body of work and discusses possible areas for future research.

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 Introduction**

This chapter provides an overview of the relevant literature associated with enteral feeding in the older people with dysphagia to obtain in-depth understanding of the effectiveness of NG versus PEG feeding as well as any potential barriers to the acceptance of PEG feeding in this area of practice. The purpose of this chapter is to retrieve and critically appraise studies surrounding enteral feeding and its associated practices in older people with dysphagia. Moreover, this chapter focuses on the issues that impede PEG delivery, showing the gap in care practice and other factors related to tube feeding complications. The critical review of the previous literature helps to justify the objectives of this study and thus assists to generate research questions.

### **2.2 NG Feeding versus PEG Feeding in Stroke Patients**

Dysphagia after stroke is common in Malaysia, where it affects 50% to 66% of stroke patients, compounding the problem of malnutrition (Hamidon *et al.* 2006, Zaherah Mohamed Shah *et al.* 2012). Over the years, there are many studies that have been conducted to assess the enteral feeding in stroke patients. Zaherah Mohamaed Shah *et al.* (2012) included 70 elderly patients (aged >60 years) with stroke and had been on NG feeding for more than eight weeks. Another 70 stroke patients who did not require NG feeding were identified as controls for nutritional parameter comparisons. They revealed that 64% of patients developed at least one complication with the most common encountered being tube dislodgement (43%), accidental tube dislodgement (9%) and aspiration of feed content (9%). They also found that the NG patients were significantly more malnourished than patients with stroke who could eat normally (Zaherah Mohamed Shah *et al.* 2012). The lower nutritional status among NG fed

patients may have been due to feed interruption caused by tube dislodgement. This was a cross-sectional observational study, which limits its ability to assign causation. The period of time each individual had received NG feeding had not been recorded.

Several randomized trials comparing PEG with NG in patients with stroke-related dysphagia have been conducted. The combined results of these trials have been summarized in a recent Cochrane review (Geeganage *et al.* 2012). This review included studies which recruited patients with a clinical diagnosis of stroke within six months of onset. They identified 5 studies (455 patients) which compared PEG with NG feeding and concluded that PEG feeding appeared to be beneficial compared to NG feeding in terms of treatment failures ( $p=0.007$ ) and gastrointestinal bleeding ( $p=0.007$ ). PEG feeding was also found to be associated with higher level of feed delivery ( $p<0.001$ ) and albumin concentration ( $p=0.040$ ).

### **2.3 NG Feeding versus PEG Feeding in Older Patients with Non-Stroke Dysphagia**

Although the evidence for PEG feeding in stroke patients with dysphagia is clear, its' benefits in patients with non-stroke related dysphagia is less obvious. Previous systematic reviews and meta-analyses on enteral nutrition approaches have been performed, but not with the broad scope related to non-stroke patients. Brooke and Ojo (2015) published a systematic review that investigated enteral feeding, specifically in dementia patients. All studies included involved enteral feeding administered via PEG tubes. However, they did not find any controlled or randomized studies (Brooke & Ojo 2015). Another systematic review compared PEG with NG feeding in patients with head and neck cancers. Unfortunately, all included studies were found to contain high risk of bias (Nugent *et al.* 2013).

Assessment of these latest studies comparing PEG and NG feeding in non-stroke patients with a wide range of pathologies, together with analysis of the optimal moment to commence nutritional support, provides the best evidence available on which to base decision.

We found no published systematic review for comparing NG versus PEG for older individuals with non-stroke dysphagia. Having identified the gap in the literature, we proceeded to undertake a systematic review on published literature addressing this topic.

### **2.3.1 Methods for systematic review on NG versus PEG feeding for non-stroke dysphagia**

#### **2.3.1.1 PICO objectives**

The objectives of the systematic review was structured according to the Problem, Intervention, Comparison, and Outcomes (PICO) objectives (Aslam & Emmanuel 2010). Systematic searching represents a critical step in enhancing external validity by matching the findings of former studies. It is based on the replications of findings across different times, people and settings to validate whether relationships between variables exist (Polit & Beck 2008). This format is compatible with the research structure; it describes the phenomena (i.e. enteral feeding practice) and after that suggests solutions. Truly, it is a way of managing and organizing the search technique to determine the objective and to avoid redundancy of data that are irrelevant to the main purpose. The PICO model works well when dealing with questions concerned with healthcare interventions and planning the search strategy (Beecroft *et al.* 2010).

As with all research, the reporting quality of systematic reviews vary, thus limiting readers' ability to assess the strengths and weaknesses of those reviews (Moher *et al.* 2009). Following that, an international group developed a guidance called the QUOROM Statement (Quality Of Reporting Of Meta-analyses) to focus on the



reporting of meta-analyses of randomized, controlled trials (Moher *et al.* 1999). Later, a revision of these guidelines were summarized within PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) that updated several conceptual and practical advances in the science of systematic review (Moher *et al.* 2009). Hence, this study used the PRISMA statement for the reporting of systematic reviews and meta-analysis.

#### **2.3.1.2 Search strategy**

Relevant peer reviewed and English language articles were identified. The search terms used were "percutaneous endoscopic gastrostomy", "gastrostomy", "PEG", "nasogastric", "nasogastric tube", "nasogastric feeding" and "intubation". The search for studies was performed without restrictions by using the Medical Subject Heading (MeSH) terms "Intubation, Gastrointestinal" OR "Enteral Nutrition" AND "Gastrostomy". The titles of all articles were screened and the abstracts of potentially relevant articles were read in full. In addition, the references of all selected articles were reviewed in order to identify potentially suitable articles that were indexed differently. This process was completed by two of the researchers (MHJ and MPT). Full text articles were then retrieved for articles identified as potentially suitable. Disagreements were resolved by discussion.

#### **2.3.1.3 Electronic databases**

The following online databases interrogated up to 18 December 2013: Ovid MEDLINE, EMBASE, Web of Science, Cochrane Database of Systematic Reviews, and PubMed.

#### **2.3.1.4 Inclusion criteria**

Various methodological designs of studies were sought such as randomized controlled trials (RCTs), controlled trials, observational studies, prospective and

retrospective studies, case control studies, and cohort studies with no restrictions of the date of publication. Studies published should compared PEG with NG feeding for non-stroke older people where dysphagia was diagnosed in a variety of medical conditions. In addition, studies with participants that had a mean age of 60 years old and above were included.

#### **2.3.1.5 Exclusion criteria**

Studies were excluded from the searching process if they were published in non-English language and did not compare PEG with NG feeding. Articles that focused mainly on acute, sub-acute stroke or head and neck patients were excluded as well.

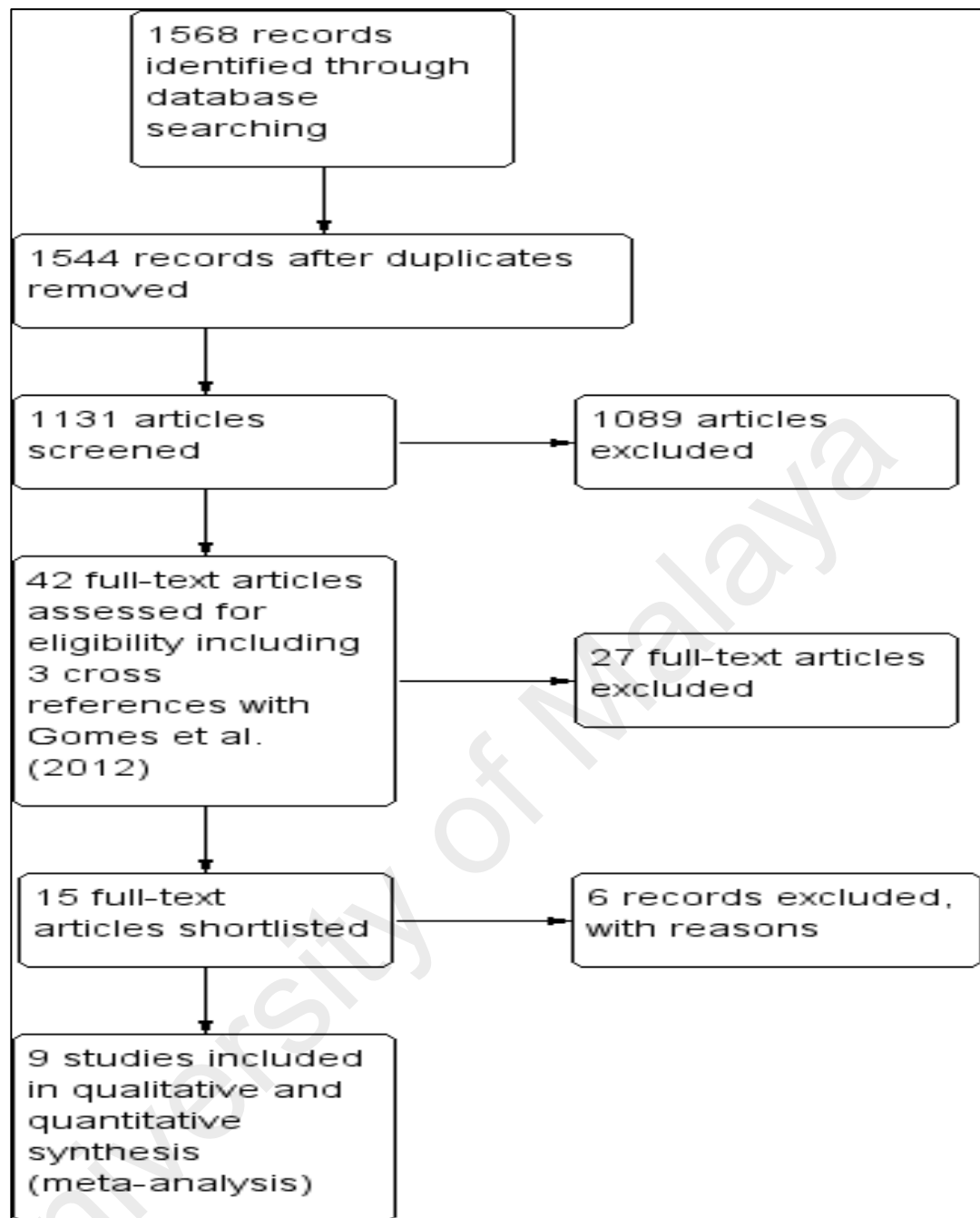
#### **2.3.1.6 Technique of critical appraisal**

In this first search, two researchers independently extracted and recorded data on study characteristics including methods, participants, interventions and outcomes (MHJ and MPT). The quality of the studies was assessed using the Cochrane Collaboration's tool for assessing risk of biases (Higgins *et al.* 2011). The assessment included selection bias, performance bias, detection bias, attrition bias, reporting bias, and other bias. The tool takes into consideration of researchers' judgement to classify each of the bias to high risk, unclear risk or low risk.

Meta-analyses for primary and secondary outcomes were conducted using the Revman 5.2.7 software. For dichotomous and continuous variables, the risk ratio (RR) with confidence interval (CI) of 95% was measured. Risk ratios were reported first of all for all studies, and subsequently for RCTs alone. The statistical heterogeneity between the studies was assessed by using the  $I^2$  statistics.  $I^2$  values were considered low (25%), moderate (50%) and high (75%).

### 2.3.1.7 Search output

A total of 1568 articles were identified through database searching. After removing duplicates, the titles of 1544 articles were screened, and 413 articles were excluded at this stage. The abstracts of 1131 articles were reviewed. 1089 articles were excluded after this stage. The primary reason for exclusion was no comparison between NG and PEG feeding. Other reasons for exclusion were inclusion of only stroke or head and neck patients. Review articles were also excluded. The full text articles were retrieved for 42 articles, and 15 articles were shortlisted. Many studies recruited patients with a mean of age of below 60 years. Fifteen potentially relevant articles including 3 articles obtained from cross-referencing were assessed. Six articles were excluded for the following reasons; one study involved only a survey of 4 patients and 12 caregivers on PEG and NG feeding (Ghosh & Eastwood 1994), two studies performed gastric decompression studies (Hoffman *et al.* 2001, Pricolo *et al.* 1989), one study included head and neck patients (Baeten & Hoefnagels 1992), one study investigated the oral flora in patients with PEG and NG tubes (Leibovitz *et al.* 2003) and the remaining study was a retrospective non-comparative study (Maitines *et al.* 2009). Nine studies were included in the qualitative and quantitative analyses. Figure 2.1 shows the process of selecting studies in the literature review using PRISMA statement (Moher *et al.* 2009). The characteristics of the included studies are reported in Table 2.1.



**Figure 2.1: The Process of Selecting Studies Included in the Review**

**Table 2.1: Summary of Studies Evaluating PEG and NG Feeding**

Reference	Total participants	Mean age (Years)	Indications	Study design	Interventions		Duration	Outcome measures	Group differences (PEG vs. NG)
					PEG group	NG group			
Ciocon 1988	70	82	Esophageal obstruction; dysphagia without obstruction; refusal to swallow	Single-centre observational study	silicone tubing (n=13), Foley's (n=3)	12 to 18 F polyvinylchloride and silicone tubes (n=54)	11 months (early complications <2 weeks; late complications >2 weeks)	Self-extubation	7/16 vs 36/54 (early), ns; 0/16 vs 21/54, p<0.003 (late)
								Aspiration pneumonia*	9/16 vs 23/54, ns (early); 9/16 vs 24/54, ns (late)
								All complications	15/16 vs 38/54 (early); 14/16 vs 35/54 (late)
Park 1992	40	PEG=56; NG=65	Neurological disease	Multi-centre randomized trial	20F silicone tube Bard 20 Fr NG (n=20)	Fine bore polyurethane (I=850 mm;	PEG: 28 days; NG: mean= 5.2	Treatment failure	0 vs. 95%
								Complications	15% vs. 0

**Table 2.1, continued**

Reference	Total participants	Mean age (Years)	Indications	Study design	Interventions		Duration	Outcome measures	Group differences (PEG vs. NG)
					PEG group	NG group			
						diameter=1.5 mm)			
Yata 2001	82	PEG=75; NG=77	Cerebrovascular disease; dementia; Parkinson's disease; others	Single-centre randomized controlled trial	Not stated**	Not stated**	Nutrition and complications =6 months; Survival up to 46 months.	Anthropometry (weight, mid-arm circumference, triceps skin fold)	Too many dropouts in NG group for comparisons
								Nutrition 3 months-	
								Albumin (g/l), mean	3.6 vs 3.2, p<0.01
								Haemoglobin (g/dl)	11.9 vs 11.7, ns
								Cholesterol (mg/dl)	184 vs 172, ns

Table 2.1, continued

Reference	Total participants	Mean age (Years)	Indications	Study design	Interventions		Duration	Outcome measures	Group differences (PEG vs. NG)
					PEG group	NG group			
								6 months-  Albumin (g/l)	3.9 vs 3.1, p<0.01
								Haemoglobin (g/dl)	12.4 vs 11.1, ns
								Cholesterol (mg/dl)	184 vs 152, p<0.05
								Pneumonia	34% vs 55%, p<0.05
								Survival (months), mean (SD)	11.4(1.6) vs 7.1(2.9), p<0.05
Dwolatzky 2001	122	PEG=85;  NG=82	Food refusal, neurogenic dysphagia	Multi-centre non-randomized clinical study	Locally accepted methods	Not stated	PEG, mean (SD)=276.9 (184.6) days;	Mortality	HR(95%CI)=0.41(0.22-0.76)
								Aspiration	HR=0.48(0.26-0.89)
								Self-extubation	HR=0.17(0.05-0.58)

**Table 2.1, continued**

Reference	Total participants	Mean age (Years)	Indications	Study design	Interventions		Duration	Outcome measures	Group differences (PEG vs. NG)
					PEG group	NG group			
							NG=102.1 (127.5) days	Albumin and weight ratio at 2, 4, 12 weeks	No significant difference except albumin at 4 weeks.
Attanasio 2009	108	78	Italian Society of parenteral and enteral nutrition guidelines (dementia, n=72)	Multi-centre observational study	15 Fr Fresenius-Kabi AG, inserted by pull technique (n = 62).  Includes 1 individual with jejunostomy	8F, fine bore, polyurethane, radio opaque, 110 cm long (n = 45)	12 months	Aspiration	7.9% vs. 15.5%
								Displacement	4.7% vs. 62.2%
								Tube clogging	7.9% vs. 11.1%
								Mortality	Not reported separately for the two groups
Rio 2010	159	62	Motor neuron disease	Single-centre retrospective case note review	Endoscopic or radiologically inserted gastrostomy	Inserted in those who refused gastrostomy	Not stated, but all patients had died by end of study	Median survival (IQR), PEG vs RIG vs NG	200(106-546) vs 216(83-383) vs 28(14-107); gastrostomy vs NG,



**Table 2.1, continued**

Reference	Total participants	Mean age (Years)	Indications	Study design	Interventions		Duration	Outcome measures	Group differences (PEG vs. NG)
					PEG group	NG group			
					(RIG)				p=0.034
Lee and Shiun 2011	15	75	Stroke (10), dementia (2), head injury (1), Parkinsonism (1), nasopharyngeal carcinoma (1)	Inter-individual comparisons before and after PEG insertion	24F feeding tubes with Ponsky's pull method (n = 15)	Not stated	1 week	Gastro-esophageal reflux (GER)	65% reduction in GER with PEG (p=0.028)
Kumagai 2012	261	79	Dementia	Single-centre observational study	Not stated	Not stated	6 months for albumin and pneumonia, 27 months for mortality	Albumin (g/dl), mean (SD)	2.9(0.6) vs 2.9(0.5), p=0.84
								Aspiration Pneumonia	36/96 vs 54/68
								Mortality	131/151 vs 102/106, p=0.019
Azzopardi and Ellul	97	Not stated	Stroke, progressive muscle	Single-centre retrospective	Referred for PEG after	55 patients who had NG tube	1 year for PEG; 85.3 (range=7-	Pneumonia rate (ratio of days of	P<0.005 between PEG with prior, PEG

**Table 2.1, continued**

Reference	Total participants	Mean age (Years)	Indications	Study design	Interventions		Duration	Outcome measures	Group differences (PEG vs. NG)
					PEG group	NG group			
2013		(only patients >65 years included)	degeneration, malignancy and persistent vegetative state	study of all patients undergoing PEG insertion	speech therapy assessment	feeding before PEG	348) days for NG	hospitalization due to pneumonia /days on NG/PEG feed)	without prior NG and NG feeding

PEG=Percutaneous Endoscopic Gastrostomy; NG=Nasogastric; GER=Gastroesophageal Reflux; HR=hazard ratio; CI=confidence interval;

ns=not significant

\*X-ray or clinical evidence of aspiration pneumonia

\*\*only abstract available

### 2.3.1.8 Comprehensiveness of reporting

The risks of bias in the included studies are shown in Figure 2.2. The RCT (n=2) conducted by Yata *et al.* (2001) did not specify their randomization method, and was therefore considered of unclear risk of bias (Yata *et al.* 2001). Park *et al.* (1992) stated that they used computer generated number sequences and was considered at low risk of bias. The method of allocation concealment reported by Park *et al.* (1992) was using sealed envelopes, which were therefore considered at low risk for allocation concealment bias (Park *et al.* 1992). The study by Yata *et al.* (2001) was considered at unclear risk of bias as inadequate information was provided for allocation concealment (Yata *et al.* 2001). The remaining studies (n = 7) were non-RCTs and were considered at high risk of systematic errors of a methodological nature. Blinding of outcomes was not possible due to the nature of the interventions for all but one of the studies. All studies were therefore judged to be of high risk of performance and detection bias, apart from Lee and Shiun (2011) which was considered as at unclear risk as the authors did not specify whether the interpreters of the scans were blinded to the treatment status (Lee & Shiun 2011). Attrition bias was considered high for two studies (Dwolatzky *et al.* 2001, Kumagai *et al.* 2012) due to the high dropout rates, particularly in the NG arms. Three studies (Attanasio *et al.* 2009, Azzopardi & Ellul 2013, Ciocon *et al.* 1988) did not report mortality outcomes separately for the two arms, and were therefore considered at high risk of reporting bias. Two studies (Lee & Shiun 2011, Park *et al.* 1992) reported all expected outcomes which we considered at low risk of attrition and reporting bias. The other two studies (Rio *et al.* 2010, Yata *et al.* 2001) were considered at unclear risk as the authors did not specify information on missing data. Three studies were considered at high risk of reporting bias due to high dropout rates (Kumagai *et al.* 2012) and the authors did not report mortality separately for the two arms (Attanasio *et al.* 2009, Ciocon *et al.* 1988). All studies (Azzopardi & Ellul 2013, Dwolatzky *et al.*

2001, Lee & Shiun 2011, Park *et al.* 1992, Rio *et al.* 2010) reported relevant outcomes which we considered at low risk of bias except Yata *et al.* (2001) which only published an abstract (Yata *et al.* 2001). The latter study was considered at unclear risk of bias. All included studies were considered at high risk of other biases mainly due to weaknesses in their methodology. Ciocon *et al.* (1988) included patients with oesophageal obstruction who were unable to have NG tubes (Ciocon *et al.* 1988), Rio *et al.* (2010) included patients who refused PEG in their NG group (Rio *et al.* 2010), Lee and Shiun (2011) only included data from one week's observation (Lee & Shiun 2011), and Azzopardi and Ellul (2013) compared complication rates in patients who had NG tubes before PEG insertion with complications after PEG insertion (Azzopardi & Ellul 2013). Dwolatzky *et al.* (2001) conducted an observational study on NG and PEG feeding (Dwolatzky *et al.* 2001) and Park *et al.* (1992) reported a 95% (19/20) dropout rate in the NG group due to the failure of treatment and death (Park *et al.* 1992). Yata *et al.* (2001) only published an extended abstract (Yata *et al.* 2001), and Attanasio *et al.* (2009) and Kumagai *et al.* (2012) did not report baseline characteristics for the two groups (Attanasio *et al.* 2009, Kumagai *et al.* 2012). Overall, the RCTs were judged to have unclear risk of selection bias, with high risk of attrition and reporting bias due to blinding difficulties. All the remaining studies were non-RCTs, and contained high risk of biases in selection, blinding, attrition and reporting.

The final selection included two randomized controlled trials, four cohort studies, one case control study and two retrospective studies. This yielded a sample of 847 subjects (PEG n = 406 and NG n = 441) from the nine selected studies. The mean age of study participants was  $75 \pm 8.1$  years and the main indications for enteral feeding were dementia and neurological disease. The duration of follow-up in all studies ranged from four weeks to six months.

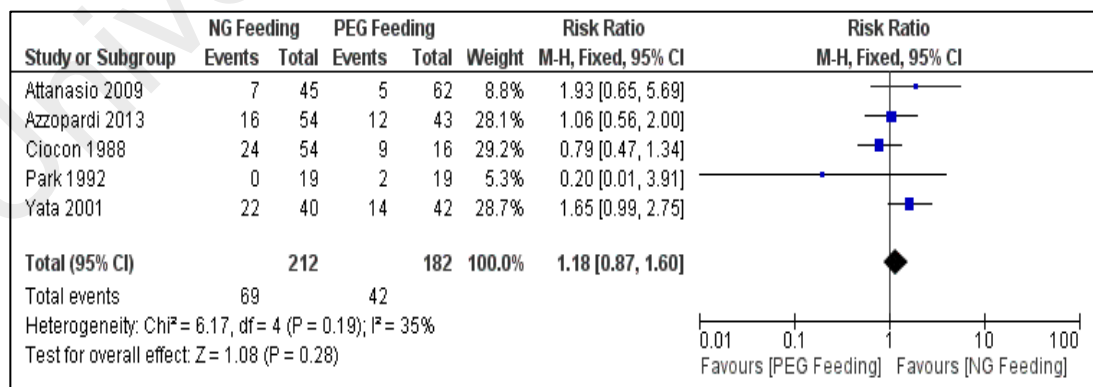
	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Attanasio 2009	-	-	-	-	-	-	-
Azzopardi 2013	-	-	-	-	-	+	-
Baeten 1992	?	+	-	-	-	-	+
Ciocon 1988	-	-	-	-	-	-	-
Dwolatzky 2001	-	-	-	-	-	+	-
Kumagai 2012	-	-	-	-	-	-	-
Lee 2011	-	-	?	?	+	+	-
Park 1992	+	+	-	-	+	+	-
Rio 2010	-	-	-	-	?	+	-
Yata 2001	?	?	-	-	?	?	-

**Figure 2.2: Summary of Risk of Bias**

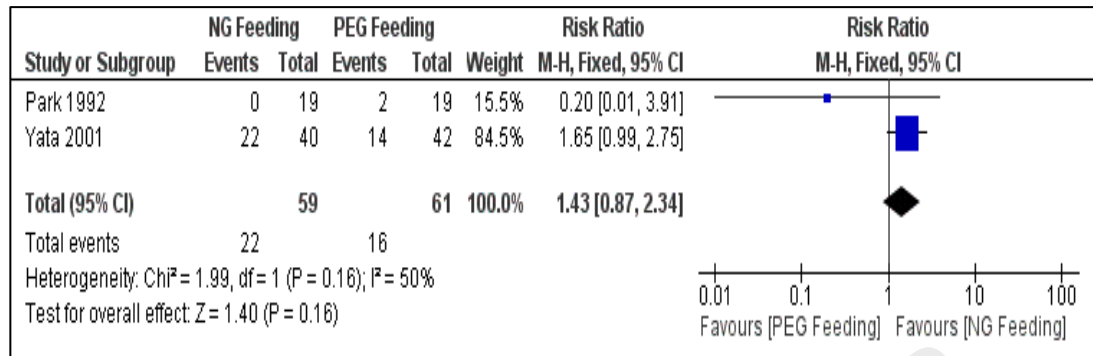
### 2.3.1.9 Aspiration pneumonia

The outcome of aspiration, pneumonia or aspiration pneumonia was evaluated in five studies (394 participants). It was considered separately in addition to overall complications as pneumonia is a commonly reported outcome. Ciocon *et al.* (1988) used

radiographic and clinical evidence of aspiration pneumonia (Ciocon *et al.* 1988). Dwolatzky *et al.* (2001) and Attanasio *et al.* (2009) reported aspiration as their outcome, no definition for aspiration was stated in their report (Attanasio *et al.* 2009, Dwolatzky *et al.* 2001). Kumagai *et al.* (2012) reported aspiration pneumonia but did not state their diagnostic criteria (Kumagai *et al.* 2012). Azzopardi and Ellui (2013) reported pneumonia episodes based on the number of documented episodes of pneumonia in patients' hospital records (Azzopardi & Ellul 2013). The results showed pneumonia occurred in 23.08% (42/182) patients in who received PEG feeding and 32.55% (69 out of 212) patients who received NG feeding. The RR using the fixed-effect model was 1.18 ( $P = 0.28$ ) with a 95% CI of 0.87 to 1.60 (Mantel-Haenszel statistical method). The result is shown in Figure 2.3. If only randomized trials were included, aspiration pneumonia occurred in 37.29% of patients with NG feeding (22/59 patients) and 26.23% patients with PEG feeding (16/61 patients). The pooled analysis revealed a RR of 1.43 (95% CI= 0.87 to 2.34) for pneumonia occurrence, indicating no significant difference in risk between PEG and NG cases (Figure 2.4).



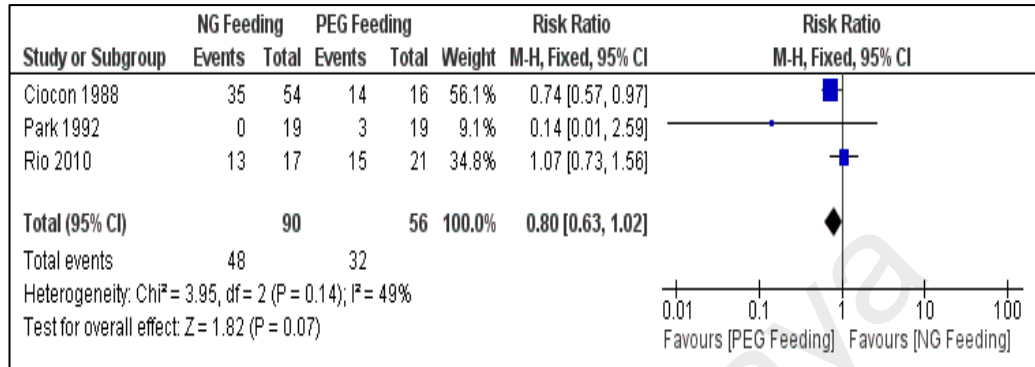
**Figure 2.3: Forest Plot of Comparison in Aspiration Pneumonia**



**Figure 2.4: Forest Plot of Comparison in Aspiration Pneumonia in Randomised Trials**

#### 2.3.1.10 Overall complications

The outcome of overall complication rates including pneumonia was evaluated in three studies (146 participants). The complications included in our studies included all method-specific and common problems during the time of enteral feeding (Baeten & Hoefnagels 1992, Park *et al.* 1992). Ciocon *et al.* (1988) reported evidence of agitation requiring multiple tube reinsertions and restraint of extremities and other tube-related problems (Ciocon *et al.* 1988). Rio *et al.* (2010) revealed complications post procedure (Rio *et al.* 2010). The results showed 57.14% (32 out of 56 patients) in the PEG group and 53.33% (48 out of 90 patients) in the NG group had complications. The RR using the fixed-effect model was 0.80 ( $P = 0.07$ ) with 95% CI 0.63 to 1.02. The results are shown in Figure 2.5. Ciocon *et al.* (1988) reported a 93.75% (15/16) early complication rate in their PEG group and 70.37% (38/54) in their NG group (Ciocon *et al.* 1988). Park *et al.* (1992) reported that three patients developed complications in their PEG group but none in their NG group (Park *et al.* 1992). Rio *et al.* (2010) reported severe pain as common complications in both groups (Rio *et al.* 2010).



**Figure 2.5: Forest Plot of Comparison in Overall Complication Rates**

#### 2.3.1.11 Nutritional status

Pooled data for nutritional assessments was not possible due to the different methods of assessments reported by the studies. Five out of 10 studies assessed nutritional status after PEG or NG feeding. Ciocon *et al.* (1988) reported laboratory measures of albumin, haematocrit and haemoglobin, but did not consider the results separately for the two groups (Ciocon *et al.* 1988). Park *et al.* (1992) attempted to assess anthropometry measures, but was unable to make meaningful comparisons due to excessively high dropout rates in their NG feeding group (Park *et al.* 1992). Yata *et al.* (2001) reported serum albumin, haemoglobin and cholesterol levels at three and six months (Yata *et al.* 2001). Dwolatzky *et al.* (2001) reported albumin and weight ratio at two, four and 12 weeks (Dwolatzky *et al.* 2001). Kumagai *et al.* (2012) reported only 6-month albumin levels (Kumagai *et al.* 2012). Yata *et al.* (2001) reported significant improvements in albumin levels at 3-6 months, and significant improvements in cholesterol levels at six month, but no significant changes in haemoglobin at both time points (Yata *et al.* 2001).



Dwolatzky *et al.* (2001) found significantly larger improvements in PEG fed patients compared to NG fed patients at 4 weeks, but no significant differences in albumin or weight ratio between their two groups at the other time points (Dwolatzky *et al.* 2001). Kumagai *et al.* (2012) did not find any significant differences in albumin levels between their PEG and NG fed participants (Kumagai *et al.* 2012).

#### **2.3.1.12 Mortality**

A meta-analysis for the outcome of mortality was not possible due to unacceptably high heterogeneity between the studies ( $I^2 = 79\%$ ). None of the two randomised trials reported any results on mortality. Of the seven non-randomized studies, three studies reported mortality outcomes, but four studies did not report specific mortality rates for their PEG and NG groups. Dwolatzky *et al.* (2001) reported that PEG patients lived significantly longer than NG patients (HR = 0.41; 95% CI 0.22 to 0.76) (Dwolatzky *et al.* 2001). Kumagai *et al.* (2012) revealed that the survival rate of PEG patients was significantly higher than NG patients at 27 months, with a 87.10% (135/155) death rate for patients in the PEG group compared to 96.23% (102/106) for patients in the NG group (Kumagai *et al.* 2012). Rio *et al.* (2010) stated that the 180-day mortality was 48% for their PEG group and 88% for their NG group ( $p = 0.001$ ) (Rio *et al.* 2010).

#### **2.3.1.13 Discussion for systematic review on NG versus PEG feeding for non-stroke dysphagia**

The findings of the present review were carefully interpreted as many studies were not randomized trials. Non-randomized studies were considered as low quality studies. Not all randomized studies clearly reported random sequence generation and allocation concealment. As a NG tube will also be visible to both participants and assessors, it was not possible to blind the participants or assessors for clinical outcome assessments, all

studies were therefore at high risk for performance and detection bias. Many authors tried to reduce the attrition and reporting bias by presenting the flow of patients and relevant outcomes. However, all except two studies (Lee & Shiun 2011, Park *et al.* 1992) did not report outcomes stated within their study objectives, failed to account for missing data, experienced high dropout rates, or failed to report mortality separately for both groups. The mean of participants included in each of this present review was 106 patients. The most likely reason for the small sample sizes in most of the studies was the high cost of the procedures and enteral feeds (Gomes Jr *et al.* 2012). Based on this systematic review, the quality of the studies included was overall of poor quality.

Aspiration pneumonia occurs when food, saliva, liquids, vomitus or stomach contents are inhaled into the lung. The likelihood of aspiration increases when the swallow mechanism is affected from neurological conditions or structural problems affecting the oropharynx or oesophagus (Norwood 2013). The subsequent development of pneumonia from aspiration is also dependent on numerous factors including the cough reflex, volume of aspirate and the integrity of the immune system. Aspiration pneumonia can also occur from regurgitation. It has been postulated that regurgitation is more common in patients with NG tube feeding, as the passage of the NG tube through the cardiac sphincter of the oesophagus compromises the integrity of the sphincter (Lee & Shiun 2011). Meta-analysis on aspiration or pneumonia outcomes did not show any significant difference between pneumonia outcomes between NG fed and PEG fed patients. It is likely that as aspiration usually results from the presence of multiple risk factors rather than a single deficit, the reduction in risk of regurgitation alone may not have an overall beneficial effect in our selected patient group of individuals with non-stroke dysphagia. In addition, two studies (Johnson *et al.* 1987, Razeghi *et al.* 2002) demonstrated that PEG insertion decreased oesophageal sphincter pressure in patients which could increase gastroesophageal reflux. The diagnoses of aspiration or

pneumonia in our studies were not verified by post-mortem. Only Ciocon *et al.* (1988) reported using radiological or clinical criteria for aspiration pneumonia, while the diagnostic criteria were unclear in the remaining studies (Ciocon *et al.* 1988).

Pooled data demonstrated that overall complication rates were similar in both types of feeding. The overall complication rate was, however, a composite measure of potential complications occurring from both types of feeding. Previous studies reported that NG and PEG feeding had equal tube clogging problems (Attanasio *et al.* 2009, Baeten & Hoefnagels 1992). Clogging of tubes can result from the administration of medications in the form of crushed tablets or capsule, instead of a liquid form (Pancorbo-Hidalgo *et al.* 2001). Some studies (Attanasio *et al.* 2009, Ciocon *et al.* 1988) revealed that nasogastric tube dislodgement was common, however, it can be prevented. Anderson *et al.* (2004) created a nasal loop which could prevent accidental removal whilst increasing the amount of prescribed daily feeds the patients received (Anderson *et al.* 2004). In addition, protective mittens have been shown to reduce the frequency of tube dislodgement (Pancorbo-Hidalgo *et al.* 2001), but they may have a negative impact on the quality of life of the patient. Attanasio *et al.* (2009) suggested that if good nurse training and domiciliary follow-up were provided for both types of the feeding, low complication rates can be expected (Attanasio *et al.* 2009). This was supported by Alvarez *et al.* (2005) which demonstrated that good quality of care determined the overall complications of the tubes (Alvarez-Fernandez *et al.* 2005).

Previous studies involving stroke patients have suggested better nutrition outcomes with PEG feeding compared to NG feeding. A randomized study which compared PEG feeding and NG feeding in patients with acute stroke reported that malnourished patients were likely to develop complications and a reduced survival rate. Their study showed that PEG feeding was superior in terms of nutritional status (Norton *et al.*

1996). As mentioned earlier Hamidon *et al.* (2006) revealed higher serum albumin levels in PEG fed acute stroke patients compared to NG fed patients after 4 weeks of intervention (Hamidon *et al.* 2006). Malnutrition among elderly inpatients is common, particularly those with dysphagia (Kaiser *et al.* 2010, Wakabayashi & Sashika 2013). Five of the ten studies included in the review reported laboratory or anthropometric measures of nutritional status, but only three of the studies reported differences between the two groups. One study reported sustained improvements in albumin levels after 6 months (Yata *et al.* 2001), while one study found improvements only at 4 weeks, but not 12 weeks (Dwolatzky *et al.* 2001). The remaining study showed no significant improvement (Kumagai *et al.* 2012). Therefore, while previous evidence favours PEG feeding in stroke patients, it remains unclear whether PEG feeding is superior to NG feeding in older patients with non-stroke dysphagia.

Pooled data to assess mortality rate was not possible due to the significant heterogeneity studies. Three studies which reported group-specific mortality outcomes (Dwolatzky *et al.* 2001, Kumagai *et al.* 2012, Rio *et al.* 2010), suggested significant mortality in their NG fed patients. Mortality among patients with dysphagia is likely to be high, as it is influenced by numerous factors including the underlying disease process. In conditions such as motor neuron disease and dementia, which are progressive and life-limiting, dysphagia often occurs at the later phases of these conditions (Serra-Prat *et al.* 2012). Presence of pressure sores also influenced the mortality of the patients (Dhandapani *et al.* 2014). Previous studies have also suggested that PEG feeding may be of limited benefit compared to oral feeding in patients with dementia. Murphy and Lipman (2003) compared the survival of individuals with dementia who received PEG feeding with those who refused PEG insertion, and found no significant survival advantage in their PEG feeding group (Murphy & Lipman 2003).

Poor quality evidence comparing PEG feeding with NG feeding was determined, and only two of the nine studies included were RCTs. It is therefore difficult to draw firm conclusions in favor of PEG feeding or NG feeding in patients with non-stroke dysphagia. A well-designed and adequately powered RCT is therefore much needed. However, robust RCTs in this group of patients will be highly challenging, as these patients are often physically quite frail and highly susceptible to physical insults, which will significantly affect the attrition rate of such a study. Other challenges include the impossibility of blinding and the difficulty in ensuring equal follow-up duration between groups. The findings of the review, however, suggest that there are no differences in aspiration or pneumonia outcomes as well as overall complication outcomes between PEG fed and NG fed patients. However, based on reported mortality, more studies favor PEG feeding for mortality outcomes. The meaningfulness of added survival for this group of patients may also be questionable, and few studies have addressed caregiver burden and quality of life. The choice for PEG feeding or NG feeding may ultimately be better dictated by local expertise, patient related factors, patient preference, as well as cost-effectiveness and future studies into these factors are urgently required.

#### **2.4 Current Knowledge of the Attitudes and Barriers to PEG Feeding**

Healthcare professionals are the main care providers in patient care, as they provide intensive care for patients, spend more time in direct contact with them, preparing enteral feeding formulae, checking the correct tube type, and assessing patients' outcomes. Therefore they are in a position to make profound impact on the decision making of PEG tube insertion. Several studies highlighted that some attitudes of HCPs might influence the type of feeding given.

A search of the literature reviewed no previously published systematic review on attitudes and barriers to PEG tube feeding. A systematic review was therefore conducted primarily to summarize available quantitative and qualitative studies on the current systematic review was conducted in order to identify potential barriers to the acceptance of PEG tube feeding among HCPs, caregivers and patients.

#### **2.4.1 Search strategy**

Relevant peer reviewed and English Language articles were identified. The search terms used were combined with Medical Subject Heading (MeSH) terms and text words such as "percutaneous endoscopic gastrostomy" OR "gastrostomy" OR "PEG" OR "enteral feeding" AND "perception" OR "opinion" OR "attitude". The titles of all articles and the abstracts of potentially relevant articles were screened and read in full. The full text articles that contained potentially relevant data or information were then retrieved to be analysed and examined for eligibility.

Qualitative and quantitative studies classified according to the authors' description were included. If the authors did not provide any kind of description, the study was classified by the type of questions that were asked. For example, if they used the same closed questions among all the participants and included some figures mentioning the percentage of participants that were satisfied or that had specific expectations, the study was categorized as quantitative. A study was determined to be qualitative if satisfaction or expectations were explored using open-ended questions in individual interviews or focus groups.

In qualitative studies, quotations from participants and text in terms of "findings" from each study were entered verbatim. The findings of the studies were categorized according to similarities and differences in relation to participant perspectives. The same applied to the quantitative studies where the frequency of answers to questions

was used to discover relevant aspects. Studies were then grouped into a structured model of themes (Lucas *et al.* 2007).

#### **2.4.2 Electronic databases**

The same following online databases as in the first literature search were interrogated up to 7 January 2015: MEDLINE via Ovid SP, CINAHL via EBSCO, EMBASE, Web of Science, and Cochrane Library (Systematic reviews of research in healthcare).

#### **2.4.3 Inclusion criteria**

The main criteria for selecting studies representing of attitudes and barriers to PEG feeding were quite the same as in the first literature search. Relevant studies, electronic theses, and review articles were sought with no restrictions of the date of publication.

#### **2.4.4 Exclusion criteria**

Studies that did not provide data on the attitudes and/or barriers to PEG feeding and focused solely on children were excluded. Non-English language articles were also excluded to prevent cultural and linguistic bias in translation.

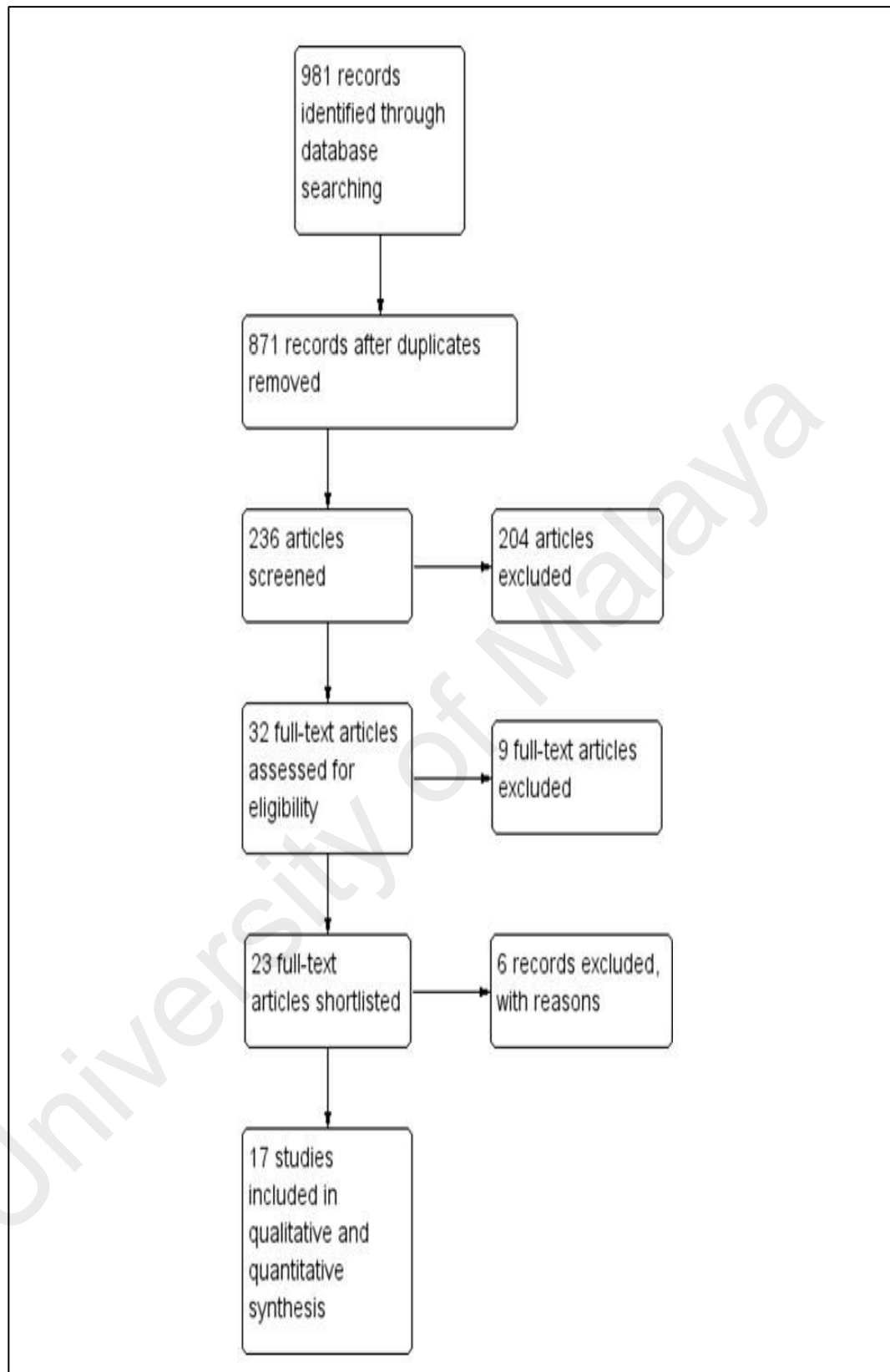
#### **2.4.5 Technique of critical appraisal**

In this second search, two of the researchers (MHJ and MPT) independently extracted qualitative and quantitative data from the studies including methods, participants, data analysis, and outcomes. The quality of studies was appraised using the standard quality assessment criteria for evaluating primary research papers from a variety of fields by Alberta Heritage Foundation for Medical Research (AHFMR 2004). If a study scored more than 55 percent, it was considered to be of high quality. Disagreements were resolved by discussion. Decisions to exclude studies were not based on the assessment of quality of reporting.

#### 2.4.6 Search output

The database search yielded 981 articles. After removing duplicates, the titles of 871 articles were screened and 636 articles which were not considered relevant were excluded. The abstracts of 236 articles were evaluated. At this stage, 204 articles were excluded as they were intervention studies which did not assess attitudes or barriers or were prognostic studies. Conference proceedings and non-primary research such as review and editorial articles were excluded as well. From the 32 full-text articles, nine articles were excluded as they involved only minors. Six other articles were excluded for the following reasons: one study focused on decision aids (Hanson *et al.* 2011), two studies evaluated medical technology (Munck *et al.* 2012, Rolland *et al.* 2009), one study evaluated ethical principles (Wilmot *et al.* 2002), one study explored PEG withdrawal (Lubart *et al.* 2004), and the remaining study discussed artificial nutrition and hydration (Bryon *et al.* 2012). As a result, 17 articles met the inclusion criteria and were included in the qualitative and quantitative analyses (Figure 2.6). The studies were carried out in England (J. Adams & Lewin 2009, Brotherton & Abbott 2009, Liley & Manthorpe 2003, Mayre-Chilton *et al.* 2011, Merrick & Farrell 2012, Rickman 1998), Sweden (Bjuresäter *et al.* 2008), Turkey (Boz Cigeroglu & Karadag 2012), Ireland (Healy & McNamara 2002, Madigan *et al.* 2007), Wales (Jordan *et al.* 2006), Taiwan (Lin *et al.* 2011, Yeh *et al.* 2010), United States (Sharp & Shega 2009), Canada (Kwong *et al.* 2014, Todd *et al.* 2005) and Malaysia (Zaherah Mohamed Shah *et al.* 2012). The characteristics of the included studies are reported in Table 2.2.





**Figure 2.6: The Process of Selecting Studies Included in the Review**

**Table 2.2: Characteristics of Included Studies**

Study	Country	Study population	Setting	No. subjects	Response rate (%)	Data collection	Methods	Issues explored
<b>North America</b>								
Kwong 2014	Canada	Patients	Cancer survivors	15	94	Semi-structured interviews	Phenomenology	Information, acceptance
Todd 2005	Canada	Nurses	Adult patients undergoing PEG placement	17	94	Semi-structured interviews, self-administered questionnaire	Mixed	Lack of knowledge, decision-making (family involvement)
Sharp 2009	US	Speech – language pathologist	Members of professional body	326	57	Survey	Quantitative	Procedural risks, decision making (family involvement), financial, HCP recommendations
<b>Europe</b>								
Adams 2009	England	Paid caregivers	Home for disabled adults	40	71%	Unstructured interviews, focus group, questionnaire,	Mixed	Vomiting, work intensity, financial, information

**Table 2.2, continued**

Study	Country	Study population	Setting	No. subjects	Response rate (%)	Data collection	Methods	Issues explored
						nursing record analysis		
Brotherton 2009	England	Patients, caregivers	PEG ≥4 weeks	16 patients, 27 caregivers	Patients- 44 %, Caregivers-75%	Semi-structured interviews	Thematic analysis	Knowledge, Attitudes of HCPs, communication, acceptance
Liley 2003	England	Patients and caregivers	Home tube feeding ≥12 weeks	6 patients, 5 caregivers	Not stated	Semi-structured interviews	Grounded theory	Decision making (patient involvement), competency, preparation, lifestyle
Mayre 2011	England	Patients, caregivers	PEG ≥ 3 months	6 patients, 3 caregivers	Patient- 43%, caregiver s-75%	Topic guided focus group interview	Constant comparison	Knowledge, support, financial, psychological
Merrick 2012	England	Patients	Head and neck patients	15 patients	87%	Semi-structured interviews	Q- methodology	Psychological issues before and after PEG insertion, coping strategies
Rickman	England	Patients,	Endoscopist	12	Patients-	Semi-structured	Phenomenology	Psychological, lifestyle restriction, information,

**Table 2.2, continued**

Study	Country	Study population	Setting	No. subjects	Response rate (%)	Data collection	Methods	Issues explored
1998		caregivers	referral, dietitian and GP	patients, 9 caregivers	86%, caregiver s - 100%	interviews		support
Jordan 2006	Wales	Patients	PEG > 12 months	20	75%	Semi-structured interviews, symptoms checklist, SF-12	Mixed	Knowledge, lifestyle restrictions, psychological, training, support
Healy 2002	Ireland	Dietitians	Members of professional body	345	45%	Survey	Quantitative	Decision-making (patient involvement), information, guidelines
Madigan 2007	Ireland	General practitioners	Past or present experience of PEG feeding	23	81	Semi-structured one to one interviews	Constant comparison	Experience, training, knowledge, decision-making, financial, communication, support
Bjuresater 2008	Sweden	Nurses	>6 months experience with HETF	10	Not stated	Interviews (open-ended questions)	Phenomenology	Competency, guidelines, work routines, information

**Table 2.2, continued**

<b>Study</b>	<b>Country</b>	<b>Study population</b>	<b>Setting</b>	<b>No. subjects</b>	<b>Response rate (%)</b>	<b>Data collection</b>	<b>Methods</b>	<b>Issues explored</b>
Boz Cigeroglu 2012	Turkey	Patients	HETF > 3 months	50	67%	Survey	Quantitative	Financial, psychological, lifestyle
<b>Asia</b>								
Lin 2011	Taiwan	Patients	Enteral tube feeding (with NG and PEG)	607	70%	Survey	Quantitative	Information, decision making (family involvement), procedural risk, familiarity
Yeh 2010	Taiwan	Directors of nursing homes	≥ 1 year experience with PEG	8	Not stated	Semi-structured interviews	Phenomenology	Body image, mortality, financial, doctors' recommendations, experience, knowledge, support
Zaherah 2012	Malaysia	Caregivers, doctors	Elderly patients > 8 weeks	70 caregivers, 20 doctors	Not stated	Survey	Quantitative	Procedural risk, financial, information, decision making (family involvement), body image

HETF=home enteral tube feeding

#### 2.4.7 Comprehensiveness of Reporting

The quality assessment of the included qualitative studies is shown in Table 2.3. The completeness of reporting varied across the studies, with three studies (Bjuresäter *et al.* 2008, Kwong *et al.* 2014, Mayre-Chilton *et al.* 2011) completing the 10-item reporting criteria. All 12 studies specified a connection to a theoretical framework, clearly described the data collection methods and data analysis, supported the conclusions by the results and had reflexivity of the account. Only five studies (Bjuresäter *et al.* 2008, Kwong *et al.* 2014, Liley & Manthorpe 2003, Mayre-Chilton *et al.* 2011, Rickman 1998) adequately described the context of the study. However, all of the studies scored 70 percent and above and were hence considered to be of high quality.

A summary of the quality assessment for five quantitative studies is shown in Table 2.4. Of the 14 items within the quality assessment checklist, only 10 items were relevant in these studies. Total score was calculated using the denominator derived from the 10 items rather than the 14 original items. The number of studies fulfilling individual criteria among the 10 relevant items specified by the reporting criteria ranged from non to five studies. All five studies sufficiently described their objectives, defined the outcomes, reported results and had conclusions which supported their results. No studies justified their sample size or estimated variance of their results. Total scores ranged between 45 to 80 percent. Only one study scored less than 55 percent (Healy & McNamara 2002). The remaining studies (Boz Cigeroglu & Karadag 2012, Lin *et al.* 2011, Sharp & Shega 2009, Zaherah Mohamed Shah *et al.* 2012) were considered high quality studies.

**Table 2.3: Checklist for Assessing the Quality of Qualitative Studies**

<b>Reporting criteria</b>	<b>Yes (%) (n=12)</b>	<b>Adams 2009</b>	<b>Bjuresat er 2008</b>	<b>Brothert on 2009</b>	<b>Jordan 2006</b>	<b>Kwong 2014</b>	<b>Liley 2003</b>	<b>Madiga n 2007</b>	<b>Mayre 2011</b>	<b>Merrick 2012</b>	<b>Rickma n 1998</b>	<b>Todd 2005</b>	<b>Yeh 2010</b>
Question / objective sufficiently described?	11(92)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	N(0)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)
Study design evident and appropriate?	9(75)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	N(0)	Y(2)	Y(2)	Y(2)	N(0)	N(0)
Context for the study clear?	5(42)	N(0)	Y(2)	N(0)	N(0)	Y(2)	Y(2)	N(0)	Y(2)	N(0)	Y(2)	N(0)	N(0)
Connection to a theoretical framework / wider body of knowledge?	12(100)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)
Sampling strategy described, relevant and justified?	7(58)	N(0)	Y(2)	Y(2)	Y(2)	Y(2)	N(0)	Y(2)	Y(2)	Y(2)	P(1)	P(1)	N(0)
Data collection methods clearly	12(100)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)

**Table 2.3, continued**

<b>Reporting criteria</b>	<b>Yes (%) (n=12)</b>	<b>Adams 2009</b>	<b>Bjuresat er 2008</b>	<b>Brothert on 2009</b>	<b>Jordan 2006</b>	<b>Kwong 2014</b>	<b>Liley 2003</b>	<b>Madiga n 2007</b>	<b>Mayre 2011</b>	<b>Merrick 2012</b>	<b>Rickma n 1998</b>	<b>Todd 2005</b>	<b>Yeh 2010</b>
described and systematic?													
Data analysis clearly described and systematic?	12(100)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)
Use of verification procedure(s) to establish credibility?	10(83)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	N(0)	Y(2)	Y(2)	Y(2)	N(0)	Y(2)	Y(2)
Conclusions supported by the results?	12(100)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)
Reflexivity of the account?	12(100)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)
<b>Total Score (%)</b>		<b>16(80)</b>	<b>20(100)</b>	<b>18(90)</b>	<b>18(90)</b>	<b>20(100)</b>	<b>14(70)</b>	<b>16(80)</b>	<b>20(100)</b>	<b>18(90)</b>	<b>17(85)</b>	<b>15(75)</b>	<b>14(70)</b>

Y=Yes equals to 2, P=Partial equals to 1, N=No equals to 0



**Table 2.4: Checklist for Assessing the Quality of Quantitative Studies**

<b>Reporting criteria</b>	<b>Yes (%) (n=5)</b>	<b>Boz Cigeroglu 2012</b>	<b>Healy 2002</b>	<b>Lin 2011</b>	<b>Sharp 2009</b>	<b>Zaherah 2012</b>
Question / objective sufficiently describe?	5(100)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)
Study design evident and appropriate?	2(40)	N(0)	N(0)	N(0)	Y(2)	Y(2)
Method of subject / comparison group selection <u>or</u> source of information / input variables described and appropriate?	3(60)	Y(2)	N(0)	N(0)	Y(2)	Y(2)
Subject (and comparison group, if applicable) characteristics sufficiently described?	1(20)	P(1)	N(0)	P(1)	Y(2)	N(0)
Outcome and (if applicable) exposure measure (s) well defined and robust to measurement / misclassification bias? Means of assessment reported?	5(100)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)
Sample size appropriate?	0(0)	P(1)	N(0)	N(0)	N/A	N/A
Analytic methods described / justified and appropriate?	3(60)	P(1)	P(1)	Y(2)	Y(2)	Y(2)
Some estimate of variance is reported for the main results?	0(0)	N(0)	N(0)	N(0)	N/A	N/A
Results reported in sufficient detail?	5(100)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)
Conclusions supported by the results?	5(100)	Y(2)	Y(2)	Y(2)	Y(2)	Y(2)
<b>Total Score (%)</b>		<b>13(65)</b>	<b>9(45)</b>	<b>11(55)</b>	<b>16(80)</b>	<b>14(70)</b>

Y=Yes equals to 2, P=Partial equals to 1, N=No equals to 0, N/A=Not available

#### 2.4.8 Specific Preferences for PEG Tube

Four studies reported outcomes both from the perspectives of patients and caregivers (Brotherton & Abbott 2009, Liley & Manthorpe 2003, Mayre-Chilton *et al.* 2011, Rickman 1998) while five studies involved only patients (Boz Cigeroglu & Karadag 2012, Jordan *et al.* 2006, Kwong *et al.* 2014, Lin *et al.* 2011, Merrick & Farrell 2012) and one study involved only caregivers (J. Adams & Lewin 2009). The remaining studies focused on solely HCPs: one on general practitioners (Madigan *et al.* 2007), three on nurses (Bjuresater *et al.* 2012, Todd *et al.* 2005, Yeh *et al.* 2010), one on speech and language therapists (Sharp & Shega 2009) one on dietitians (Healy & McNamara 2002) and one on both doctors and caregivers (Zaherah Mohamed Shah *et al.* 2012).

When a choice of type of feeding was offered to patients, this was usually between NG feeding and PEG feeding. Fourteen studies described attitudes of participants towards PEG feeding (Table 2.5). Positive attitudes were reported by seven studies (Healy & McNamara 2002, Jordan *et al.* 2006, Kwong *et al.* 2014, Liley & Manthorpe 2003, Rickman 1998, Sharp & Shega 2009, Todd *et al.* 2005). Two studies reported negative attitudes towards PEG (Boz Cigeroglu & Karadag 2012, Lin *et al.* 2011). One study showed paternalistic attitudes on the part of doctors to decision making (Brotherton & Abbott 2009). Two studies revealed only half of the participants would agree to PEG (Madigan *et al.* 2007, Zaherah Mohamed Shah *et al.* 2012). One study mentioned negative attitudes towards PEG but at the same time highlighted the benefits of PEG tube feeding (Mayre-Chilton *et al.* 2011). Another study reported the development of coping strategies by accepting the reality of illness which led to initial negative attitudes evolving into eventual dependency on PEG tube feeding (Merrick & Farrell 2012).

**Table 2.5: Perceptions towards PEG Tube**

Perceptions of PEG		Region	Interpretations of Findings Offered by Authors
Positive	Most would recommend PEG to patients	North America	The most frequent recommendation was PEG tube feeding (56%). Fewer than 10% of respondents would recommend nasogastric tube feeding, and 44% would be likely to recommend a combination of oral feeding and ANH (Sharp & Shega 2009).
	All participants regarded PEG as a necessity for cancer treatment	North America	The tube was viewed as a functional benefit—equipment that helped participants manage side effects of cancer treatment (Kwong <i>et al.</i> 2014).
	PEG was seen as a life-saving measure	North America	For young patients with a good prognosis, PEG feeding was viewed as a life-saving measure, an intermediate step to keep the patient healthy while other medical issues were resolved (Todd <i>et al.</i> 2005).
	75% are positive about PEG	Wales, Europe	Most (15/20) participants spoke positively of their PEGs, commenting that insertion had been lifesaving (Jordan <i>et al.</i> 2006).
	Overall satisfied with HETF	England,	Both patients and caregivers demonstrated their abilities to cope with

Table 2.5, continued

Perceptions of PEG		Region	Interpretations of Findings Offered by Authors
		Europe	and adapt to the demands of HETF, and had a realistic appreciation of the benefits (Liley & Manthorpe 2003).
	Patients were grateful for nutritional benefits	England, Europe	Patients were grateful for the nutritional benefits, but as one said, <i>They all say I've managed very well. I suppose I have really, I have no option. I am lucky to get the nourishment otherwise I should have been down to five stones</i> (Rickman 1998).
	Most dietitians choose tube feeding for their cancer patients	Ireland, Europe	The majority of dietitians were in favour of tube feeding the patient with cancer (n=118, 77%). Respondents who were never involved in the care of cancer patient on tube feeds (n ¼ 48) were more likely to be opposed to tube feeding this patient however (P < 0.05) (Healy & McNamara 2002).
Paternalism	Paternalism to decision making	England, Europe	Patients described how they found the attitudes of many health care professionals to be paternalistic and prescriptive in how they had made the recommendation for PEG placement (Brotherton & Abbott

Table 2.5, continued

Perceptions of PEG		Region	Interpretations of Findings Offered by Authors
			2009).
Equivocal	Half of the clinicians agree to PEG	Asia	Among the 20 clinicians, 11 (55%) answered "yes" to a question if they would routinely recommend PEG in patients requiring long term enteral feeding, whilst the other 9 (45%) answered "no" (Zaherah Mohamed Shah <i>et al.</i> 2012).
	Just under half agreed to HETF	Ireland, Europe	Just under half the sample perceived HETF as a positive treatment for patients (Madigan <i>et al.</i> 2007).
Negative (understood benefits)	Patients and caregivers had negative perceptions and feelings.  However they agreed that PEG can improve weight and survival rate and developed a dependency to PEG	England,  Europe	It was clearly observed that there was a negative impact of perception and feelings of both groups, specifically for the social aspects of their lives and also their personal views of the situation and how they perceived each other to feel. Both groups found the main benefit and positive impact of the tube placement to be weight management... (Mayre-Chilton <i>et al.</i> 2011).
Negative	Patients developed a coping	England,	Driven by the need to re-establish a state of normality, the patient

**Table 2.5, continued**

<b>Perceptions of PEG</b>		<b>Region</b>	<b>Interpretations of Findings Offered by Authors</b>
(acceptance and dependency)	strategy by accepting the reality of illness	Europe	interprets the problem posed by the illness within a cognitive and emotional framework, develops a coping strategy based on this and then appraises the success of the coping strategy (Merrick & Farrell 2012).
Negative	Most of the patients / surrogates would not want PEG	Asia	Among these 179 subjects, 153 (85.5%) refused to use PEG/PEJ (Lin <i>et al.</i> 2011).
	Patients experience anxiety, weeping, impaired body perception and self-esteem, and disruption of relationship	Turkey	The first four psychological problems experienced by the patients were anxiety, crying-weeping, impairment of body perception and self-esteem and disruption of relations with family and friends (Boz Cigeroglu & Karadag 2012).

HETF=home enteral tube feeding

### **2.4.9 Synthesis**

Three major themes were determined in terms of barriers to PEG feeding and are presented in Table 2.6. They were lack of choice (poor knowledge, inadequate competency and skills, insufficient time given, not enough information given, lack of guidelines or protocol, resource constraints), confronting mortality (choosing life or death, risk of procedure) and weighing alternatives (adapting lifestyle, family influences, attitudes of HCPs, fear and anxiety). Table 2.7 presents a selection of quotes from participants and the interpretation offered by the authors to explain each theme.

#### **2.4.9.1 Lack of choice**

The theme lack of choice explained the perceived lack of individual choice in decision making about PEG tube insertion. “Poor knowledge” referred to HCPs not knowing about the availability, indications, contraindications, procedures or complications related to PEG insertion or tube feeding. “Inadequate competency and skills” described insufficiency in expertise and operating procedures and training received in relation to PEG tube care. “Insufficient time given” indicated pressure placed on patients and caregivers to make decisions quickly. The subtheme “not enough information provided” indicated that caregivers and patients were not provided with sufficient information in order to make informed decisions regarding PEG insertion and to be able to adequately deal with daily care, feeding tasks and possible complications subsequently. “Lack of guidelines or protocols” referred to inadequate standardized written instructions provided by existing professional bodies or authorities for HCPs to refer to. “Resource constraints” indicated restrictions in funding, human resources and necessary equipment which adversely affect the insertion of the PEG tube or delivery of subsequent PEG care and feeding.

*Poor knowledge* – Five out of 17 studies (Jordan *et al.* 2006, Madigan *et al.* 2007, Mayre-Chilton *et al.* 2011, Todd *et al.* 2005, Yeh *et al.* 2010) mentioned insufficient understanding on the part of HCPs. Mayre-Chilton *et al.* (2011) described that this negatively impacted patients' and caregivers' experience by increasing anxiety about having a PEG tube inserted (Mayre-Chilton *et al.* 2011). Jordan *et al.* (2006) commented that poor knowledge among HCPs, especially those working in accident and emergency departments, would increase the burden of treatment for patients (Jordan *et al.* 2006).

*Inadequate competency and skills* – Six studies (Bjuresäter *et al.* 2008, Jordan *et al.* 2006, Liley & Manthorpe 2003, Madigan *et al.* 2007, Todd *et al.* 2005, Yeh *et al.* 2010) reported inadequacies in training and expertise with respect to enteral feeding. Some caregivers complained that they did not receive enough training before discharge and this led to problems of management at home (Jordan *et al.* 2006). They were also shocked when they found out that even HCPs did not know how to handle PEG tubes (Yeh *et al.* 2010).

*Insufficient time given* – Three studies (Bjuresäter *et al.* 2008, Todd *et al.* 2005, Zaherah Mohamed Shah *et al.* 2012) described that patients and caregivers were not given enough time to consider whether they should have a PEG tube. This could lead to the refusal of a PEG tube due to either inadequate information provided or the lack of opportunity to carefully consider their decisions. Nurses expressed some frustration that they could not spend more time with the patients and caregivers to discuss and provide support (Todd *et al.* 2005). One study reported that nine percent of caregivers would not agree to a PEG due to inadequate family consensus (Zaherah Mohamed Shah *et al.* 2012). It was likely that if more time and preparation had been provided, the family would have arrived at a different decision.



*Not enough information given* – Seven studies (J. Adams & Lewin 2009, Brotherton & Abbott 2009, Healy & McNamara 2002, Jordan *et al.* 2006, Kwong *et al.* 2014, Lin *et al.* 2011, Zaherah Mohamed Shah *et al.* 2012) reported patients and caregivers did not have enough information on treatment options. One study showed that 67% of dietitians felt that inadequate information were given to the patients in order for them to make informed decisions whether or not to have PEG tube feeding (Healy & McNamara 2002). Another study mentioned that the main reason caregivers did not opt for PEG tube feeding was because they were not informed about the option of a PEG by the treating clinician (Zaherah Mohamed Shah *et al.* 2012).

*Lack of guidelines or protocols* – Two (Bjuresäter *et al.* 2008, Healy & McNamara 2002) out of 17 studies talked about the lack of or inadequacy of available local guidelines or protocols stating clearly procedures that should be observed with PEG tube care or feeding. One study mentioned that some improvements could be made to the existing guidelines (Bjuresäter *et al.* 2008). The other study revealed that 78% of respondents reported that no guidelines or protocols were available in their workplace (Healy & McNamara 2002).

*Resource constraints* – One study (Yeh *et al.* 2010) discussed about limited access to PEG insertion services. They reported that only three out of 20 acute care hospitals provided PEG tube insertion services. Seven studies (J. Adams & Lewin 2009, Boz Cigeroglu & Karadag 2012, Madigan *et al.* 2007, Mayre-Chilton *et al.* 2011, Sharp & Shega 2009, Yeh *et al.* 2010, Zaherah Mohamed Shah *et al.* 2012) suggested that lack of funding was a factor that hindered the use of PEG. Another study reported that 10 percent of clinicians would not recommend a PEG due to its' cost (Zaherah Mohamed Shah *et al.* 2012). In Taiwan, NG tube feeding is fully reimbursed by national insurance but not PEG tube feeding (Yeh *et al.* 2010).

#### 2.4.9.2 Confronting mortality

The theme confronting mortality described the thoughts, feelings and attitudes of patients and caregivers confronting a life-threatening illness that may lead to the use of a PEG tube as a life sustaining or prolonging treatment. Choosing between life and death was defined by the patient's acceptance of palliative care and the effects that would have on their family. The "risk of procedure" highlights the feelings of patients regarding the potential risks associated with PEG tube insertion and the efforts others would have put in to support this decision.

*Choosing life or death* – Two studies (Brotherton & Abbott 2009, Yeh *et al.* 2010) mentioned how caregivers perceived the possibility of the patient's death without the use of PEG tube feeding. One caregiver described the situation as 'the patient hadn't particularly wanted feeding, he was just wanting to die, he was so ill' (Brotherton & Abbott 2009). At the end-of-life, caregivers desired stability when they thought that PEG tube would not improve patient's overall condition (Yeh *et al.* 2010).

*Risk of procedure* – Four studies (Lin *et al.* 2011, Merrick & Farrell 2012, Sharp & Shega 2009, Zaherah Mohamed Shah *et al.* 2012) reported that the fear of procedural risks led to clinicians, patients and family members to decline PEG tube feeding. Family members would not agree to PEG tube feeding because they did not want the patients to have a surgical procedure that they were not sure was necessary (Lin *et al.* 2011). Some HCPs also thought that the risk of PEG tube insertion was high (Zaherah Mohamed Shah *et al.* 2012) while others would consider the patients' medical condition before recommending a PEG (Sharp & Shega 2009).

### 2.4.9.3 Weighing alternatives

The theme weighing alternatives relates to patients' decisions to adapt their original lifestyle and the influence of the opinions of family, friends and HCPs on their decision. The importance of fear and anxiety about decision-making was also addressed.

*Adapting lifestyles* – Four studies (Jordan *et al.* 2006, Liley & Manthorpe 2003, Lin *et al.* 2011, Mayre-Chilton *et al.* 2011) reported that caregivers had to adapt to the patients' lifestyle. Patients' physical limitations restricted some of the activities and impacted on the caregivers' own behaviour (Jordan *et al.* 2006, Liley & Manthorpe 2003, Mayre-Chilton *et al.* 2011). Some patients had gotten used to NG tube feeding and did not want to change to another type of feeding (Lin *et al.* 2011).

*Family influences* – Three studies (Lin *et al.* 2011, Sharp & Shega 2009, Zaherah Mohamed Shah *et al.* 2012) reported that the family's decision could be a factor for choosing or not choosing PEG. Sharp & Shega (2009) revealed that 64% of the speech therapists who participated in their study had discussed PEG feeding with family members. In one study, the majority of clinicians who would not advocate a PEG for long-term enteral feeding had based their decision on the reluctance of family members (Zaherah Mohamed Shah *et al.* 2012). However, the opinion of family members regarding PEG tube feeding appeared to relate to their education levels, with greater acceptance amongst those with higher educational qualifications (Lin *et al.* 2011).

*Attitudes of HCPs* – Four studies (Brotherton & Abbott 2009, Liley & Manthorpe 2003, Sharp & Shega 2009, Yeh *et al.* 2010) showed that decisions made by HCPs influenced the perception of patients towards PEG. Many patients described how the advice from HCPs had been taken without hesitation (Brotherton & Abbott 2009, Liley & Manthorpe 2003). Some participants claimed that HCPs had never mentioned the option of PEG tube feeding (Yeh *et al.* 2010).

*Fear and anxiety* – Two studies (Jordan *et al.* 2006, Zaherah Mohamed Shah *et al.* 2012) described the perception and feelings that could lead to refusal of PEG tube feeding. Zaherah *et al.* revealed that 26% of HCPs would not advocate PEG tube feeding for their patients for fear of complications (Zaherah Mohamed Shah *et al.* 2012). In another study, patients reported developing low mood and depression following a PEG tube inserted (Jordan *et al.* 2006).

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**Table 2.6: Themes Identified in Each Study According to Regions**

Themes	North America			Europe											Asia		
	Kwo ng 2014	Sharp 2009	Todd 2005	Ada ms 2009	Broth erton 2009	Liley 2003	Mayr e 2011	Merri ck 2012	Rick man 1998	Jorda n 2006	Heal y 2002	Madi gan 2007	Bjure sater 2008	Boz Ciger oglu 2012	Lin 2011	Yeh 2010	Zahe rah 2012
Lack of choice :																	
Poor knowledge			√				√			√		√				√	
Inadequate competency and skills			√			√				√		√	√			√	
Insufficient time given			√						√				√				√
Not enough information given	√			√	√				√	√	√				√		√
Lack of guidelines/protocol											√		√				
Resource constraints*		√		√			√					√		√		√	√

Table 2.6, continued

Themes	North America			Europe											Asia		
	Kwo ng 2014	Sharp 2009	Todd 2005	Ada ms 2009	Broth erton 2009	Liley 2003	Mayr e 2011	Merri ck 2012	Rick man 1998	Jorda n 2006	Heal y 2002	Madi gan 2007	Bjure sater 2008	Boz Ciger oglu 2012	Lin 2011	Yeh 2010	Zahe rah 2012
Confronting mortality :																	
Choosing life or death					√											√	
Risk of procedure		√						√							√		√
Weighing alternatives :																	
Adapting lifestyle						√	√		√	√					√		
Family influences		√													√		√
Attitudes of HCPs		√			√	√										√	
Fear and anxiety									√	√							√

\*includes financial

**Table 2.7: Quotations from Participants and Authors of Primary Studies to Illustrate Each Theme**

Themes	Quotations from participants in primary study	Interpretations of findings offered by authors
<b>Lack of choice:</b>		
Poor knowledge	I don't know enough about them to know what difficulties there are because I have only had one patient and they had no problems (Madigan <i>et al.</i> 2007).	Some doctors felt that because they did not know enough about the treatment and their knowledge of the problems that may arise was also lacking.
	Although we did not quite understand what, why the tube would be so necessary (Mayre-Chilton <i>et al.</i> 2011).	The lack of knowledge and understanding had an evident negative impact on the care-givers, especially once they got home, which reflected their anxiety towards having the gastrostomy tube removed.
	We had no idea how the PEG tube was removed by a resident...No one knew how to handle it, so we sent him back to the hospital's emergency unit. We were surprised to find that even the doctor did not know how to handle it (Yeh	The nursing directors' interviews revealed health professions' lack of experience in caring for PEG residents.

**Table 2.7, continued**

Themes	Quotations from participants in primary study	Interpretations of findings offered by authors
	<i>et al.</i> 2010).	
Inadequate competency and skills	The district nurse would have connected her and then left her on her own ... She doesn't like that (Liley & Manthorpe 2003).	Conversely, recognition of inexpert practice by a health professional was a matter of concern. Some distress was reported when health professionals did not meet caregivers' or patients' standards.
	You could be very much up to scratch now and because you have no practice with it in five years' time you are back to square one (Madigan <i>et al.</i> 2007).	GPs also felt that training is much more appropriate when they have a patient rather than having random training sessions
Insufficient time given	It's easier to... it's a waitress thing, like 'it's not my table' (laughing) you have an opinion, and you can share it with them, but you don't want to be ultimately responsible for swaying them one way or another (Todd <i>et al.</i> 2005).	Most participants [nurses] expressed some frustration with the lack of time they had available to spend with patients/families to discuss their concerns, answer questions, and provide support.
Not enough information given	The nurses still haven't been told how to treat it, to move the PEG in and out, to make sure it doesn't stick inside my	Participants explained how district nursing care could have been improved



**Table 2.7, continued**

<b>Themes</b>	<b>Quotations from participants in primary study</b>	<b>Interpretations of findings offered by authors</b>
	stomach, causing ulcers. We've been given a leaflet, but they haven't been sent it (Jordan <i>et al.</i> 2006).	
	They are always very pleased and eager to have this put in, if it's going to prolong the life of their family member – they don't see beyond that. [But] the disease is going to deteriorate whether they have it or not (J. Adams & Lewin 2009).	That generally left their relatives acting in an advocacy role, but there was a strong consensus within the group that relatives had little information on which to base such a decision.
	Hospitals do not provide any PEG information to the family; it is difficult to introduce a technique that cannot be done in the nursing home. We, as an after-care service, have little power to influence the family (Yeh <i>et al.</i> 2010).	Nursing directors commented that the scarcity of PEG tubes in LTC facilities was because acute care facilities did not provide PEG information or offer the insertion procedure.
Lack of guidelines/protocol	What kind of tube it is, there are different models and I feel my knowledge of that is very vague, how often they are supposed to be changed and so on... If I used them [feeding	This could lead to inadequate support to the enrolled nurses, who often handled the daily care of HETF after delegation from community nurses.

**Table 2.7, continued**

Themes	Quotations from participants in primary study	Interpretations of findings offered by authors
	tubes] more often I would try harder to get that information, I believe. I might have received information about this button model a long time ago, but you know... I do understand that they insert a kind of tube in different ways in the patient's stomach... (Bjuresäter <i>et al.</i> 2008).	Guidelines were not considered to be used regularly.
Resource constrains (including financial)	I would have a fair idea that quite a lot of GPs would say we are not going to just take this on, this is not going to become an additional thing that we have to look after without some consideration of funding (Madigan <i>et al.</i> 2007).	The feeling that funding was not following the patient from secondary care into primary care was apparent as demonstrated in the following statements from respondents.
	I am waiting for my Primary Care Trust to grant the funding for one... (low profile PEG) (Mayre-Chilton <i>et al.</i> 2011).	Issues about waiting for funding for a low profile gastrostomy tube by the Primary Care Trust were expressed as a negative impact.
	Six thousand dollars plus additional expenses is a large amount to many families and they will consider whether it is	National Health Insurance covers the cost of hospitalization but not the cost of the PEG tube.

**Table 2.7, continued**

Themes	Quotations from participants in primary study	Interpretations of findings offered by authors
	worth it or not .... Besides, families have to pay extra fees for transportation from nursing home to the hospital, which would also be included when weighing the pros and cons of accepting a PEG or not (Yeh <i>et al.</i> 2010).	
<b>Confronting mortality:</b>		
Choosing life or death	My mother is so sick; she can only lie in bed 24 hours a day.  She does not need anymore [suffering] ...She is old enough, she does not need to take anymore. Maintaining her condition is good enough. Since the NGT is working well, there is no need to do the PEG (Yeh <i>et al.</i> 2010).	Nursing directors indicated that the effect of applying a new modality (e.g. PEG) is uncertain and does not lead to an improvement in the resident's overall condition.
Risk of procedure	I was really frightened about the procedure to insert the tube (Merrick & Farrell 2012).	These acknowledgements notwithstanding, their primary response of this group was fear and anxiety, which appeared to be focused on the PEG tube but specifically the procedure to insert the

Table 2.7, continued

Themes	Quotations from participants in primary study	Interpretations of findings offered by authors
		tube.
<b>Weighing alternatives:</b>		
Adapting lifestyle	There's no birthday cake. You can't have a party. They say, 'He'll be 80, but I said, 'How can we have a party?' (Jordan <i>et al.</i> 2006).	The practical difficulties associated with shopping, family mealtimes, eating out, special occasions and holidays limited all participants, and had entailed the loss of important social aspects of their lives.
	He doesn't want anyone to know [that he has to be enterally fed] and so we can't go out [for a meal]. He even gets bad tempered and if I want any one around he can't find a reason for not eating in front of them, not even a cup of tea. We always used to be out ... (Liley & Manthorpe 2003).	One caregivers reported that they no longer went out to eat as a couple because of her husband's embarrassment
	You've taken away the pleasure aspect of food. Food then just becomes fuel and not a leisure or pleasure activity (Mayre-Chilton <i>et al.</i> 2011).	It was clearly observed that there was a negative impact of perception and feelings of both groups, specifically for

**Table 2.7, continued**

Themes	Quotations from participants in primary study	Interpretations of findings offered by authors
		the social aspects of their lives and also their personal views of the situation and how they perceived each other to feel.
Attitudes of AHPs	We wouldn't have chosen it. They put us through hell about this PEG because we said he wouldn't want this and they said are you willing to stand by and watch him starve to death. I didn't know ... but the Doctor said you can't ... and we knew we didn't have a leg to stand on ... but, believe you me, two and a half years on which would have been the kinder, I ask myself? He has never been out of bed, never had a meal, can't talk to us ... it puts you in such a dilemma, it was horrendous, you wouldn't wish it on your worst enemy (Brotherton & Abbott 2009).	Some caregivers described the conflict and anguish that this prescriptive attitude created, 'the consultant made the decision but if I could just elaborate', quite determined that I hear her story
	Oh, and I got some nice advice from the dietitian, who said,	One person reported that his consent had been

**Table 2.7, continued**

Themes	Quotations from participants in primary study	Interpretations of findings offered by authors
	‘If you wish it, you can stop any time you want ... if you get fed up or you’re not happy with it you can stop it (Liley & Manthorpe 2003).	influenced by discussion with the dietitian who had left the decision more open.
	The doctor and dietician come in only once a week...They have never questioned the NGT or mentioned a PEG (Yeh <i>et al.</i> 2010).	Participants remarked that the physicians and dieticians who provided part-time services in LTC facilities had never mentioned the PEG option. The discourse also revealed that the PEG care provided in the LTC facilities was fragmented and not interdisciplinary.
Fear and anxiety	You feel down in the dumps because when you’ve got this, it’s never going to go (...) If you’ve got this you understand. If you haven’t got it, you don’t understand. You think, you shouldn’t be like that, but you can’t help being angry. You can’t be happy and full of the joys of spring, can you? I	One mental health score fell outside some quoted ranges, and some evidence of depression was apparent from this person’s interview

**Table 2.7, continued**

<b>Themes</b>	<b>Quotations from participants in primary study</b>	<b>Interpretations of findings offered by authors</b>
	don't think so, anyway. Lately I've gone to feel more down (Jordan <i>et al.</i> 2006).	

GP=general practitioners

#### **2.4.10 Factors influencing decision-making**

From the three themes, four major factors that influenced decision making were determined. They were: 1) lack of funding; 2) not enough information given to patients and caregivers; 3) inadequate competency and skills; and 4) poor knowledge among HCPs regarding indications for, and maintenance of PEGs.

#### **2.4.11 Regional variations**

All three main themes were identified in the various studies conducted in three separated continents. Most subthemes were common between regions, including poor knowledge, inadequate competency or skills, insufficient time given, not enough information given and attitudes of HCPs. Resource constraints were more prominent in Asia and Turkey than America and Europe, with three out of the four studies from Asia and Turkey reporting this subtheme (Boz Cigeroglu & Karadag 2012, Yeh *et al.* 2010, Zaherah Mohamed Shah *et al.* 2012), and only one out of three (Sharp & Shega 2009) and three out of ten studies (J. Adams & Lewin 2009, Madigan *et al.* 2007, Mayre-Chilton *et al.* 2011) mentioning lack of resources in America and Europe respectively. Family influences in weighing alternatives were only mentioned in one study in North America (Sharp & Shega 2009), and two out of three Asian studies (Lin *et al.* 2011, Zaherah Mohamed Shah *et al.* 2012) and none of the European studies. Two out of three Asian studies (Lin *et al.* 2011, Zaherah Mohamed Shah *et al.* 2012) highlighted “risk of procedures” as a barrier to PEG, whilst this was only reported by a single American (Sharp & Shega 2009) and one European (Merrick & Farrell 2012) study.

There were clear regional variations in perceptions. All three North American and European studies (Kwong *et al.* 2014, Sharp & Shega 2009, Todd *et al.* 2005) reported positive perceptions, whilst the two Asian (Lin *et al.* 2011, Zaherah Mohamed Shah *et*



*al.* 2012) and one Turkish (Boz Cigeroglu & Karadag 2012) studies reported equivocal to negative perceptions.

#### **2.4.12 Discussion for systematic review on attitudes and barriers to PEG**

The three major themes which have emerged from this synthesis of primary studies on attitudes towards PEG feeding were i) a lack of choice, ii) confronting mortality and iii) weighing alternatives. When a choice was offered, preferences for PEG tube were based on privacy, freedom, flexibility, regular social contact and previous knowledge about treatment. Overall, patients were more concerned about its impact on their quality of life rather than longevity. This review suggests that HCPs should always consider complex issues and shared decisions are perhaps best taken when the patients and caregivers know their choices and the impact of choices they would face.

The quality of qualitative and quantitative papers included in this systematic review was generally high. All authors in qualitative studies managed to fulfil most of the reporting criteria except some studies (J. Adams & Lewin 2009, Brotherton & Abbott 2009, Jordan *et al.* 2006, Madigan *et al.* 2007, Merrick & Farrell 2012, Todd *et al.* 2005, Yeh *et al.* 2010) did not report the recruitment strategy used. Most qualitative and quantitative studies recruited their own participants which could have led to a selection bias. However, as the studies have originated from different countries across three continents, this data has wide representation and validity.

The lack of choice driven by inadequacy in knowledge, time, guidelines, skills and information were common subthemes which had emerged from studies conducted in all three continents of North America, Europe and Asia. Attention to staff competency and skills should be a continual process. Regular training by experts in the field in formal courses is one method of improving the lack of knowledge and skill amongst HCPs involved in the care of patients requiring PEG feeding. Regular review of patients with

a PEG has also been suggested as a method for HCPs to improve their experience with handling issues relating to the care and maintenance of PEGs. Adequate knowledge and familiarity of HCPs would additionally help instil confidence in patients and caregivers/families who were undecided about PEG placement.

Health systems and resource allocation appear to influence PEG tube decisions. Resource constraints were more prominent in Asian studies. In Taiwan, where two of the Asian studies were conducted, reimbursement was not available for PEG tubes (Yeh *et al.* 2010), whilst in Malaysia, cost of healthcare among older people are usually out-of-pocket, as majority of older people do not have health insurance (Kananatu 2002). Similar issues with availability of public funding was found in some Eastern European countries, including Estonia, Russia, Latvia, Ukraine, Lithuania, and Belarus, where government agencies had decided against reimbursements for enteral feeding due to concerns about the cost-efficiency of the procedures (Klek *et al.* 2014). This is in stark contrast to the United States, Poland, and Germany, where medical insurance coverage includes the cost enteral feeding products (Klek *et al.* 2014, National Center for Health Statistics (US) 2015, Pahne 2009).

Family influences were only considered in American (Sharp & Shega 2009) and Asian (Lin *et al.* 2011, Zaherah Mohamed Shah *et al.* 2012) studies. The differences in involvement of family members in decision making may be influenced by cultural beliefs (Clarke *et al.* 2013), as well as legal provisions. In Asia and North America, next-of-kins would be expected to make decisions for patients who lack mental capacity, whilst in European studies (mostly England and Wales), best interest decisions were made by physicians in the event of loss of mental capacity (Shickle 2006).

The area of feeding at the end of life is highly emotive in Asian cultures, where families often express concerns on dying of starvation, due to the strong cultural stance

on filial piety (Nordin *et al.* 2015). The provision of long term nutritional needs through the safer methods of PEG feeding is, however, paradoxically rejected due to concerns with loss of body integrity (Lin *et al.* 2011). Nursing directors in Taiwan are known to express disappointment when families refused PEG due to strong cultural beliefs (Yeh *et al.* 2010). Japanese geriatricians would opt for tube feeding when the patient had advanced dementia with loss of appetite, despite available guidelines that enteral feeding in individuals with advanced dementia would not benefit from such intervention (Flaschner & Katz 2015). Ironically, they were more likely to reject tube feeding for themselves on their own deathbed (Komiya *et al.* 2012).

The results of this study need to be considered in the light of the limitations of the methodology. Standardized methods for literature searches were used which had been developed to conduct systematic reviews of qualitative and quantitative studies in order to determine all related articles and minimized bias in the identification of the studies. The use of content analysis techniques to extract data has its own strengths and limitations. The same theme in different studies conducted among different populations was identified. In addition, articles of experiences in treatment decision-making from various aspects were combined in order to achieve higher level analytical abstraction that is aimed for in thematic analysis. Qualitative studies, however, usually only involve small sample sizes which cannot be used to form laws of cause and effect or make claims about populations or trends (Madigan *et al.* 2007).

## **2.5 Overall Conclusion**

PEG tube feeding is a widely used in long-term nutritional care in the elderly. While PEG tube feeding has been found to be beneficial in terms of complications compared to NG feeding in stroke patients in a recent Cochrane systematic review in terms of complications and nutritional outcomes, our systematic review on PEG vs NG tube

feeding in older patients non-stroke dysphagia have found mainly poor quality small studies evaluating this area, with our pooled analysis revealing equivocal results. Only half of the articles which reported attitudes towards PEG feeding described positive attitudes toward PEG feeding. Financial problems, not enough information, inadequate competency and skills and poor knowledge among HCPs affect the choice and delivery of PEG tube feeding. We therefore proceeded to conduct quantitative and qualitative studies to address the attitudes and barriers to PEG in the Malaysian context as well as a quasi-experimental study to determine whether PEG is indeed better than NG feeding for older Malaysians.

## **CHAPTER 3: ATTITUDES OF HEALTHCARE PROFESSIONALS TOWARDS GASTROSTOMY FEEDING IN OLDER ADULTS IN MALAYSIA**

### **3.1 Introduction**

Our systematic review of published literature (Section 2.3) has revealed that nearly all published studies on attitudes to PEG had been conducted in Western, developed, predominantly Caucasian populations, and that regional variation exists in the attitude towards PEG. The cultural practice and economic status of Malaysians differ greatly from the populations studies in these published studies. Studies specifically evaluating attitudes on PEG feeding in the Malaysian context are therefore considered necessary to ensure that recommendation for PEG for our setting is culturally and economically appropriate.

An explanatory sequential mixed methods design was used to address the above highlighted issue. The rationale for using a mixed methods approach was to attain a more complete picture of barriers to PEG feeding, using different forms of complimentary data. In this chapter, we report the findings of a quantitative survey conducted among HCPs. The findings of a subsequent qualitative study to compliment the findings of the quantitative survey will then be reported in the following chapter (Chapter 4). This approach enabled exploration and possible explanation of the quantitative findings and while the quantitative findings were used to assist in sampling and defining the semi-structured interviews conducted in the qualitative study.

This study will fulfil the first two objectives in Chapter 1.4 which were to determine the perception of Malaysian HCPs towards PEG feeding, and to explore potential differences in perception according to clinical experience, profession and specialty.

### **3.2 Materials and Methods**

A brief survey was conducted among HCPs attending a geriatric medical conference in Kuala Lumpur. The delegates of the conference included doctors, nurses, pharmacists, therapists and caregivers in a variety of fields of interest from all over Malaysia, including the East Malaysian states of Sabah and Sarawak. The survey questionnaire only enquired whether individual respondents would recommend PEG tube feeding for patients who are likely to require enteral feeding for more than eight weeks. They were also asked to select their reasons for agreeing or disagreeing from a list of responses. Respondents were allowed to choose more than one reason for agreeing or disagreeing. The questionnaire had been first pre-assessed by an expert panel, and was pre-tested in a smaller survey (Zaherah Mohamed Shah *et al.* 2012). As the conference was conducted entirely in English, participants would have had adequate English proficiency to complete the questionnaire which was short and used simple English.

Information about years of experience, occupation and specialty were collected from all participants through the questionnaire. To encourage truthfulness, no personally identifiable information was collected within the questionnaire and participants were informed that the questionnaires were anonymous.

This study was approved by the University of Malaya Medical Centre Medical Ethics Committee.

#### **3.2.1 Statistical analysis**

Data analysis was conducted using SPSS Version 20. Years of experience was non-parametric and therefore expressed as median with interquartile ranges and compared with the Mann-Whitney U test. Categorical variables were presented as frequencies with percentages. Participants were grouped according to whether they were doctors, whether

they have had over five years' experience (5YE), and whether they were workers in Geriatric Medicine (WGM). Pre-planned comparisons were made according to the above characteristics, and presented as odds ratios (OR) with 95% confidence intervals (CI). Statistical significance was determined with the  $\chi^2$ -test. Potential confounders were adjusted for using logistic regression analysis. A p-value of  $<0.05$  was considered statistically significant. No corrections were made for multiple comparisons.

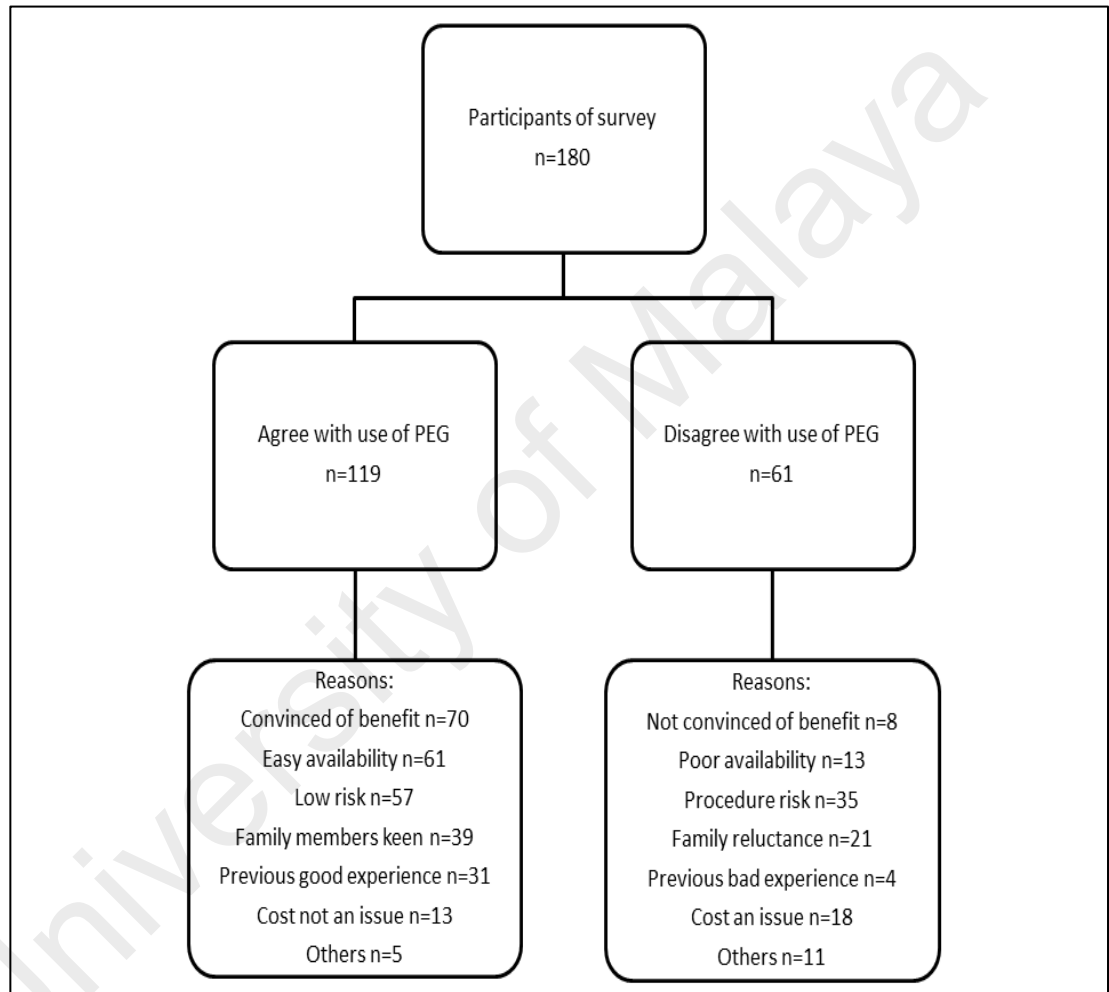
### **3.3 Results of the Survey**

#### **3.3.1 Baseline characteristics**

Two hundred and eighty-one delegates registered for the conference. Eighty-seven (31%) of the delegates were doctors, and 202 (72%) were women. One hundred and seventy (60%) conference delegates worked for the Ministry of Health, 73 (26%) for universities and 28 (14%) for the private sector. Two hundred and one (72%) worked in a hospital, 46 (16%) in the community and 34 (12%) in academia. Table 1 shows the states of origin of the 281 delegates compared to the population distribution of Malaysia according to the 2010 national census (Department of Statistics 2011). Twelve of the 14 states of Malaysia were represented within the conference. A total of 180 (61%) respondents participated in this survey. One hundred and seven of the 180 (59%) respondents were nurses, 43 (24%) were doctors and the remaining 30 (17%) were other allied health professionals. There was no significant difference in the proportion of doctors attending the conference compared to the proportion of doctors responding to the survey ( $p = 0.268$ ).

Of the 180 respondents, the median year of experience (range) of doctors was 5 (3-10) years and non-doctors was 6 (3-13) years. Eighty of the 180 (44%) individuals had five or more years' experience as a HCP. There was no significant difference in the proportion of doctors or non-doctors with five or more years' experience (52% vs 44%;

$p = 0.335$ ). Forty (22%) worked within the specialty of geriatric medicine. The remaining 140 worked in general medicine (36%), psychiatry (8%), intensive care (6%), nursing homes (2%), other medical specialties (26%), and no specific specialty (23%). WGM were significantly more likely to have five or more years' experience compared to non-WGMs [28/40 (70.0%) vs 66/134 (49.3%);  $p = 0.021$ ].



**Figure 3.1: Flow Chart of Participants Agreeing and Disagreeing to PEG Feeding**



### **3.3.2 Perception on PEG feeding**

One hundred and nineteen (66%) respondents agreed that PEG feeding should be used for patients requiring long-term enteral feeding, defined as requiring enteral feeding for over eight weeks (Figure 3.1).

Using categorical analysis, there was no significant difference in likelihood of acceptance of PEG tube feeding according to profession, years of experience or subspecialty interest (Table 3.2).

University of Malaya

**Table 3.1: State of Origin of Delegates versus Population Distribution**

<b>States</b>	<b>No. Malaysian Delegates</b>	<b>Percentage</b>	<b>Population Distribution of Malaysia</b>
Johor	11	4%	12%
Kedah	2	1%	7%
Kelantan	6	2%	5%
KL	115	41%	6%
Labuan	1	0%	0%
Melaka	6	2%	3%
NS	12	4%	4%
Pahang	2	1%	5%
Penang	6	2%	6%
Perak	26	9%	8%
Sabah	9	3%	11%
Sarawak	29	10%	9%
Selangor	54	19%	19%
Perlis	0	0%	1%
Terengganu	0	0%	4%
<b>Total</b>	<b>279</b>	<b>100%</b>	<b>100%</b>

**Table 3.2: Factors Associated with Agreement to PEG Feeding**

	N	Yes*	No	OR (95% CI)	p-value
<b>Doctor</b>	180	29 (67.4)	90 (65.7)	1.082 (0.522-2.242)	0.833
<b>5YE</b>	174	61 (64.9)	56 (70.0)	0.385 (0.696-2.557) <sup>a</sup>	0.474
<b>WGM</b>	182	29 (72.5)	92 (64.8)	0.347 (0.309-1.511) <sup>b</sup>	0.361

5YE = > 5 years' experience; WGM = workers in Geriatric Medicine; OR = odds ratio;

CI = confidence interval

\*"Yes" implies belonging to the profession in the first column, while "No" implies not belonging to the profession in the first column

<sup>a</sup>adjusted for differences in subspecialty

<sup>b</sup>adjusted for differences in years of experience

### 3.3.3 Reasons for agreeing to PEG tube feeding

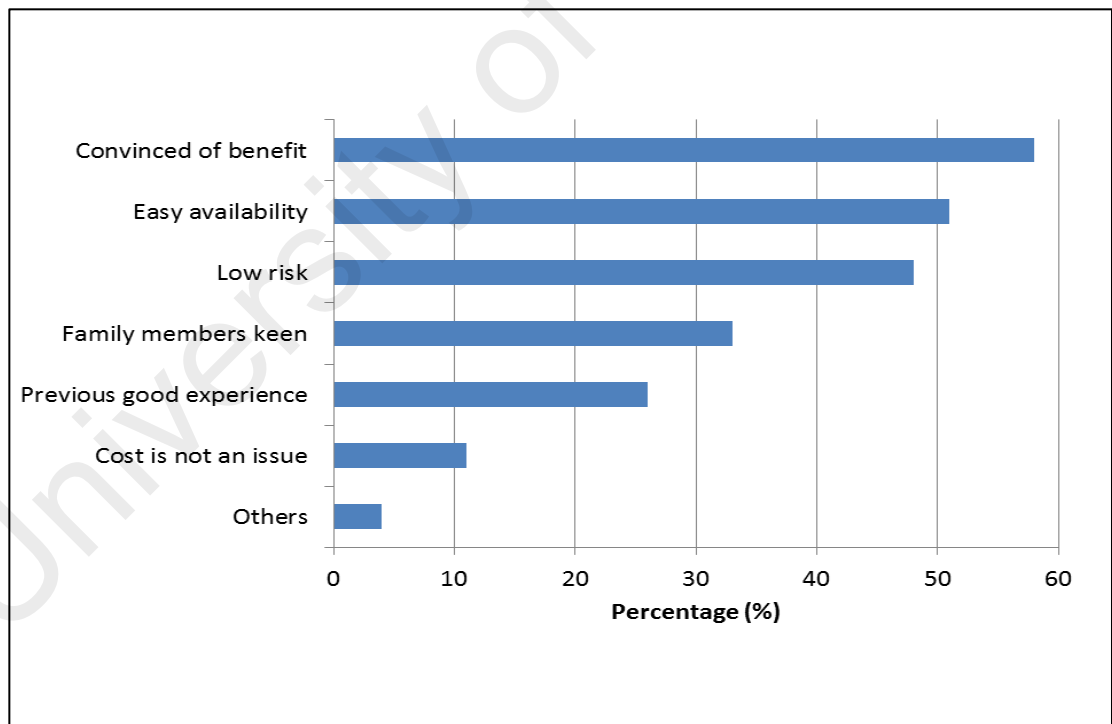
Figure 3.2 summarizes the reasons for all HCPs agreeing to PEG feeding. The three most common reasons for agreeing to PEG feeding were: being convinced of the benefit of PEG tube feeding (70 [59%]), easy availability of PEG tubes (61 [51%]), and perceived low procedural risk (57 [48%]).

Table 3.3 summarizes the reasons behind HCPs agreeing to PEG feeding according to profession, years of experience and subspecialty. As individuals were allowed to choose more than one answer, the total is greater than 100%. Doctors were significantly more likely than non-doctors to indicate they were convinced of the benefit of PEG feeding as their reason for agreeing to PEG feeding ( $p = 0.032$ ). Non-doctors were

significantly more likely to agree to PEG feeding because they felt the procedural risk of PEG insertion was low ( $p = 0.003$ ).

HCPs with more than five years' experience were significantly more likely to consider PEG tube feeding because they felt family members would be agreeable to PEG tube insertion ( $p = 0.009$ ), they had previous good experience ( $p = 0.014$ ) or they felt the cost of PEG tube insertion was not an issue ( $p = 0.013$ ) compared to health care professionals with five years or less than five years' experience.

WGMs were significantly more likely to agree to PEG tube feeding based on previous good experience ( $p = 0.001$ ) and lack of cost issues ( $p = 0.008$ ) than non-WGMs.



**Figure 3.2: Percentage of Participants Based on the Reasons for Agreeing**

**Table 3.3: The Perceptions of Healthcare Professionals Based on the Reasons for Agreeing**

Reasons for Agreeing	N, Total (%)		Doctors vs. Non-Doctors <sup>a</sup>			Experience <sup>a</sup>			Geriatrics vs. Non-Geriatrics <sup>b</sup>		
			Doctors	Non-Doctors	p-value	>5 yrs, n (%)	≤5 yrs	p-value	Geriatrics	Non-Geriatrics	p-value
Convinced of benefit	70 (58)	n (%)	22 (31)	48 (69)	0.032*	39 (56)	31 (44)	0.344	18 (25)	54 (75)	0.747
		OR (95% CI)	2.76 (1.06-7.17)			1.46 (0.68-3.17)			1.02 (0.41-2.52)		
Easy availability	61 (48)	n (%)	11 (18)	50 (82)	0.099	28 (48)	31 (52)	0.307	13 (21)	49 (79)	0.428
		OR (95% CI)	0.51 (0.21-1.22)			0.75 (0.35-1.59)			0.83 (0.34-1.98)		
Low risk	57 (33)	n (%)	7 (12)	50 (88)	0.003*	34 (60)	23 (40)	0.113	17 (29)	41 (71)	0.186
		OR (95% CI)	0.21 (0.08-0.57)			1.91 (0.87-4.23)			1.81 (0.72-4.58)		
Family members keen	39 (33)	n (%)	7 (18)	32 (82)	0.255	27 (69)	12 (31)	0.009*	13 (33)	27 (67)	0.122
		OR (95% CI)	0.51 (0.19-1.39)			2.56 (1.11-5.92)			1.79 (0.72-4.45)		
Previous good	31 (26)	n (%)	8 (26)	23 (74)	0.828	22 (71)	9 (29)	0.014*	14 (45)	17 (55)	0.001*
		OR (95% CI)	0.91 (0.33-2.52)			2.51 (1.00-6.27)			3.29 (1.30-8.34)		

**Table 3.3, continued**

Reasons experience	N,		Doctors vs. Non-Doctors <sup>a</sup>			Experience <sup>a</sup>			Geriatrics vs. Non-Geriatrics <sup>b</sup>		
Cost is not an issue	13 (11)	n (%)	4 (31)	9 (69)	0.569	11 (85)	2 (15)	0.013*	7 (54)	6 (46)	0.008*
		OR (95% CI)	1.12 (0.29-4.39)			4.87 (1.00-23.70)			3.29 (0.95-11.41)		
Others	5 (4)	n (%)	1 (20)	4 (80)	0.816	3 (60)	2 (40)	0.719	3 (60)	2 (40)	0.054
		OR (95% CI)	0.62 (0.06-6.08)			1.05 (0.16-7.03)			4.98 (0.76-32.75)		

\*Significant at  $p < 0.05$

<sup>a</sup>Adjusted for differences in subspecialty experience

<sup>b</sup>Adjusted for years of experience

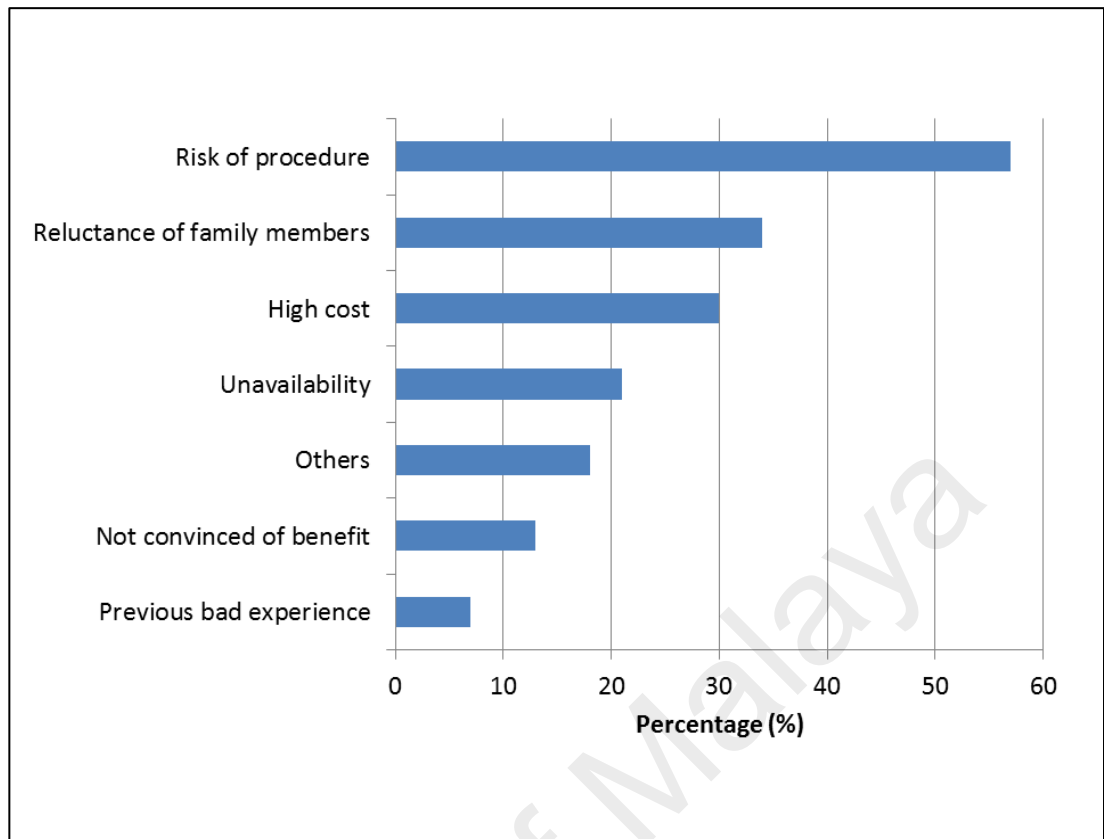
### 3.3.4 Reasons for disagreeing to PEG tube feeding

Figure 3.3 summarizes the reasons behind all HCPs disagreeing to PEG tube feeding. The three most common reasons for disagreeing to PEG tube feeding was the perceived procedural risk of PEG tube insertion (35 [57%]), reluctance of family members (21 [34%]), and the perceived high procedural and equipment cost (18 [30%]).

Table 3.4 summarizes the reasons for disagreeing based on profession, years of experience and subspecialty. Doctors were significantly more likely the non-doctors to disagree with the use of PEG tube feeding due to lack availability of PEG tubes ( $p < 0.001$ ), and significantly less likely to disagree with use of PEG tube due to the fear of complications ( $p < 0.001$ ).

HCPs with over five years' experience were significantly more likely to disagree with PEG tube insertion due to the risk of the procedure ( $p = 0.016$ ) than those with five years' or less than five years' experience.

WGMs were significantly more likely to indicate the issue of high costs ( $p = 0.044$ ) as well as being unconvinced of the benefit of PEG tube feeding as their reasons for disagreeing ( $p = 0.012$ ) than those who were working in other medical disciplines including non-specialized areas.



**Figure 3.3: Percentage of Participants Based on the Reasons for Disagreeing**



**Table 3.4: The Perceptions of Healthcare Professionals Based on the Reasons for Disagreeing**

Reasons for Disagreeing	N, Total (%)		Doctors vs. Non-Doctors <sup>a</sup>			Experience <sup>a</sup>			Geriatrics vs. Non-Geriatrics <sup>b</sup>		
			Doctors	Non-Doctors	p-value	>5 yrs, n (%)	≤5 yrs	p-value	Geriatrics	Non-Geriatrics	p-value
Risk of procedure / complications	35 (57)	n (%)	1 (3)	34 (97)	<0.001*	23 (72)	9 (28)	0.016*	8 (23)	27 (77)	0.255
		OR (95% CI)	0.04 (0.00-0.35)			3.35 (0.92-12.24)			1.00 (0.20-4.86)		
Reluctance of family members	21 (34)	n (%)	7 (33)	14 (64)	0.162	10 (50)	10 (50)	0.375	5 (24)	16 (76)	0.395
		OR (95% CI)	2.07 (0.53-8.06)			0.62 (0.19-1.95)			2.38 (0.57-10.00)		
High cost	18 (30)	n (%)	3 (17)	15 (83)	0.450	9 (50)	9 (50)	0.412	6 (33)	12 (67)	0.044
		OR (95% CI)	0.67 (0.14-3.16)			0.47 (0.14-1.61)			3.64 (0.85-15.66)		
Unavailability	13 (21)	n (%)	10 (77)	3 (23)	<0.001*	6 (50)	6 (50)	0.533	1 (8)	12 (92)	0.274
		OR (95% CI)	40.29 (5.59-290.42)			1.63 (0.26-10.18)			1.47 (0.12-18.15)		
Others	11 (18)	n (%)	3 (27)	8 (73)	0.707	7 (64)	4 (36)	0.668	0 (0)	11 (100)	0.086

**Table 3.4, continued**

Reasons for	N,		Doctors vs. Non-Doctors <sup>a</sup>			Experience <sup>a</sup>			Geriatrics vs. Non-Geriatrics <sup>b</sup>		
		OR (95% CI)	1.05 (0.22-4.98)			1.67 (0.40-6.94)			0.00 (0.00-0.00)		
Not convinced of benefit	8 (13)	n (%)	0 (0)	8 (100)	0.098	5 (71)	2 (29)	0.439	4 (50)	4 (50)	0.012*
		OR (95% CI)	0.00 (0.00-0.00)			1.27 (0.20-8.21)			5.57 (1.00-31.05)		
Previous bad experience	4 (7)	n (%)	1 (25)	3 (75)	0.920	2 (50)	2 (50)	0.740	0 (0)	4 (100)	0.332
		OR (95% CI)	0.79 (0.07-8.78)			0.79 (0.10-6.42)			0.00 (0.00-0.00)		

\*Significant at  $p < 0.05$

<sup>a</sup>Adjusted for differences in subspecialty experience

<sup>b</sup>Adjusted for years of experience

### 3.4 Discussion

Majority of HCPs involved in the care of older people would advocate PEG tube feeding should patients require enteral feeding beyond eight weeks. The results appear incongruent with the uptake of PEG tube feeding in the Asian region (Lin *et al.* 2011, Zaherah Mohamed Shah *et al.* 2012). A previous study has shown that a proportion of patients had gotten used to NG feeding even though they recognize the benefit of PEG (Holland *et al.* 2011). Some authors had also advocated that if NG tube feeding was well tolerated, the placement of PEG was not necessary (Attanasio *et al.* 2009, Park *et al.* 1992). Previous study has demonstrated that individuals on NG tube feeding in Malaysian setting are significantly poorer nourished than orally fed individuals and that 70% of NG tube fed individuals did not receive their required calories (Zaherah Mohamed Shah *et al.* 2012). Other studies also demonstrated that patients who received PEG feeding had better serum albumin levels (Hamidon *et al.* 2006, Kumagai *et al.* 2012), experienced improved survival and better tube tolerance than those with NG tube feeding (Dwolatzky *et al.* 2001). The reasons behind this apparent discrepancy between HCPs' preference for PEG tube feeding and the uptake of PEG tube among patients remains unclear, and therefore deserves further evaluation. A Taiwanese study has highlighted a decline in uptake of tracheostomy among older ventilated patients compared to a slight increase among younger patients. The authors suggested that the decline could be attributed to an increase in palliative care services (Chung *et al.* 2013). Similarities in the opinions of HCPs on tracheostomy tube insertion and PEG tube insertion are likely to be present. Some of our findings may therefore also apply for the reluctance in tracheostomy tube use among older people in this region.

The most common reason for disagreeing to PEG feeding was concerns with the risk of PEG tube insertion. Interestingly, non-doctors were more likely to agree to PEG tube feeding due to a perception of low procedural risk, and more likely to disagree to PEG

feeding again due to the perceived risk of high procedural risk. The perceived risk of procedures are therefore more likely to influence the decision making process for or against PEG tube feeding among non-doctors than doctors. Procedure-related mortality and morbidity for PEG tube insertion is considered low (Dwolatzky *et al.* 2001, Kumagai *et al.* 2012), including site infection (Blomberg *et al.* 2010, Chaudhary *et al.* 2002), leakage (Nicholson *et al.* 2000) and post-procedural pain. The main complication of the minor operation is infection, but this is nearly always mild and appropriately treated with a course of antibiotics (Lipp & Lusardi 2013). Antibiotic prophylaxis has also led to a significant reduction in wound infections (Mahadeva *et al.* 2009). Other complications of PEG insertion are infrequent.

Workers in geriatric medicine and more experienced HCPs based their decision on previous good experience, while more experienced HCPs were more likely to consider the opinion of patients' family members. However, previous studies suggested that substitute decision makers may not be adequately informed to make such decisions (Holland *et al.* 2011). Educational programs targeted at more experienced HCPs and geriatricians should include experiential learning, while it would be less relevant for younger, less experienced workers and workers in other specialty areas. Effective delivery methods for educational programs are often ignored by academicians and it is often assumed that presentation of research evidence is adequate to convince clinicians and HCPs.

This study revealed that doctors were more likely not to recommend PEG tube feeding because they felt that the procedure of PEG tube insertion was not easily available. Feeding tubes are not seen as an essential medical item and most patients have to bear the cost of PEG tubes, which comes in the form of pre-packed commercial kits. Some hospitals, especially government hospitals, could not afford to buy PEG

tubes in large quantities due to higher cost. This was raised by studies which reported that overall costs for patients with PEG feeding were higher compared to NG tube feeding (Corry *et al.* 2009, Nicholson *et al.* 2000). Half of geriatrics workers in this study who were against PEG tube feeding (55%) would not recommend PEG due to concerns about cost. Sixty percent of delegates attending the conference where our questionnaire was distributed were from government hospitals where patient affordability is often an issue. However, PEG tube feeding is likely to be more cost-effective long term, as while an NG tube may be cheaper than PEG tubes initially, this initial cost saving may be offset by the increased cost of frequent tube changes required for NG tubes, and increased hospitalization due to NG complications.

The main limitation of the study is that the delegates who attended the conference were likely to be more aware of the benefits of PEG tube feeding. Furthermore, while this study was able to include respondents from nearly all the states of Malaysia in the survey, the composition of respondents are not necessarily representative of the population distribution of the states, which may lead to some bias in the results. However, as one-third of the respondents were still against the use of PEG tube feeding, this study has confirmed that PEG feeding is still not widely accepted in our setting. In view of the discrepancies between the opinion of HCPs on the benefits of PEG tube feeding and the use of the percutaneous gastrostomy route for non-oral feeding in Malaysian setting, future research should aim to expose the barriers behind the acceptance and utility of PEG tube feeding in order to identify modifiable factors to improve the use of PEG tube feeding.

### **3.5 Conclusion**

Two-thirds of HCPs surveyed agreed with PEG tube feeding as the preferred route for long-term enteral feeding. There was no significant difference in opinion on PEG

feeding according to profession, years of experience and specialty. The most common reason for agreeing to PEG tube feeding was being convinced of the evidence while the most selected reason for disagreeing with PEG tube feeding was fear of complications. There were significant differences in reasons for agreeing as well as disagreeing to PEG tube feeding according to profession, years of experience and specialty. The information gleaned from this study will therefore inform future interventions to improve the use of PEG tube feeding among our HCPs. Future studies should also evaluate the barriers to acceptance of PEG tube feeding among patients.

## **CHAPTER 4: PERCEPTIONS OF HEALTHCARE PROFESSIONALS TOWARDS BARRIERS TO THE ACCEPTANCE OF PERCUTANEOUS ENDOSCOPIC GASTROSTOMY FEEDING IN MALAYSIA**

### **4.1 Introduction**

The work in this chapter is the extension from the previous quantitative survey (Chapter 3) where it was found that key barriers for disagreeing to PEG feeding were the perceived procedural risk of PEG tube insertion (57%), reluctance of family members (34%) and the perceived high procedural and equipment cost (30%). Data on the preferences and practices of enteral tube feeding among older patients in South East Asia is sparse at the moment, as highlighted by the systematic review (Section 2.4.9).

A qualitative methodology was adopted to explore in depth the HCPs' views and perceptions of the barriers to the acceptance of PEG tube feeding. Therefore, this chapter investigates why qualitative inquiry was chosen as the methodology and how it guided the direction of this research.

Interpretative phenomena always occurs in daily social life where human beings will make interpretations and judgements about their own as well as others' behaviour, experiences, beliefs and perceptions (Gubrium & Holstein 1997). The interpretive interaction perspective is dedicated to the philosophical logic of naturalistic inquiry, because there is only interpretation in social life. The interpretative approach highlights the understanding of human experiences as it focuses on explanation, predication and control by the positivist.

In this study, HCPs were interviewed to ascertain their perceptions of the use of PEG feeding, and to identify any potential barriers to the acceptance of PEG tube feeding

from the HCP perspectives. Interpretative research helps to explore structures of experience, the meaning-perspectives of the study sample and the impact of the environment. This methodology suits this research since it explores HCPs' perceptions of why people would not accept PEG tube feeding. This approach will enable an explanation of their views and opinions based on their experiences of dealing with PEG use. The result of this qualitative research would be able to explain the survey that had been conducted earlier.

## **4.2 Materials and Methods**

An exploratory qualitative study using in-depth interviews, which used a pragmatic approach of enquiry, was conducted. This study could also be described as a descriptive qualitative study as it was based on the premise of naturalistic enquiry (Polit & Beck 2010). Naturalistic enquiry provides rich descriptions of people and their interactions in natural settings. It also seeks to understand social reality in its own terms (Gubrium & Holstein 1997).

A purposive sample of 17 HCPs of various levels of seniority from all relevant healthcare disciplines was obtained at a 1000-bedded teaching hospital in Kuala Lumpur. The HCPs included two doctors, four nurses, three dietitians and eight therapists in five different fields of interest. The mean age ( $\pm$ standard deviation) of participants was 31.7 ( $\pm$ 6.6) years. Most HCPs interviewed were female (82%); married (59%); specialized in geriatric medicine (47%); and had more than 10 years' working experience (59%).

The study was approved by the Medical Ethics Committee of the University of Malaya Medical Centre. Written informed consent was obtained from all participants prior to embarking on the interview process. Individual face-to-face interviews were conducted in a private, comfortable environment in a quiet room in the hospital between



January 2015 and May 2015. Handwritten notes were made throughout the interviews and they were additionally recorded, transcribed and verified against the original recording.

A trained researcher, unfamiliar to the participants, conducted the interviews. A semi-structured interview guide with open-ended questions was used. The guided questions facilitated individuals' sharing of perceptions and experience in dealing with PEG tubes, including their benefits and challenges. After each interview was completed and transcribed, the transcripts were reviewed to ensure that the questions fulfilled the information needed and answered the research questions. Each interview lasted between 20-40 minutes.

Interviews were undertaken until no new information could be obtained and data saturation was achieved (Polit & Beck 2010). Data saturation became apparent following the fifteenth interview. No new themes emerged and there was redundancy associated with the deductions made from the themes. Two further interviews were conducted in order to validate this decision. Transparency and coherence was maintained throughout the study. Aside from clearly specifying our research aims and by adopting a reflexive stance, two researchers (M.P.T. and P.S.) checked the final interview findings.

Qualitative data analysis was performed together with the data collection process. After five interviews were completed and transcribed, two transcriptions were randomly selected for the initiation of a coding manual. Two researchers (M.H.J. and P.S.) reviewed entire transcriptions separately, identified text segments that appeared meaningful to the research questions and translated Malay language transcriptions to English language by using forward and backward translations. A coding system which identified themes, patterns and inter-relationships was then created. Each transcript was

fully coded by using NVivo 10 (QSR International Pty Ltd, Doncaster, VIC, Australia). Lastly, both researchers (M.H.J. and P.S.) met several times, reviewed, discussed and confirmed the codes in order to understand key ideas and summarized the perspectives participants had shared. This defined themes pinpointed and relationships even further. Disagreements were resolved by cross-referencing the unclassified data with previous findings to determine whether it was supporting or opposing, or if new themes were identified. Finally, the themes were examined and approved by a third researcher (M.P.T.). These steps had been taken to ensure the consistency and validity of the coding and interpretation of narrative data.

**Table 4.1: Interview Questions**

<b>No.</b>	<b>Question</b>
1.	What do you know about tube feeding?
2.	Have you used tube feeding (direct or indirectly)? If yes, please describe your experience with PEG tube feeding.
3.	How many patients with PEG tubes have you looked after?
4.	What do you think about the use of PEG tube feeding in the community?
5.	Would you recommend a PEG tube to anyone, and if yes, which cases would you recommend a PEG tube to?
6.	Based on your experiences, what makes someone decide whether to have a PEG tube inserted?
7.	What problems do you think are encountered when someone has PEG tube feeding in the community?
8.	How would you manage a patient who is experiencing complications with their PEG tube?
9.	What do you think we can do to improve the care of patients with PEG tubes in the community?
10.	Few patients actually use PEG tubes in Malaysia. In your opinion, how could we improve the uptake of PEG tubes among healthcare professionals and patients?
11.	Is there anything more you would like to say about PEG tube feeding in the community?

### 4.3 Results of the Interviews

#### 4.3.1 Factors limiting PEG use in a community

The perceptions of HCPs on factors that limit the usage of PEG tube feeding in a community revealed four main themes: ‘knowledge of healthcare professionals’, ‘communication’, ‘understanding among patients’, and ‘financial and affordability’. ‘Knowledge of healthcare professionals’ relates to the awareness of PEG tubes as necessary items for long-term enteral feeding. ‘Communication’ in this context includes forms of communication used among HCPs to express their views on the best possible care for patients. ‘Understanding among patients’ describes the process of receiving and interpreting information on PEG feeding. ‘Financial and affordability’ explains the affordability of patients/caregivers. Similarities and differences in perceptions found between HCPs were described within each theme.

**Table 4.2: Demographic Data**

Characteristics	n (%)
Age, mean (SD)	31.71 (6.6)
Gender	
Male	3 (17.6)
Female	14 (82.4)
Ethnicity	
Malay	12 (70.6)
Chinese	2 (11.8)
Indian	3 (17.6)
Marital Status	
Married	11 (58.8)
Single	6 (41.2)

**Table 4.2, continued**

<b>Characteristics</b>	<b>n (%)</b>
Occupation	
Doctor	2 (11.8)
Nurse	4 (23.5)
Dietitian	3 (17.6)
Occupational Therapist	3 (17.6)
Physiotherapist	2 (11.8)
Speech Therapist	3 (17.6)
Years of Experience	
≤10	10 (58.8)
>10	7 (41.2)
Specialty	
Geriatric	8 (47.1)
Neurology	5 (29.4)
Rehabilitation	2 (11.8)
Gastroenterology	1 (5.9)
Surgical	1 (5.9)
Received Formal Swallowing Training	
Yes	7 (41.2)
No	10 (58.8)

**Table 4.3: Main Themes on Factors Limiting PEG Use in a Community**

Theme	Subthemes	
Knowledge of Healthcare Professionals	Lack of training/ familiarity	
	Lack of Protocols	
Communication	Within health team	Teamwork
		Time constraints
	With patient/ family	Patient education/ engagement/ empowerment
Understanding Among Patients	Patient education / awareness/ familiarity	
	Patient and family perceptions/ fears	
Financial and Affordability	Cost	
	Financial assistance	

#### 4.3.1.1 Knowledge of healthcare professionals

HCPs who have regular contact with patients with dysphagia should have a good grasp of what PEG feeding entails, including its method of insertion, complications related to its placement, and its use and care. However, this study's findings showed a lack of knowledge among HCPs. Without adequate knowledge and experience, HCPs are unable to determine the potential benefits of PEG tube feeding. Some HCPs felt that they lacked sufficient knowledge about PEG tube feeding in order to contribute effectively to decision making and the subsequent care of patients with PEG tube feeding.

*"I'm not sure as I do not know enough about that [PEG feeding]." (Nurse D)*

Many HCPs emphasized that education about alternative feeding was necessary and had not been included in adequate detail in their undergraduate curricula:

*“Doctors do not have enough knowledge about PEG tubes because it is not covered in the undergraduate curriculum. PEG tubes have not really caught on in our country. I think if doctors are not well educated, then nurses would be even more so [know even less about PEG tubes].”* (Doctor A)

*“...during my training our syllabus included only one chapter about alternative feeding... [But] There is actually a lot to learn about alternative feeding.”* (Speech therapist C)

When asked about standardized protocols, HCPs described that they were not aware of any standardized protocols available. However, they had indicated that they would like local guidelines to be developed:

*“Our country doesn’t have any standardized protocol on [the management of] swallowing...”* (Speech therapist A)

*“I hope that all health care practitioners can sit down and develop a consensus on PEG tube feeding. We need criteria to help us decide when we should recommend PEG feeding to patients. This is then not just the job of the dietitian or surgeon. If the standard protocol is there, it will be easier for other members of the team too.”* (Dietitian B)

While many HCPs expressed inadequate knowledge about PEG feeding, others felt that improvements were needed in education on alternative feeding and the development of a standardized protocol was also necessary.

**Table 4.4: Key Findings of Knowledge of Healthcare Professionals**

Topic	Healthcare Professionals (n=17)
Lack of training/familiarity	Nurse D: ‘I’m not sure as I do not know enough about that [PEG feeding]’
	Doctor A: ‘Doctors do not have enough knowledge about PEG tubes because it is not covered in the undergraduate curriculum. PEG tubes have not really caught on in Malaysia. I think if doctors are not well educated, then nurses would be even more so [know even less about PEG tubes]’
	Speech therapist C: ‘...during my training our syllabus included only one chapter about alternative feeding. [But] There is actually a lot to learn about alternative feeding’
	Dietitian C: ‘We haven’t had any Continuous Medical Education (CME) on PEG tube feeding. It is however easily accessible information online. So whatever information we get is from the other hospitals, and this includes protocols’
	Physiotherapist A: ‘No, because we rarely see patients with PEG tubes, and sometimes do not notice them. We don’t routinely ask if someone has a PEG tube. In hospital, we regularly see nurses inserting NG tubes because it is frequently replaced [but not PEG tubes]’
	Occupational therapist B: ‘I don’t know of any patients on PEG tube feeding, and have never seen one’



**Table 4.4, continued**

Topic	Healthcare Professionals (n=17)
Lack of protocols	Speech therapist A: ‘Our country doesn’t have any standardized protocol on [the management of] swallowing...’
	Dietitian B: ‘I hope that all healthcare practitioners can sit down and develop a consensus on PEG tube feeding. We need criteria to help us decide when we to suggest PEG feeding to patients. This is them not just the job of the dietitian or surgeon. If the standard protocol is there, it will be easier for other members of the team too’
	Dietitian B: ‘In our hospital I’ve never seen any protocols, the properly written one...’

#### 4.3.1.2 Communication

All HCPs collaborated by meeting and by referring to and making entries into patient’s notes. Relevant information was written in the patient’s notes such as patient’s history, results of treatments given and any plan for follow-up or future treatment plans. Yet, some HCPs described they were not communicating enough to meet the patient’s individual needs. Doctors rarely contacted dietitians and therapists personally, which resulted in a lack of monitoring and losses to follow-up:

*“If there is no communication, no team work... Then the doctors do not know we need that [blood tests and follow up]. So this is the part that we are lacking.”* (Dietitian B)

*“Sometimes the patient still has an NG tube in, but they have already been discharged, and no referral is made to us [speech therapists] for follow-up management of their swallowing.”* (Speech therapist A)

Several members of the multidisciplinary team felt that it was not within their job scope to discuss PEG tube feeding with their clients. In addition, many had felt that decisions should be made by doctors only and that they had no role in the decision-making process:

*“[Occupational] therapists are not exposed to PEG tubes much. For example, [we don’t know] how much it costs and how to insert the tube... Maybe because it is not in our job scope.”* (Occupational therapist A)

*“For OTs like us, we cannot explain more to patient because it can be considered an offence. This is because it is the doctor’s role and only doctors know what is best for the patient.”* (Occupational therapist C)

*“We are not the one making the decision because basically the doctor will decide. We can just suggest it to the doctor, so the decision has to be from the doctor.”* (Dietitian C)

As some doctors felt that it was difficult to discuss PEG feeding with nurses, they would still consider their opinion especially regarding nursing management:

*“As much as possible I try to involve or take into consideration other opinions. PEG tube insertion is a difficult decision to discuss with the nurses, but we usually ask nurses about their opinion for most aspects of patient care, especially when it is about nursing management.”* (Doctor A)

Furthermore, doctors acknowledged that sometimes they did not have adequate time to explain procedures, risks, benefits and technical concepts clearly and fully to patients and their families:

*“I think as a doctor, sometimes, we do not spend enough time talking to patients and explaining treatment options and the reason for particular treatments.” (Doctor A)*

Doctors’ communication with patients was perceived as inadequate. Some HCPs described that some doctors had provided information to patients with regard to the benefits of PEG tube feeding, but were unable to provide the information in a way that could be understood, or convincing to the patient or next-of-kin:

*“I think the patients do have the information though; the doctors seem unable to convince them because some of them [patients] cannot see the long term benefits, but think about the short term, as they don’t know that they are likely to save cost in the long run, as they only see the high initial price that they have to pay.” (Physiotherapist B)*

*“...maybe they have enough explanation by doctors but they don’t seem to understand it very well. I say this because the patient will ask the nurses after they have discussed it with the doctor. Firstly the doctor will explain and if the patients don’t understand, then they will come to the nurses to ask.” (Nurse B)*

This theme concerning trust and communication skills was observed in all groups of HCPs. Input from other HCPs such as therapists, dietitians and nurses were also seen as an important catalyst for having PEG tubes considered by doctors.

**Table 4.5: Key Findings of Communication**

<b>Topic</b>		<b>Healthcare Professionals (n=17)</b>
Within health team	Teamwork	Dietitian B: ‘If there is no communication, no team work... Then the doctors do not know we need that [blood tests and follow up]. So this is the part that we are lacking’
		Speech therapist A: ‘Sometimes the patient still has an NG tube in, but they have already been discharged, and no referral is made to us [speech therapists] for follow-up management of their swallowing’
		Occupational therapist A: ‘[Occupational] therapists are not exposed to PEG tubes much. For example, [we don’t know] how much it costs and how to insert the tube... Maybe because it is not in our job scope’
		Occupational therapist C: ‘For OTs like us, we cannot explain more to patient because it can be considered an offence. This is because it is the doctor’s role and only doctors know what is best for the patient’
		Dietitian C: ‘We are not the one making the decision because basically the doctor will decide. We can just suggest it to the doctor, so the decision has to be from the doctor’
		Doctor A: ‘As much as possible I try to involve or take into consideration other opinions. PEG tube insertion is a difficult decision to discuss with the nurses, but we usually ask nurses about their opinion for most aspects of patient

Topic		Healthcare Professionals (n=17)
		care, especially when it is about nursing management'

**Table 4.5, continued**

Topic		Healthcare Professionals (n=17)
	Time constraints	Doctor A: 'I think as a doctor, sometimes, we do not spend enough time talking to patients and explaining treatment options and the reason for particular treatments'
With patient/family	Patient education/engagement/empowerment	Physiotherapist B: 'I think the patients do have the information though; the doctors seem unable to convince them because some of them cannot see the long term benefits, but think about the short term, as they don't know that they are likely to save cost in the long run, as they only see the high initial price that they have to pay'
		Nurse B: '...maybe they have enough explanation by doctors but they don't seem to understand it very well. I say this because the patient will ask the nurses after they have discussed it with the doctor. Firstly the doctor will explain and if the patients don't understand, then they will come to the nurses to ask'

#### **4.3.1.3 Understanding among patients**

The HCPs perceived that some patients and caregivers did not have sufficient understanding of PEG insertion procedures, usage and daily care. They observed significant confusion regarding information provided to patients and caregivers. One of

the HCPs described that patients and caregivers refused to accept PEG feeding because they expected to be able to eat in the near future:

*“I think some patients prefer to use NG tube feeding first, early on in their illness, because they expect that the patient’s swallowing will recover.”* (Occupational therapist A)

Another HCP reported patient anxiety surrounding the insertion of PEG tubes due to the misperception that it would take away the chance for oral feeding:

*“Usually when we ask the patient to have a PEG tube inserted, they think the PEG tube is for the whole life. They think they will need to wear it for the rest of their life and that is the only way they will be fed. There will be no chance of oral feeding after that.”* (Speech therapist B)

A concern for nutrition was consistently reported as being essential to healing and recovery. These comments demonstrated that caregivers often hoped that patients would be able to eat normally in the future.

While most HCPs described a high level of satisfaction among patients with PEG, several HCPs expressed that patients and caregivers voiced out negative perceptions around the PEG insertion procedure. The main concerns appeared to be fear of potential complications as well as interference with body integrity.

*“It is because some families have financial problems, are afraid of complications and feel it is very hard to take care of PEG tubes”.* (Nurse B)

*“I think since the patient needs to go for a procedure, some family members are not keen to use PEG tubes. That will be the main reason why most family members prefer NG tubes than PEG tubes...”* (Dietitian C)

*“For a few patients it is a traumatic experience since the PEG tube needs to be inserted into the stomach.” (Dietitian A)*

While it was accepted that such dilemmas could not be easily resolved, there was a strong feeling that the patients and caregivers would benefit from a discussion with HCPs in which all views could be shared.

**Table 4.6: Key Findings of Understanding among Patients**

Topic	Healthcare Professionals (n=17)
Patient education / awareness/familiarity	Occupational therapist A: ‘I think some patients prefer to use NG tube feeding first, early on in their illness, because they expect that the patient’s swallowing will recover’
	Speech therapist B: ‘Usually when we ask the patient to have a PEG tube inserted, they think PEG tube is for the whole life. They think they will need to wear for the rest of their life and that is the only way they will be fed. There will be no chance of oral feeding after that’
Patient and family perceptions/fears	Nurse B: ‘It is because some families have financial problems, are afraid of complications and feel it is very hard to take care of PEG tubes’
	Dietitian C: ‘I think since the patient needs to go for a procedure, some family members are not keen to use PEG tubes. That will be the main reason why most family members prefer NG tubes than PEG tubes...’
	Dietitian A: ‘For a few patients it is a traumatic experience since the PEG tube needs to be inserted into the stomach’

#### 4.3.1.4 Financial and affordability

Financial issues were among the barriers that were highlighted by HCPs in PEG use. They felt that PEG tubes were expensive for patients and families:

*“Yes. There is the issue. (pause) [Its] because the PEG tube is quite expensive compared to NG tube.” (Nurse D)*

*“There are several cases in which the patient’s family refused to use PEG tube because it is expensive.” (Physiotherapist B)*

*“Some patients may have financial difficulties.” (Dietitian B)*

Some of the HCPs suggested that financial assistance is available for those who could not afford it. However, delays often occurred in the application process for financial assistance. As a result of long delays, patients and their caregivers had gotten used to the NG tube, and subsequently declined a PEG tube as they then perceived the insertion procedure as an unnecessary risk.

*“Some patients are able to afford it (PEG tube insertion) because it (the cost) is not really that high. But if they are still unable to afford it, then we can ask the welfare department to help.” (Doctor A)*

*“A lot of problems are financial. The family needs to be able to pay for the PEG tube. There [It] should come to a point where the PEG tube is like an NG tube... so it can freely be given to patients... that'll be good... But it is difficult... Our gastro[enterology] colleagues also agree that financial support is a problem to them. So they put in an NG tube. By the time they obtain the financial approval, they (patients) have probably gotten used to NG tubes already [sic].” (Doctor A)*



Affordability becomes an important factor in advocating PEG tube feeding. HCPs generally agreed that the application process to obtain financial support for PEG tubes should be improved in order to influence practice around the use of PEG tubes.

**Table 4.7: Key Findings of Financial and Affordability**

Topic	Healthcare Professionals (n=17)
Cost	Nurse D: ‘Yes. There is the issue. (pause) [Its] because the PEG tube is quite expensive compared to NG tube’
	Physiotherapist B: ‘There are several cases in which the patient’s family refused to use PEG tube because it is expensive’
	Dietitian B: ‘Some patients may have financial difficulties’
Financial assistance	Doctor A: ‘Some patients are able to afford it because it is not really that high. But if they are still unable to afford it, then we can ask the welfare department to help’
	Doctor A: ‘A lot of problems are financial. The family needs to be able to pay for the PEG tube. There (It) should come to a point where the PEG tube is like an NG tube... so it can freely be given to patients... that’ll be good... But it is difficult... Our gastro[enterology] colleagues also agree that financial support is a problem to them. So they put in an NG tube. By the time they obtain the financial approval, they (patients) have probably gotten used to NG tubes already (sic)’

#### 4.4 Discussion

This research reveals that the poor uptake of PEG tube feeding among patients with dysphagia in our setting is affected by a lack of knowledge among HCPs, inadequate communication, insufficient understanding among patients, and financial and affordability issues. The widespread use of NG feeding in patients who require long-term enteral feeding have been documented in several Asian studies, which have highlighted by an approximate of 80% prevalence of NG tube feeding (Jaafar *et al.* 2015, Yeh *et al.* 2010). This suggests that the difficulty with acceptance of PEG tube feeding is a regional issue among East Asians.

Deficiencies in knowledge about PEG tube feeding appear to stem from a lack of emphasis on teaching about non-oral routes of feeding in the undergraduate and diploma training curricula of medical and allied health professionals (K. M. Adams *et al.* 2010). A previous qualitative study had similarly reported that most respondents expressed requiring some basic training in the area (Madigan *et al.* 2007). Todd *et al.* (2005) administered a questionnaire to 17 nurses experienced in PEG decision-making. The results showed that the nurses felt they did not have adequate knowledge about PEG tubes to comment on the information provided by doctors when asked (Todd *et al.* 2005).

The lack of local or regional guidelines/protocols to aid decision making processes potentially unmask issues surrounding the lack of consensus on the use of PEG tube feeding. A survey among dietitians reported that more than half of the respondents indicated an absence of artificial nutrition policy in their workplace (Healy & McNamara 2002). In Malaysia, a cross sectional study of 77 ventilated patients in intensive care units (ICU) reported an absence of Enteral Nutritional Protocol (Yip *et al.* 2014). The adoption of existing American guidelines had been evaluated by 162

physicians from 45 ICUs in China. They reported that the overall attitudes were positive (Xu *et al.* 2015). This may indicate that these guidelines were currently easily adaptable despite the large cultural differences and differences in opinions that may be present between Asians and Americans. Guidelines now exist in China for parenteral and enteral nutrition support in geriatric patients (Wei *et al.* 2015). The Japanese HCPs have their own Japanese language guidelines (Kobayashi 2001).

Good communication improves the effectiveness of decision-making (Propp *et al.* 2010), helps dealing with conflicting perceptions of treatment (Carmel 1999) and enhances family satisfaction (McDonagh *et al.* 2004). However, doctors and nurses have different roles in decision-making. Doctors often conduct formal discussions and form decisions while nurses expound, translate, and review plans with patients and caregivers (Oberle & Hughes 2001). Interdisciplinary communication between doctors and nurses are frequently poor (Puntillo & McAdam 2006). A separate study reported the presence of stress among nurses occurring due to conflicting views to the decision made by doctors (Oberle & Hughes 2001). In addition, staffing shortages especially during weekends and holidays added to the difficulties in discussing decisions (Cahill *et al.* 2012).

A previous qualitative study revealed that nurses felt that they were often left to 'deal' with the decisions made by doctors (Oberle & Hughes 2001). Bryon *et al.* (2012) reported the most passive form of communication used by nurses was 'listening and receiving'. This lack of resistance on the part of the nurses often leads to an one-way communication (Bryon *et al.* 2012). A previous study has also found that nurses avoided influencing patients and caregivers in their decision-making (Todd *et al.* 2005). This problem was amplified by doctors' opinion in our study that it was difficult to discuss PEG decisions with nurses. Strong hierarchical structures exist in cultural

settings throughout most of Asia. This is supported by a study which described open-minded partnership style communication versus ‘traditional’ one-way style communication which applied in both Western and Southeast Asian cultures. The main barrier that prevented doctors from adopting a partnership style of communication was due to the social gap between people of lower and higher social levels (Claramita *et al.* 2013). This study had not exposed the reasons behind these difficulties.

Doctors, however, may not have enough time to explain everything to patients and caregivers, who often require the information to be repeated in several sittings before adequately informed decisions can be made. As a result, decisions are often made by patients and caregivers based on inadequate information (Baker *et al.* 2000, Healy & McNamara 2002, Mitchell *et al.* 2000). A central focus of multidisciplinary care is the multidisciplinary meeting (MDM) where HCPs from various backgrounds can jointly discuss a patient’s case and recommend a treatment plan. It has been shown to improve adherence to evidence based-guidelines (Conron *et al.* 2007) and clinical decisions (Lamb *et al.* 2014). The team-based approach to decision-making also allows patients and relatives access to alternative sources of information and ensures the consistency of information being relayed. As patients and caregivers would approach nurses and other hospital staff if they had problems understanding information provided, it is therefore important that other HCPs are adequately informed and empowered.

PEG insertion is recognized as an advanced therapeutic endoscopic procedure in Malaysia. It is therefore always conducted by senior, experienced endoscopists or by trainees under senior supervision. As such, the prevalence of major complications during or post PEG complications are rare. However, minor complications due to poor post-PEG care, such as stomal wound infections, can have a negative impact on HCPs, and may affect PEG recommendation for other patients (Mahadeva *et al.* 2008). Hence,

a comprehensive service involving careful selection of cases that require a PEG, followed by meticulous post-PEG insertion care, will undoubtedly help to improve perceptions of PEG feeding among HCPs.

In the latest edition of the Malaysian Medical schedule of fees, the surgeon/endoscopist and anesthetist may charge RM1760 and RM625 respectively, for insertion of a PEG (Subramaniam 2013). The insertion of a PEG tube therefore has financial implications for the family (Yeh *et al.* 2010). In addition, the majority of the elderly in Malaysia do not have health insurance (Kananatu 2002). However, the initial cost of PEG tube feeding is expected to be offset by the cost of regular feed interruptions from tube displacements, frequent need for the NG tube changes, and other complications associated with NG tube feeding (Jaafar *et al.* 2015).

Funding is a major challenge in the management of enteral nutrition anywhere in the world (Ojo 2015). BANS reported that only 51% of Cancer Centres provided specific dietetic funding for their patients (Smith 2011). The use of enteral feeding in different countries appear to be generally associated with the overall expenditure on health (government and private), and percentage of the gross domestic product (GDP) expended on health (Elia 1995). Less than nine percent of the government budget and <7% of their GDP are allocated to health in most Southeast Asian countries. This leads to high amounts of out-of-pocket health expenditure (up to 80%) and raising healthcare costs (Tangcharoensathien *et al.* 2011) compared to the UK (56%) and the United States (22%) (Rechel *et al.* 2013).

#### **4.5 Conclusion**

The uptake of PEG tubes in Asian cultures remain much lower than Western cultures, where they are now universally accepted. Our study which explored the perspectives of HCPs on the barriers to the use of PEG tube feeding in our setting has

revealed several universal barriers, including education, knowledge, communication and team work. Several unique cultural and political barriers had also emerged including the deeply hierarchical work cultures, autocratic approaches to leadership, and lack of funding structures. Moving forward, further studies examining the cost-effectiveness of the ideal type of enteral tube feeding choice in individual Asian cultures/healthcare systems are recommended. Furthermore, the findings of our study will now provide valuable information with which we can reform health service delivery in order to embrace patient involvement and empower patients in informed decision-making.

## **CHAPTER 5: CLINICAL OUTCOMES AND COMPLICATIONS OF NASOGASTRIC FEEDING VERSUS PERCUTANEOUS ENDOSCOPIC GASTROSTOMY FEEDING AMONG OLDER ADULTS IN MALAYSIA**

### **5.1 Introduction**

As stated in Section 1.3.2, enteral feeding should be started as early as possible for elderly patients who are found to have unsafe swallow as it provides several advantages including reduction of infection rates (Xiao-Bo *et al.* 2014), improves nutritional status (Yu *et al.* 2013) and protection of intestinal mucosal integrity (Cui *et al.* 2013). While the guidelines of BAPEN for the use of enteral nutrition recommend NG tube for short-term feeding, the use of PEG is recommended for patients requiring tube feeding for periods longer than four weeks (Stroud *et al.* 2003). In this chapter, the potential usage of NG and PEG tube feeding are investigated through a non-randomized clinical study in order to compare morbidity and nutritional outcomes related to the two enteral routes. The results from this study will help to justify the preference for the use of PEG in long-term enteral feeding in dysphagic older patients.

### **5.2 Materials and Methods**

This was a comparative, non-randomized controlled trial in which all NG and PEG insertions performed among dysphagic elderly Asian subjects were analysed between April 2013 and October 2015.

A RCT was initially intended. A computer generated random number sequence was used to randomize individuals to either PEG or NG tube feeding. However, the study had only managed to recruit one patient after 3 months, as individuals approached and their legal representatives did not like the option of not being able to choose. Based on this, a randomized approach was deemed not possible in this area of research. A new recruitment method which allowed patients or their legal representatives to choose to either PEG or NG feeding long-term was subsequently adopted.

Patients on long-term enteral feeding at the University of Malaya Medical Centre, Kuala Lumpur were recruited via the endoscopy unit or in-patient facilities. The medical teams within the hospital helped identify potential participants for this study, who were then approached by the researcher. The patients or their legal representatives were given information about PEG tube feeding and advice to consider PEG tube feeding. Those who declined PEG tube insertion, and chose to continue on long-term NG tube feeding were included in the NG tube arm, while those who agreed to PEG tube feeding were included in the PEG tube arm. Written informed consent was obtained from patients or their legal representatives. This study has received ethical approval from the UMMC medical ethics committee.

#### **5.2.1 Inclusion criteria**

Patients were recruited if they were aged 65 years and above with a diagnosis of dysphagia and likely to require artificial feeding for at least six weeks. All participants were also required to have been recommended long-term nutritional support via the enteral route.

#### **5.2.2 Exclusion criteria**

Patients excluded from the study were those medically unstable and not suitable for NG or PEG tube insertion. Also excluded were patients with contraindications to either



NG or PEG feeding and/or had other comorbidities such as acute gastrointestinal hemorrhage, acute coronary syndrome and end-stage dementia.

### **5.2.3 PEG tube placement technique**

The procedure of PEG insertion was performed using a standard endoscopy-assisted pull technique (Tang & Wu 2014) under conscious sedation and with antibiotic prophylaxis. All procedures were performed by trained gastroenterologists or trainee gastroenterologists under supervision. A standard 24 French PEG-tube (Kimberley Clark, USA) was inserted into all patients. Training of caregivers was given regarding the care of the PEG tube and feeding, by using commercially based nutritional feeds, along with homemade blended diets.

### **5.2.4 Duration and follow – up**

This study was conducted within a two-year period. Patients were assessed after tube insertion and followed up at three weeks, two months and four months after enrolment. Information on tube-related and gastrointestinal complications was recorded during each follow-up. Tube-related complications were defined as problems or complications that occurred which were directly associated with the feeding tube or its insertion site such as tube blockage, dislodgement, site infection and leakage. Gastro-intestinal complications were explained as gut-related problems or complications that occurred as the result of artificial feeding leading to diarrhoea, vomiting, constipation, pain and bloating. The first two follow-ups were conducted either during a routine hospital visit or via a telephone consultation. The 4th month follow-up was conducted face-to-face either through hospital attendance or a home visit by the researcher. At this time, patients were also reassessed for nutritional status and activities of daily living (ADL).

### **5.2.5 Mortality and hospitalization**

Prior to contacting individuals, the hospital database was interrogated to determine vital status and subsequent hospitalizations to our institution. The National Registry Department was contacted to verify the vital status of participants.

### **5.2.6 Data Collection**

Demographic data were collected through patients' case notes. Information obtained included patient characteristics, indication for PEG referral, number of complications, mortality figures at three weeks, two months, and four months and hospital admission.

Nutritional status was determined by the measurement of mid-arm circumference, calf circumference, triceps skinfold thickness, the Mini Nutritional Assessment (MNA), and actual weight. Routine laboratory blood tests were conducted and the albumin and haemoglobin levels recorded. Performance in ADL was assessed using the Barthel Index (BI) and the modified Rankin Scale (mRS).

All the assessments were performed at baseline (after patient enrolment) and then again at 4 months. The decision to reassess patients at 4 months was based on a Cochrane systematic review (Gomes *et al.* 2015). Considering the high mortality rates identified previously (Khor *et al.* 2014, Tan *et al.* 2016), the decision also allowed sufficient time for tube feeding to have any potential influence on outcomes.

### **5.2.7 Nutritional and functional assessment tools used in this study**

The use of body weight to assess nutritional state is limited by the difficulty in obtaining body weight in immobile and bed fast older adults. While healthcare equipment is now available to weigh patients using weighing hoists or even weighing mechanisms incorporated within hospital beds, they are large, non-portable and expensive. Therefore the usage of weighing equipment is limited in the community

setting and in developing countries with limited resources. The MNA is widely used to measure malnutrition and risk of malnutrition in older people, which takes into account these difficulties. The MNA form consists of 5 parts which are questions about food intake; weight loss during the last 3 months; mobility; psychological stress; neuropsychological problems; and body mass index (BMI). In situations where it's not possible to measure weight and height to calculate the BMI, the calf circumference (CC) could be used as a suitable alternative. Low CC indicates loss of muscle mass associated with sarcopenia (Bollwein *et al.* 2013). This test classifies the patient as “malnourished”, “at risk of malnutrition” and “normal nutritional status”.

Anthropometric assessment begins by measuring patients' height and weight. It can be difficult to determine height in bedridden patients, so various estimation models can be used. The most accurate model to be used in Malaysia is measuring knee height (Chumlea *et al.* 1985), by using Chumlea's equation (Chumlea *et al.* 1998) which has been validated in Malaysia (unpublished data):

$$\text{Men : Height (cm)} = 78.31 + [1.94 \times \text{knee height (cm)}] - [0.14 \times \text{age (in years)}]$$

$$\text{Women: Height (cm)} = 82.21 + [1.85 \times \text{knee height (cm)}] - [0.21 \times \text{age (in years)}]$$

Anthropometric indices are often difficult to interpret in geriatric nutritional assessment (Shahar & Pooy 2003). This is because it must take the multifactorial aetiology of undernutrition and the wide-ranging variability of assessed subjects into account (Camina-Martín *et al.* 2015). Recent reports advocate a BMI between 25 and 28 kg/m<sup>2</sup> in elderly as related to a better state of health for older adults (Dorner & Rieder 2012). These differences could be associated with changes in fatty mass and fat-free mass (muscle and bone mass) (Peterson *et al.* 2014). Mid-arm circumference is a useful measure of nutritional status which can be applied in almost all acutely ill patients. It

correlates closely with BMI which helps to draw attention to undernutrition in patients where weight and height may be inappropriate or impossible (Powell-Tuck & Hennessy 2003).

Risk factor for frailty can be seen in MNA such as low BMI, low muscle mass, decrease of mobility and low caloric intake. In fact, a significant “U-shaped” association has been found between frailty and BMI (Hubbard *et al.* 2010) together with the fact that identified frail elderly are more likely to be at risk of malnutrition measured by MNA (Abellan Van Kan & Vellas 2011). This was supported by Bollwein *et al.* who found that over 90% of those at risk of malnutrition were frail or pre-frail (Bollwein *et al.* 2013).

The BI is a measurement of a person’s daily functioning especially mobility and activities of daily living. It has 10 items consisting feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers from bed to chair and back, mobility on level surfaces and using stairs. The individual item scores range from 0 to 15 and total maximum score is 100 points (Quinn *et al.* 2009a). The BI is the most widely used measurement score for basic activities of daily living in healthcare settings.

A qualitative review of the literature reported that studies that used BI early for their patients were able to demonstrate improvements as long-term outcomes. On the other hand, 11 studies that measured mortality provided insufficient information to support the prognostic value (Huybrechts & Caro 2007). A recent systematic review revealed that BI was more a reliable outcome measure and excellent reliability for stroke outcome measure (Duffy *et al.* 2013) although it did less well for responsiveness to clinical change and has well-recognized floor and ceiling effects (Quinn *et al.* 2011).

According to the Malaysian National Neurology Registry, 6088 (79.4%) out of 7668 elderly patients within the stroke registry experienced ischemic stroke (Aziz *et al.* 2015). Therefore, the mRS is commonly used in secondary prevention and acute stroke trials. It contains a six-point score for disability ranging from 0 (no symptoms at all) to 6 (dead). However, it has been criticized for its subjectivity (Wilson *et al.* 2002). The mRS is good for its broad range of activities included at each grade but distinctions between grades are poorly defined. To overcome potential bias, the users need to be trained on rating the score (Quinn *et al.* 2008). Lack of guidance leaves it open for inter-observer variability.

A systematic review on the reliability of the mRS showed that the overall reliability was moderate and the effect of structured interviews remained unproven. Studies that used larger numbers of observers and patients exhibited poorer reliability. However, all the studies in the review were likely underpowered and had limited generalizability. The authors concluded that reliability of the mRS remains unanswered and they admitted a degree of inter-observer variability was inherent in mRS (Quinn *et al.* 2009b).

#### 5.2.8 Sample size and statistical analysis

An estimated sample size of 50 patients in each arm was obtained using the statistical formula (Kadam & Bhalerao 2010):

$$n = \frac{2(Z_{\alpha} + Z_{1-\beta})^2 \sigma^2}{\Delta^2}$$

Where  $n$  is the required sample size. For

$Z_{\alpha}$  is the standard score corresponding to a given confidence level (95%). (Value = 1.96)

$Z_{1-\beta}$  is the standard score corresponding to power of the study (80%). (Value = 0.84)

$\sigma$  is the standard deviation (estimated). (Value = 0.90)

$\Delta$  is the difference in effect of two interventions (estimated effect size). (Value = 0.66)

Assuming a 50% drop-out rate, this study would need to include approximately 50 patients per arm. Assuming that the morbidity rate with NG feeding in one year is 50%, 100 subjects will provide 80% power to detect a 50% difference in morbidity between PEG and NG feeding. Sample size calculation was based on the proportion reported in a Malaysian study (Zaherah Mohamed Shah *et al.* 2012).

The quantitative data obtained were analyzed using the statistical packages for the social sciences (SPSS Inc., Chicago, Illinois, USA), version 20.0. Baseline characteristics were analyzed by using the Independent t-test, after the Shapiro-Wilk normality testing indicated a good fit (p-value >0.05). Non-normally distributed data were compared using the Mann-Whitney U test and categorical data with the Chi-squared test. The groups differed significantly in age, calf circumference, mid-arm circumference, weight, hemoglobin and albumin. These variables were, therefore, statistically controlled for in further analyses. The primary outcome in this study was assessment of complication rates between NG and PEG groups. Complication rates were compared at three weeks, two months and four months using the Chi-squared test and adjusted for potential confounders using logistic regression. Missing values were replaced by using the last observation carried forward (LOCF) method. Intention-to-treat analysis was performed for the composite outcome of mortality and any complication.

Secondary outcomes related to differences in nutritional status and survival between NG and PEG feeding groups. Nutritional outcomes were assessed only in those patients with a minimum period of follow-up of four months. An independent t-test was used to compare findings between differing groups, with p-value <0.05 considered statistically significant. For within group analysis, baseline and 4 month post tube insertion data were compared using a paired t-test. Due to the high mortality rate especially in NG group, it was not possible to conduct intention-to-treat analysis for nutritional outcomes. A survival analysis was therefore used. Missing data were only replaced for those lost to follow-up using multiple imputation and linear interpolation (Twisk & de Vente 2002).

A Kaplan-Meier survival analysis and the Log-Rank test were used to compare survival between the NG group and PEG group. The Cox-regression model was then used to determine the effect of tube feeding on survival controlling for differences in the co-variables at baseline. To determine differences in time to first hospitalization and death, sets of similar survival analyses were performed using the Cox-regression method controlling for age, calf, mid-arm, weight, albumin, and hemoglobin at baseline.

### **5.3 Results of the Study**

#### **5.3.1 Baseline characteristics of patients**

A total of 102 patients were recruited into this study, of whom 52 received NG feeding and 50 were fed via PEG. The mean age of all participants was  $79.83 \pm 7.79$  years, with a higher age among the NG compared to the PEG group ( $82.67 \pm 7.15$  vs  $76.88 \pm 7.37$ ;  $p < 0.001$ ). Table 5.1 compares the baseline characteristics at entry of the two groups. There were no differences between the groups with regard to gender, ethnicity, education, residence, and dwelling.

The NG group had lower nutritional parameters compared to the PEG group, particularly for calf circumference (21.24cm vs 22.95cm;  $p = 0.002$ ), mid-arm

circumference (21.97cm vs 23.92cm;  $p = 0.012$ ), weight (30.33kg vs 37.32kg;  $p = 0.002$ ), hemoglobin (110.20g/L vs 118.92g/L;  $p = 0.035$ ), and albumin (28.43g/L vs 31.91g/L;  $p = 0.010$ ).

**Table 5.1: Baseline Characteristics of Study Population (n = 102)**

Variable	NG (n = 52)	PEG (n = 50)	p-value <sup>†</sup>
Age, mean (SD)	82.67 (7.15)	76.88 (7.37)	<0.001*
Gender***			
Male (%)	22 (42.3)	27 (54.0)	0.237
Female (%)	30 (57.7)	23 (46.0)	
Ethnicity***			
Chinese (%)	27 (51.9)	25 (50.0)	0.123
Malay (%)	12 (23.1)	19 (38.0)	
Indian (%)	13 (25.0)	6 (12.0)	
Education***			
None (%)	12 (23.1)	12 (24.0)	0.094
Primary (%)	27 (51.9)	15 (30.0)	
Secondary (%)	9 (17.3)	14 (28.0)	
Tertiary (%)	4 (7.7)	9 (18.0)	
Residence***			
Residential home (%)	40 (76.9)	41 (82.0)	0.526
Nursing home (%)	12 (23.1)	9 (18.0)	
Dwelling***			



Variable	NG (n = 52)	PEG (n = 50)	p-value <sup>†</sup>
Spouse and children (%)	18 (34.6)	28 (56.0)	0.083
Offspring / children (%)	21 (40.4)	12 (24.0)	
Relative / friend (%)	13 (25.0)	10 (20.0)	
Indications***			
Stroke (%)	33 (63.5)	27 (54.0)	0.332
Non-stroke (%)	19 (36.5)	23 (46.0)	

**Table 5.1, continued**

Variable	NG (n = 52)	PEG (n = 50)	p-value <sup>†</sup>
Calf, mean (SD)**	21.24 (2.70)	22.95 (3.03)	0.002*
Mid-arm, mean (SD)**	21.97 (3.25)	23.92 (4.23)	0.012*
Weight, mean (SD)	30.33 (9.26)	37.32 (12.14)	0.002*
Triceps skinfold, mean (SD)**	0.95 (0.43)	1.61 (3.42)	0.070
Hemoglobin, mean (SD)	110.20 (20.98)	118.92 (20.26)	0.035*
Albumin, mean (SD)**	28.43 (6.68)	31.91 (6.35)	0.010*
Barthel, mean (SD)**	10.96 (15.84)	11.10 (16.58)	0.835
MNA, mean (SD)**	4.63 (1.47)	4.88 (1.55)	0.451
MRS, mean (SD)**	4.50 (0.51)	4.17 (1.15)	0.480

\*Significant at 0.05

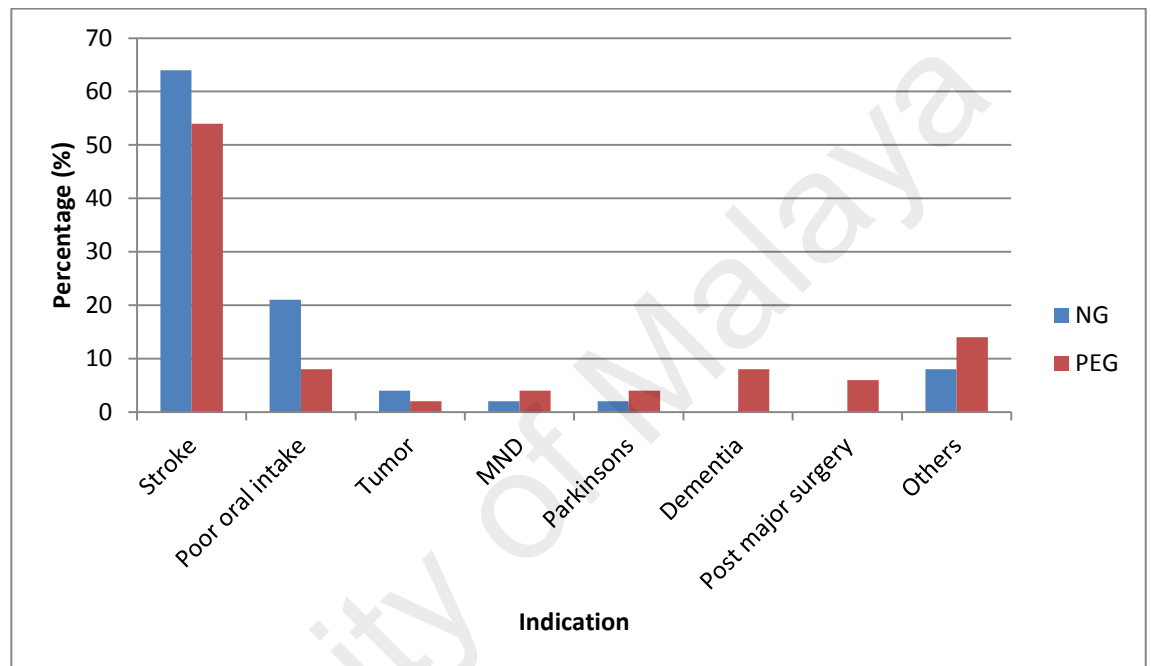
\*\*Mann-Whitney U

\*\*\*Chi-Square Test

<sup>†</sup>T-test unless otherwise indicated

### 5.3.2 Indication for referral

The indications for NG and PEG insertion are shown in Figure 5.1. The main indication was stroke in both NG (63.5%) and PEG (54.0%) participants ( $p = 0.332$ ). Other total indications for tube feeding were poor oral intake (15%), tumour (3%), motor neuron disease (MND) (3%), and others (11%).



**Figure 5.1: Indications for Tube Feeding**

### 5.3.3 Hospitalization and survival probability at four month's follow - up

At four month's follow-up, patients with NG feeding had a higher frequency of hospitalization with a mean (SD) of 0.65 (0.97) compared to 0.42 (0.81) in those with PEG, but this was not statistically significant ( $p = 0.128$ ). The number of days of hospitalization was also greater in the NG group, with 5.14 (9.56) days compared to 3.30 (8.29) days in PEG group, but this was also not statistically significant ( $p = 0.148$ ). The results are shown in Table 5.2.

Table 5.3 shows that there was no difference in days to first hospitalization or death between the NG and PEG groups (log rank test  $p = 0.908$ ). A multivariate Cox's proportional hazards regression model also showed no significant difference between groups (hazard ratio (HR) = 1.27; 95% CI = 0.78-2.09) (Table 5.4).

**Table 5.2: Number and Days of Hospitalization between NG and PEG**

<b>Group</b>	<b>No. hospitalization, median (IQR**)</b>	<b>Days of hospitalization, mean (SD)</b>
NG	0.00 (0 - 4)	5.14 (9.56)
PEG	0.00 (0 - 4)	3.30 (8.29)
p-value*	0.128	0.148

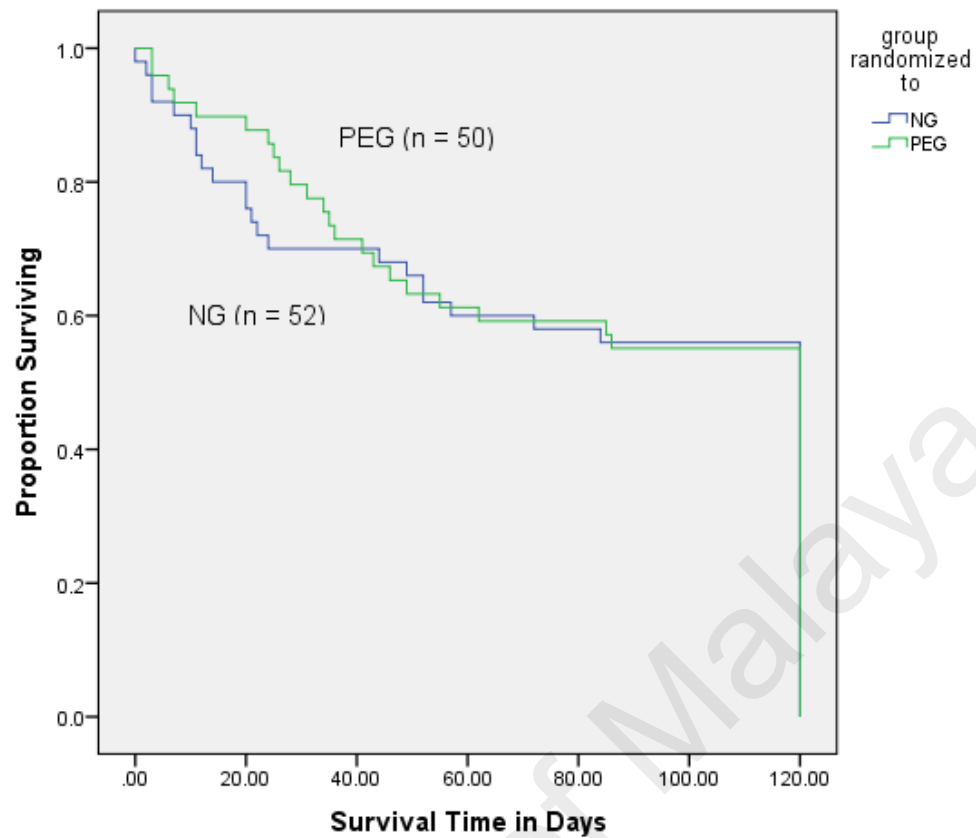
\* T-test unless otherwise indicated

\*\*Mann-Whitney U

**Table 5.3: Mean Days of First Hospitalization or Death between NG and PEG**

<b>Group</b>	<b>Days to first hospitalization / death, mean (SD)</b>
NG	79.00 (49.37)
PEG	81.55 (45.73)
p-value*	0.908

\*Log Rank Test



**Figure 5.2: Survival Analysis Comparing First Hospitalization or Death between NG and PEG**

**Table 5.4: First Hospitalization or Death between NG and PEG based on Multivariate Cox Proportional Hazard Model**

Variable	B (SE)	p-value	Hazard ratio	95% Confidence Interval
Type of Feeding**	0.24 (0.25)	0.338	1.27	0.78 - 2.09
Age	0.02 (0.010)	0.156	1.02	0.99 - 1.05
Calf circumference	-0.10 (0.08)	0.183	0.90	0.77 - 1.05
Mid-arm circumference	-0.06 (0.08)	0.504	0.95	0.81 - 1.11
Weight	0.04 (0.04)	0.274	1.04	0.97 - 1.13
Hemoglobin	0.00 (0.01)	0.815	1.02	0.99 - 1.02
Albumin	-0.04 (0.02)	0.024*	0.92	0.92 - 0.99

\*Significant at 0.05

\*\*For type of tube, NG = 0 PEG = 1

#### 5.3.4 Nutritional outcome within and between groups

The nutritional outcome was assessed in the 71 patients who completed four months' follow-up (31 with NG and 40 with PEG). Within group analysis (Table 5.5) showed significant improvements in both groups for albumin (NG,  $p = 0.002$  versus PEG,  $p = 0.005$ ), MNA (NG,  $p = 0.031$  versus PEG,  $p = 0.011$ ), and Barthel index (NG,  $p = 0.004$  versus PEG,  $p = 0.011$ ). However, there was a significant reduction in MRS for the NG group ( $p = 0.021$ ) compared to PEG group ( $p = 0.770$ ).

For between group analysis (Table 5.6), adjustment for confounders such as age, calf circumference, mid-arm circumference, weight, haemoglobin, and albumin were conducted. There was a significantly greater mean difference in mid-arm circumference

was in the PEG group compared to the NG group ( $p = 0.040$ ). There was, however, no significant difference in the other nutritional parameters.

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**Table 5.5: Mean Difference within Group after 4 Months**

Variable	NG (n = 31)		PEG (n = 40)	
	Mean difference (95% CI)	p-value**	Mean difference (95% CI)	p-value**
Calf	0.89 (-0.11-1.89)	0.079	0.03 (-0.74-0.79)	0.943
Mid-arm	0.37 (-0.65-1.40)	0.464	0.96 (-0.08-2.01)	0.071
Weight	2.43 (-0.68-5.55)	0.120	0.87 (-2.02-3.75)	0.547
Triceps skinfold	0.15 (-0.01-0.30)	0.058	-0.46 (-1.67-0.76)	0.453
Hemoglobin	5.09 (-3.49-13.67)	0.235	1.80 (-4.25-7.84)	0.551
Albumin	4.21 (1.73-6.69)	0.002*	3.66 (1.20-6.12)	0.005*
Barthel	8.39 (2.91-13.86)	0.004*	8.63 (2.09-15.16)	0.011*
MNA	0.94 (0.09-1.78)	0.031*	0.88 (0.21-1.54)	0.011*
MRS	-0.45 (-0.83--0.07)	0.021*	-0.09 (-0.70-0.52)	0.770

\*Significant at 0.05

\*\*Paired-Sample T-test unless otherwise indicated

**Table 5.6: Mean Difference between NG and PEG after 4 Months from Outcomes Measured**

Variable	$\Delta$		Mean difference (95% CI)	p-value**	p-value <sup>†</sup>
	NG	PEG			
Calf, mean (SD)	0.89 (2.73)	0.03 (2.39)	0.87 (-0.35-2.08)	0.159	0.742
Mid-arm, mean (SD)	0.37 (2.79)	0.96 (3.28)	-0.59 (-2.06-0.88)	0.424	0.040*
Weight, mean (SD)	2.44 (8.48)	0.87 (9.02)	1.57 (-2.63-5.77)	0.458	0.751
Triceps skinfold, mean (SD)	0.15 (0.41)	-0.46 (3.81)	0.60 (-0.77-1.97)	0.385	0.477
Hemoglobin, mean (SD)	5.09 (23.39)	1.80 (18.90)	3.29 (-6.71-13.30)	0.514	0.770
Albumin, mean (SD)	4.21 (6.76)	3.66 (7.70)	0.55 (-2.93-4.04)	0.753	0.626
Barthel, mean (SD)	8.39 (14.91)	8.63 (20.44)	-0.24 (-8.95-8.47)	0.957	0.759
MNA, mean (SD)	0.94 (2.31)	0.88 (2.08)	0.06 (-0.98-1.10)	0.908	0.867
MRS, mean (SD)	-0.45 (0.86)	-0.09 (1.41)	-0.36 (-1.07-0.34)	0.300	0.722

\*Significant at 0.05

\*\*T-test unless otherwise indicated

<sup>†</sup>Adjusted with age, calf, mid-arm, weight, hemoglobin and albumin



### 5.3.5 Complications in NG and PEG tube – fed patients

Complications were reported for each follow-up interval of 0-3 weeks, 3 weeks- 2 months, and 2-4 months, as well as overall complications from 0-4 months (Table 5.7). Survival analysis were presented for each follow-up interval, while for the 0-4 month interval, an intention-to-treat analysis was reported with missing values replaced as detailed in Section 5.2.8. After adjustment for the confounders of age and other baseline differences, survival analysis between NG and PEG groups revealed significantly greater tube-related complications (NG 41% versus PEG 13%,  $p = 0.009$ ) but not gastro-intestinal complications (NG 2% versus PEG 10%,  $p = 0.096$ ) at three weeks in the former. Furthermore, no significant difference in overall complications was observed between both groups of patients ( $p = 0.109$ ).

Tube-related complications remained significantly different at three weeks-two months and two-four months, with PEG tubes displaying a greater advantage over NG tubes. However, no significant differences were found for gastro-intestinal complications and overall complications during the period.

Intention-to-treat analysis found that patients with PEG had a significantly lower rate of tube-related complications compared to those with NG for 0-4 months ( $n = 102$ , NG 39% versus PEG 18%,  $p = 0.005$ ) after adjustment for baseline differences (Table 5.7). There were no significant differences in gastro-intestinal (NG 8% versus PEG 20%,  $p = 0.324$ ) and overall complications (NG 40% versus PEG 34%,  $p = 0.141$ ).

For complication free survival, patients with PEG tube feeding showed better tolerance over patients with NG tube feeding at baseline to three weeks' follow-up ( $n = 102$ , NG 46% versus PEG 74%,  $p = 0.030$ ). There were no significant differences between groups at three weeks-two months' follow-up ( $n = 90$ , NG 50% versus PEG

69%,  $p = 0.177$ ) and at two-four months' follow-up ( $n = 77$ , NG 63% versus PEG 74%,  $p = 0.127$ ).

Moreover, intention-to-treat analysis at baseline to four months' follow-up exhibited overall significantly better complication free survival in the PEG group compared to the NG group ( $n = 102$ , NG 23% versus PEG 48%,  $p = 0.027$ ).

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**Table 5.7: Complication Rate and Mortality between Groups**

Presence of Complication	0 - 3 weeks					3 weeks - 2 months					2 months - 4 months					0 - 4 months				
	n	NG (n=42)	PEG (n=48)	p- value**	p- value <sup>†</sup>	n	NG (n=35)	PEG (n=42)	p- value**	p- value <sup>†</sup>	n	NG (n=31)	PEG (n=40)	p- value**	p- value <sup>†</sup>	n	NG (n=52)	PEG (n=50)	p- value**	p- value <sup>†</sup>
All types of complications (%) ***	90	18 (42.9)	11 (22.9)	0.043*	0.109	77	14 (40.0)	9 (21.4)	0.076	0.099	71	9 (29.0)	9 (22.5)	0.530	0.189	102	21 (40.4)	17 (34.0)	0.505	0.141
Tube-related complications (%) ***		17 (40.5)	6 (12.5)	0.002*	0.009*		13 (37.1)	4 (9.5)	0.004*	0.014*		8 (25.8)	2 (5.0)	0.012*	0.010*		20 (38.5)	9 (18.0)	0.022*	0.005*
Blockage (%)		1 (2.4)	2 (4.2)	0.638	0.322		2 (5.7)	0 (0)	0.116	0.798		0 (0)	1 (2.5)	0.375	0.999		2 (3.8)	3 (6.0)	0.615	0.308
Dislodgement (%)		16 (38.1)	0 (0)	<0.001*	0.997		12 (34.3)	2 (4.8)	0.001*	0.002*		8 (25.8)	1 (2.5)	0.003*	0.011*		19 (36.5)	2 (4.0)	<0.001*	<0.001*
Site infection (%)		1 (2.4)	3 (6.2)	0.374	0.280		0 (0)	2 (4.8)	0.191	0.995		1 (3.2)	0 (0)	0.253	0.999		2 (3.8)	4 (8.0)	0.373	0.423
Leakage (%)		0 (0)	3 (6.2)	0.099	0.997		0 (0)	2 (4.8)	0.191	0.987		0 (0)	1 (2.5)	0.375	0.982		0 (0)	4 (8.0)	0.037*	0.997
Gastro-intestinal complications (%) ***		1 (2.4)	5 (10.4)	0.127	0.096		2 (5.7)	5 (11.9)	0.347	0.802		2 (6.5)	7 (17.5)	0.165	0.356		4 (7.7)	10 (20.0)	0.071	0.324
Diarrhea (%)		0 (0)	3 (6.2)	0.099	0.996		2 (5.7)	2 (4.8)	0.851	0.309		1 (3.2)	3 (7.5)	0.439	0.712		2 (3.8)	6 (12.0)	0.126	0.488
Vomiting (%)		1 (2.4)	1 (2.1)	0.924	0.999		0 (0)	2 (4.8)	0.191	1.000		1 (3.2)	2 (5.0)	0.712	0.930		2 (3.8)	3 (6.0)	0.615	0.654

**Table 5.7, continued**

Presence of Complication	0 - 3 weeks					3 weeks - 2 months					2 months - 4 months					0 - 4 months				
	n	NG (n=42)	PEG (n=48)	p- value**	p-value <sup>†</sup>	n	NG (n=35)	PEG (n=42)	p- value**	p- value <sup>†</sup>	n	NG (n=31)	PEG (n=40)	p- value**	p- value <sup>†</sup>	n	NG (n=52)	PEG (n=50)	p- value**	p- value <sup>†</sup>
Constipation (%)		0 (0)	1 (2.1)	0.347	0.999		0 (0)	1 (2.4)	0.358	1.000		0 (0)	2 (5.0)	0.207	0.998		0 (0)	2 (4.0)	0.145	1.000
Pain (%)		0 (0)	1 (2.1)	0.347	0.998		0 (0)	0 (0)	N/A	N/A		0 (0)	0 (0)	N/A	N/A		0 (0)	1 (2.0)	0.305	1.000
Bloating (%)		0 (0)	0 (0)	N/A	N/A		0 (0)	1 (2.4)	0.358	0.999		0 (0)	1 (2.5)	0.375	0.986		0 (0)	2 (4.0)	0.145	0.976
Mortality (%)	102	10 (19.2)	2 (4.0)	0.017*	0.193	90	7 (16.7)	6 (12.5)	0.575	0.644	77	4 (11.4)	2 (4.8)	0.277	0.330	102	0 (0)	0 (0)	N/A	N/A
Complications free survival (%)		24 (46.2)	37 (74.0)	0.004*	0.030*		21 (50.0)	33 (68.8)	0.070	0.177		22 (62.9)	31 (73.8)	0.302	0.127		12 (23.1)	24 (48.0)	0.008*	0.027*
Any complications / mortality (%)		28 (53.8)	13 (26.0)				21 (50.0)	15 (31.2)				13 (37.1)	11 (26.2)				40 (76.9)	26 (52.0)		

\*Significant at 0.05

\*\*Chi-Square Test unless otherwise indicated

\*\*\*In some cases, patient might develop more than one complication

<sup>†</sup>Adjusted for age, calf, mid-arm, weight, hemoglobin and albumin

### 5.3.6 Mortality

Table 5.7 describes the baseline to three week, three week to two month and two to four month mortality figures. From baseline to four months' follow-up, 21 patients in the NG group and 10 patients in the PEG group had died.

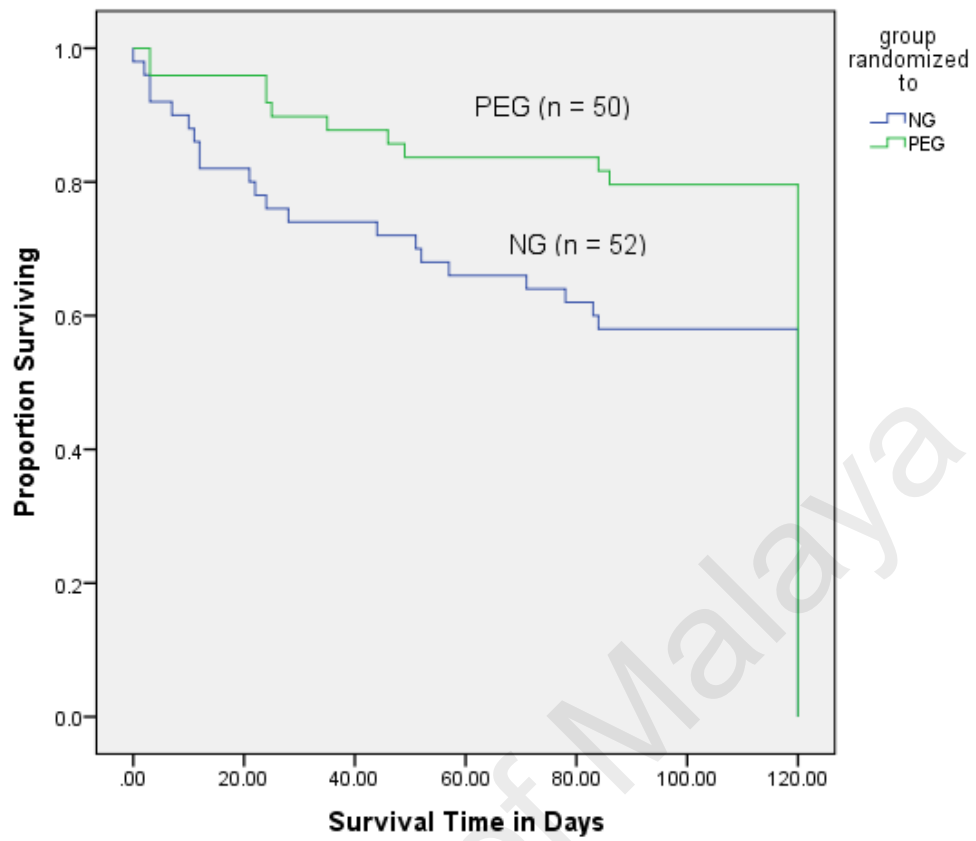
The survival of patients with PEG was significantly higher than those with NG patients (103 days vs 83 days; log rank test  $p = 0.017$ ) (Figure 5.3) as determined by the Kaplan - Meier analysis. A multivariate Cox's proportional hazard model adjusted for potential confounders showed no significant difference between groups (hazard ratio = 0.86; 95% CI = 0.54-1.36) (Table 5.9). A second model was proposed controlling for baseline age, calf circumference, mid-arm circumference, weight, hemoglobin, and albumin. However, the results did not differ between NG and PEG.

**Table 5.8: Mean Days of Survival**

<b>Group</b>	<b>Days of Survival, mean (SD)</b>
NG	83.10 (47.54)
PEG	103.25 (35.73)
p-value**	0.017*

\*Significant at 0.05

\*\*Log Rank Test



**Figure 5.3: Survival Probability by Type of Feeding**

**Table 5.9: Survival Analysis from a Multivariate Cox Proportional Hazard Model**

Variable	B (SE)	p-value	Hazard ratio	95% Confidence Interval
Type of Feeding*	-0.16 (0.24)	0.509	0.86	0.54 - 1.36
Age	0.02 (0.01)	0.292	1.02	0.99 - 1.04
Calf circumference	-0.10 (0.08)	0.195	0.90	0.77 - 1.05
Mid-arm circumference	-0.07 (0.08)	0.395	0.93	0.80 - 1.09
Weight	0.06 (0.04)	0.170	1.06	0.98 - 1.14
Hemoglobin	-0.01 (0.01)	0.467	1.00	0.98 - 1.01
Albumin	-0.04 (0.02)	0.065	0.97	0.93 - 1.00

\*For type of tube, NG = 0 PEG = 1

#### 5.4 Discussion

While PEG tubes are now widely used among patients requiring long-term enteral feeding, few RCTs have been conducted. Most published studies were non-randomized studies, perhaps indicating difficulties in randomizing this group of patients. Issues that have been identified in reduced recruitment were resistance to the placement of a feeding tube before the development of treatment side-effects (Zaherah Mohamed Shah *et al.* 2012) and high cost (Corry *et al.* 2009). This study provides evidence for the use of PEG among patients requiring long-term enteral feeding in an Asian setting, with PEG associated with improved overall complication-free survival. We were unable to demonstrate any nutritional benefits in our study population, but intention-to-treat analysis was limited by high mortality rates particularly among the NG fed group. Our

observations were comparable to that of available studies comparing PEG with NG tube feeding.

#### **5.4.1 Nutritional assessment**

In this study, there were significant improvements in albumin and MNA score in both groups over time. Between groups comparisons, however, revealed no significant differences. In particular, no beneficial effects in hemoglobin concentration nor serum albumin were observed between groups. In a prospective study of 122 patients that compared NG to PEG for up to a period of 12 weeks, significant differences were found in serum albumin at the 4-week follow-up ( $p < 0.05$ ) but no significant differences at other time points (Dwolatzky *et al.* 2001). This is supported by two more studies which did not find any significant differences in albumin levels between NG and PEG after six months (Kumagai *et al.* 2012, Sadasivan *et al.* 2012). Albumin and hemoglobin levels are associated with sepsis, severe illness, and inflammatory conditions (Geeganage *et al.* 2012) and do not respond on a daily or weekly basis to nutrition support (Sadasivan *et al.* 2012). The nutritional benefits observed among survivors both in the NG and PEG groups were surprising, as a previous study had demonstrated that NG tube-fed patients in our setting were universally malnourished compared to orally-fed patients (Zaherah Mohamed Shah *et al.* 2012). The NG tube patients who were involved in our study were more likely to have received greater clinical input, a benefit observed in all patients involved in clinical studies, which would have explained the improved nutritional outcomes with NG tube feeding in our study participants (Maloney *et al.* 2013). In addition, as an incentive to participate in our studies, NG and PEG tubes were provided free, while enteral meal replacements were made available at a subsidized price through a special arrangement with a main distributor of commercial enteral meal replacement products. As the previous nutritional disadvantage observed from NG tube feeding were likely explained by poor clinical support and financial difficulties, our efforts to



offset the cost of enteral feeding itself, would have helped with clinical outcomes. This finding may, therefore, have important implications for our local healthcare funding policies.

A greater increase in mid-arm circumference in patients with PEG feeding compared to NG feeding suggested that the use of PEG does confirm nutritional benefits over a short-term follow-up period. This is consistent with a study done in India, comparing the use of PEG and NG for long-term enteral feeding among head and neck cancer patients. At six weeks, they found that patients with PEG performed better in terms of mid-arm circumference ( $p < 0.001$ ) (Sadasivan *et al.* 2012). However, Corry *et al.* (2009) found no significant difference between NG ( $n = 73$ ) and PEG ( $n = 32$ ) groups in upper-arm circumference ( $p = 0.940$ ), mid-arm circumference ( $p = 0.900$ ), or triceps skinfold thickness ( $p = 0.960$ ) within the first week of tube insertion and no difference between the groups in upper and mid-arm circumference at six weeks post treatment (Corry *et al.* 2009). The follow-up period for Corry *et al.* (2009) was likely to be too short to demonstrate any clear nutritional benefits. The relatively short length of follow-up on between our two groups may explain the lack of statistical difference in other nutritional outcomes between the two groups. Longer term follow-up is, however, highly challenging among these extremely frail individuals, with nearly all of them being severely debilitated at baseline. The high attrition rate at four months, mainly due to death has already limited our analysis, and will further limit the studies attempting longer term follow-up periods to demonstrate nutritional outcomes.

#### **5.4.2 Complications**

A comparable study among NG and PEG showed NG patients had significantly more site infections (NG 64% versus PEG 4%) and tube dislodgements (NG 36% versus PEG 0%) (Sadasivan *et al.* 2012). In the study by Corry *et al.* (2009), PEG site infection rate

was disappointingly high (Corry *et al.* 2009). Another study reviewed 78 head and neck cancer patients and reported a 46% PEG complication rate, including a 4% mortality rate (Rustom *et al.* 2006). In a retrospective study of 156 head and neck cancer patients, PEG tube insertion had a 42% complication rate (Ehrsson *et al.* 2004). In this study, among NG patients, 40% had all types of complications with significant tube-related complications at four months' follow-up. In contrast, the PEG group had 34% overall complications with higher gastro-intestinal complications. Our data has been corroborated by other studies which reported similar or lower complication rates. We had observed obvious difference between the care of PEG group and the NG group to explain this difference.

To our knowledge, no study has compared the composite outcome of complications and mortality for NG vs PEG feeding. This study found that the PEG group exhibited better complication-free survival compared to the NG group. It was not possible to determine time to mortality or first complication, as the exact date of complications could not be verified. Nevertheless, this observation is likely to have an impact on health-related quality of life in older patients with dysphagia, which has been demonstrated in other studies (Sadasivan *et al.* 2012, Timmerman *et al.* 2014).

#### **5.4.3 Limitations of the study**

Results of the present analysis were subject to several limitations. Firstly, a RCT was not feasible in our Malaysian setting. A multitude of factors, explored in earlier chapters in this thesis, including poor communication by HCPs, poor knowledge by patients and caregivers, and local cultural beliefs made it difficult to obtain informed consent for randomization in such a study. Secondly, the age factor became one of the biggest influences of outcomes such as mortality, as PEG patients were younger than NG patients. Thirdly, the level of attrition was high due to the high mortality rate. It was

therefore no longer possible to perform intention-to-treat analysis for nutritional outcomes, as our study protocol measured these at baseline and four months. An intention-to-treat analysis was still possible, however, for complications and mortality as we had collected this data at regular follow-up periods.

Subsequent biases due to a lack of randomization may, therefore, have led to any or all the differences found between the two groups. Standard statistical techniques were then utilized in order to control for imbalances in baseline prognostic factors that were present.

In order to answer conclusively which method of enteral feeding is superior, a randomized controlled study involving sufficient patients and long enough duration would be required. While this may become possible in the future once our population is more accustomed to clinical research being incorporated with clinical care, it may not be necessary if adequate clinical surveillance data involving large numbers of patients could be held, to confirm the differences, found in our small clinical study. Furthermore, much controversy now surrounds the relevance of large multi-centre randomized controlled studies for interventions involving older adults. Despite the widespread use of cholesterol lowering therapy using statins for stroke, there is currently no evidence supporting any benefit of statins in individuals aged 80 years and over (Alpérovitch *et al.* 2015, Fleg *et al.* 2011). While, the Hypertension in the Very Elderly Trial (HyVET) was intended to answer the important question of whether hypertension treatment benefits the elderly and many would accept that the study confirmed that the study provided overwhelming evidence for hypertension treatment in the elderly with the trial being discontinued early due to overwhelming mortality benefits, the authors of the study admitted that the older people involved in the study consisted of an unusually healthy older population, as majority of older adults would

have been excluded from the study with the multiple exclusion criteria (Beckett *et al.* 2012). Therefore, the issue with attrition will remain in this group of older frail adults, and the introduction of more stringent criteria to minimize attrition will likely then affect the relevance of the study. In short, the question of whether PEG is clinically superior to NG may never be addressed appropriately using a randomized-controlled design. Our study, therefore, represents a pragmatic design, taking into account potential attritional factors and overcoming these factors through statistical adjustments.

The sample size was calculated based on an estimated primary outcome difference between NG and PEG fed patients. Hence, the lack of difference observed for our secondary outcomes of nutrition and mortality may have been due to a statistical type II error.

## **5.5 Conclusion**

This study has demonstrated using a case-comparison design that PEG tube feeding was superior to NG tube feeding in terms of the composite outcome of complication-free survival among older adults requiring long-term enteral feeding. Survival analysis revealed nutritional improvements in both NG and PEG groups, while greater improvements in mid-arm circumference was observed in the PEG group compared to the NG group after adjustment for potential confounders. While a randomized controlled design is considered the strongest level of evidence, its feasibility as well as generalizability to older adults is limited. Therefore, comparisons using robust, large real-world datasets in Asia where NG tube feeding remains common place, using statistical methods to adjust for confounders may be the most feasible method to confirm our findings.

## **CHAPTER 6: CONCLUSION AND FUTURE RESEARCH**

### **6.1 Summary of Overall Findings**

The present PhD thesis was a detailed exploration of the issues surrounding enteral tube feeding, with a particular focus on PEG issues in Malaysia. The literature review consisted of two systematic reviews. The first systematic review highlighted a gap in the literature with regards to evidence supporting the use of PEG above NG in long-term enteral feeding in older adults with non-stroke dysphagia. The second systematic review then highlighted existing issues with regards to world-wide perceptions and barriers to PEG, which were summed up in the themes surrounding lack of choice, confronting mortality, and weighing alternatives. Moreover, major factors that influenced decision making were found to be lack of funding, insufficient information given to patients and caregivers, inadequate competency and skills, and poor knowledge among HCPs regarding PEG tube feeding. Subsequently, barriers and perceptions surrounding PEG in the Malaysian population were explored in a quantitative survey and with semi-structured qualitative interviews, which found that HCPs were generally in favour of PEG for long-term enteral feeding, but its usage is inhibited by training, knowledge, communication, a hierarchical culture and fear of complications. Finally, the gap in evidence of PEG benefits in the general older population was addressed by the comparative study which confirms the benefit of PEG above NG in terms of complication-free survival after four months.

### **6.2 Implications for Clinical Practice**

#### **6.2.1 PEG use in older people**

Our literature review found that a Cochrane systematic review comparing PEG and NG tube feeding in stroke favoured the use of PEG in terms of treatment failures, feed

delivery and gastrointestinal bleeding (Geeganage *et al.* 2012). Subsequently, our systematic review on studies comparing PEG and NG in non-stroke dysphagia revealed no differences in overall complications, with no RCTs included reporting on mortality. The few studies included were generally small and of poor quality. Our comparative study therefore filled in a crucial evidence gap, in identifying that PEG is advantageous among the general older population requiring long-term enteral feeding. We were unable to focus our study on just the non-stroke group, as this was a single-centre study and the recruitment period was limited by availability of funding. Therefore, stroke and non-stroke patients were included to ensure adequate recruitment. Our study had, however, excluded all patients with advanced dementia. In this group of patients, clear guidelines are in place advocating the continuation of oral feeding and discouraging the use of tube feeding (American Geriatrics Society 2014).

One main barrier to HCPs recommending PEG was fear of complications. Our study has confirmed that PEG is in effect associated with fewer complications than NG feeding. While this finding had previously been reported by other studies (Attanasio *et al.* 2009, Azzopardi & Ellul 2013), none of these studies had been conducted in Asia, let alone Malaysia, which may have led to doubts of the effectiveness of PEG in our setting. Another reason for the lack of advocacy due to fear of complications may be lack of knowledge and team work. Both these factors were clearly highlighted in our survey and qualitative study, which had revealed that HCPs would not advocate PEG for long-term enteral feeding for fear of complications. In addition, many multi-disciplinary team members felt that they did not have adequate knowledge as they had not received adequate training on artificial feeding with some even believing it was an offence to talk to patients about PEG. As a result, the decision to recommend PEG was left solely to the doctor, who themselves felt that they did not have enough time to explain about PEG to patients. Furthermore, both our quantitative survey and qualitative

study had found that most HCPs would advocate PEG for long-term enteral feeding (which suggests that they were aware of available evidence on the advantage of PEG) but the poor uptake of PEG had occurred from other factors such as limited communication and lack of teamwork.

The systematic review, the quantitative, and qualitative studies conducted all suggest that the uptake of PEG is influenced by healthcare funding policies and guidelines. This was apparent when regional differences in uptake of PEG were compared, with the Taiwanese and Malaysian study reporting low PEG uptake due to absence of healthcare coverage for PEG tube insertion (Yeh *et al.* 2010, Zaherah Mohamed Shah *et al.* 2012). In addition, in our prospective clinical study, both the NG and PEG groups had shown improvements in nutritional parameters over the four-month follow-up period, in comparison to a previous studies which demonstrated malnutrition and poor outcomes with NG tube feeding (Nordin *et al.* 2015, Zaherah Mohamed Shah *et al.* 2012). This improvement could be influenced by the relatively small subsidy and increased clinical input associated with participation of the study. This provides indirect evidence that a shift in healthcare services to provide better follow-up care for those on enteral feeding and the provision of subsidies for those who require long-term enteral feeding may be required to help improve the outcomes in our setting.

Confronting mortality and weighing up alternatives were considered important aspects of decision making with regards to PEG. Communication on the risks and benefits associated with PEG and enteral feeding in general at a point of life where the life-expectancy is limited by the patients' physical condition and comorbidities is vital (Rio *et al.* 2010). Ethical considerations often arise, and the involvement of the patient and the family in decision making is vital. However, cultural differences are apparent in this area and the involvement of family members in this decision vary across continents

and different legal systems. The involvement of family members in decision making in Asia is strong (Yeh *et al.* 2010), often to the point of exclusion of the patient, as was our experience when we attempted to pursue randomization. Family members were not willing to leave the decision for PEG and NG to chance. The high mortality rate among our participants supports the difficult nature of the decision. However, it also raises a separate argument that perhaps in some of our patients, long-term enteral feeding should have been withheld and withdrawn based on their poor prognosis (Papadimos *et al.* 2011, Volkert *et al.* 2015). This area is highly emotive, particularly in the Asian culture where food is viewed to be of extreme importance (Nordin *et al.* 2015). While food is considered a basic human right, tube feeding is considered a medical treatment. Even though American guidelines suggest reviewing the use of artificial feeding for the dying (Truog *et al.* 2008), several ethnic groups including the Chinese would interpret feeding as an expression of filial piety (Chai *et al.* 2014), while Islam would view nutritional support as basic care and not medical treatment (Alsolamy 2014). Withholding tube feeding within the healthcare setting is, however, considered equivalent to withholding medical treatment which is considered acceptable when the intervention is unlikely to be of benefit. An example includes situations where the intervention may prolong life but at the same time lead to prolong unacceptable suffering, or when the intervention is view as futile (Volkert *et al.* 2015). In the US, the Patient Self Determination Act (PSDA) clearly established the right of patients or caregivers to decide whether to not to have artificial nutrition or to withdraw administration of such support (Gostin 2005).

Nevertheless, when tube feeding is deemed necessary, our intervention study suggests that PEG is advisable. The reduction in mortality observed in the PEG group in this study was confounded by age differences, as demonstrated by the lack of significance after statistical adjustment for potential confounders. However, beyond just prolonging life, quality of life is more important. The assessment of quality of life is



highly challenging in a group of patients with communication difficulties, often requiring an informant to provide the necessary information (Papadimos *et al.* 2011). Therefore the effects of long-term enteral feeding on quality of life can only be inferred through other measures. This is confirmed by the fact that not many studies have reported quality of life (Gomes *et al.* 2015). Most quality of life research relied on specific questionnaires pertaining to its most important components that include physical, psychological, and social domain of health (Stathopoulos *et al.* 2011). However, some of the patients might experience difficulty in narrating their subjective feelings, and family members may report opposing opinions (Dharmarajan *et al.* 2001). Factors which may negatively affect patients' quality of life are difficulty in tube feeding in public, patients experience pain, fatigue and burden (Rio *et al.* 2010), sleep interrupted by feeding times, and the development of pressure sores and oral infections. The greatest positive aspect of PEG is its low complication rates including tube dislodgement (Attanasio *et al.* 2009), discomfort in the naso-pharyngeal area (Anderson *et al.* 2004), and tube clogging (Pancorbo-Hidalgo *et al.* 2001). A previous study had also mentioned improved survival rate associated with PEG feeding (Kumagai *et al.* 2012). Therefore, the advantage observed in terms of complication-free survival with PEG in our setting is likely to favourably influence quality of life, but effective tools to measure quality of life in this setting is very much needed.

### **6.3 Improving PEG Care**

When caring for patients with unavoidable adverse effects, some steps should be taken into considerations such as the need for a baseline nutritional assessment carried out by a dietitian for patients who receive tubes before treatment or at the time of diagnosis, taking the estimated time of tube feeding, and the psychological characteristics of patients. To ensure that patients obtain optimum benefit, it is important that HCPs consider nutritional support on an individual basis based on the

nutritional status, potential nutritional problems and dietetic interventions prior to incorporating into the treatment plan (Wang *et al.* 2014). In this way, the best method for tube feeding can be fairly chosen. It is important that those who care for patients with PEG feeding are also aware of gastrointestinal effects, as it indicates the need to adjust administration of feeds (Jordan *et al.* 2006). New techniques or intervention methods may also contribute to improving the effectiveness and safety of tube feeding (Wang *et al.* 2014).

#### **6.4 Future Research**

There are opportunities for further analysis and examination of the experiences, as well as potential for further research. While a randomized, controlled clinical trial with a larger sample size would provide the strongest evidence, it may not now be considered ethical to pursue such a design, with our relatively small study confirming an advantage for PEG. The utilization of alternative approaches such as large real-world datasets comparing the two interventions and using increasingly sophisticated statistical modelling to control for group differences, may be the preferable approach for the future. In addition, this approach will also allow for longer periods of follow-up and help identify patients who are most likely to benefit from PEG interventions, and to single out groups which may not benefit from enteral feeding at all. Accurate cost-analysis, incorporating good quality nutritional care, will also help inform policies and resource allocation in order to improve outcomes. Finally, the universally apparent lack of knowledge, communication and team work needs to be addressed by the development of educational resources and training.

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## List of Publications and Papers Presented

### Journal Publications

- 1) Jaafar, M. H., Mahadeva, S., Morgan, K. and Tan, M. P. (2015). Percutaneous Endoscopic Gastrostomy versus Nasogastric Feeding in Older Individuals with Non-Stroke Dysphagia: A Systematic Review. *Journal of Nutrition, Health and Aging*, 19(2): 191-197.
- 2) Jaafar, M. H., Mahadeva, S., Tan, K. M. and Tan, M. P. (2015). Attitudes of Health Care Professionals towards Gastrostomy Feeding in Older Adults in Malaysia. *International Journal of Gerontology*, 9(1): 40-45.
- 3) Jaafar, M. H., Mahadeva, S., Morgan, K. and Tan, M. P. (2016). Systematic Review of Qualitative and Quantitative Studies on Attitudes and Barriers to Percutaneous Endoscopic Gastrostomy Feeding. *Clinical Nutrition*.
- 4) Jaafar, M. H., Mahadeva, M., Subramanian, P. and Tan, M. P. (2016). Perceptions of Healthcare Professionals on the Usage of Percutaneous Endoscopic Gastrostomy in a Teaching Hospital in a Middle-Income South East Asian Country. *Journal of Nutrition, Health and Aging*.

## Papers Presented at Conferences

- 1) Jaafar, M. H., Mahadeva, S., Ahmad, N. T., Tan, K. M. and Tan, M. P. (2013). Is Percutaneous Endoscopic Gastrostomy Superior to Nasogastric Feeding in Geriatrics Patients in Malaysia? Paper presented at the 9<sup>th</sup> National Geriatrics Conference, Kuala Lumpur, Malaysia.
- 2) Jaafar, M. H., Mahadeva, S., Ahmad, N. T., Tan, K. M. and Tan, M. P. (2013). A Randomized-Controlled Study of Nasogastric Tube Feeding Versus Percutaneous Endoscopic Gastrostomy in a Middle Income Developing Nation in South East Asia. Paper presented at British Geriatric Society Meeting, Liverpool, England.
- 3) Jaafar, M. H., Mahadeva, S., Morgan, K. and Tan, M. P. (2014). Percutaneous Endoscopic Gastrostomy versus Nasogastric Feeding in Older Individuals with Non-Stroke Dysphagia: A Systematic Review. Paper presented at Malaysian Healthy Ageing, Kuala Lumpur, Malaysia.
- 4) Jaafar, M. H., Mahadeva, S., Tan, K. M. and Tan, M. P. (2014). Opinion of Doctors and Non-Doctors towards Gastrostomy Feeding in Malaysia. Paper presented at Australia & New Zealand Society for Geriatric Medicine, Melbourne, Australia.
- 5) Jaafar, M. H., Mahadeva, S., Tan, K. M. and Tan, M. P. (2014). Acceptability of Gastrostomy Feeding in Malaysia. Paper presented at Asia Pacific Geriatric Conference, Taipei, Taiwan.
- 6) Jaafar, M. H., Mahadeva, S., Morgan, K. and Tan, M. P. (2014). Percutaneous Endoscopic Gastrostomy Feeding in Older Individuals with Non-Stroke Dysphagia: A Systematic Review. Paper presented at Parenteral & Enteral Nutrition Society of Malaysia, Melaka, Malaysia.

- 7) Jaafar, M. H., Mahadeva, S., Tan, K. M. and Tan, M. P. (2014). Attitudes of Health Care Professionals towards Gastrostomy Feeding in Geriatrics Population in Malaysia. Paper presented at 10<sup>th</sup> National Geriatric Conference, Perak, Malaysia.
- 8) Jaafar, M. H., Mahadeva, S., Subramanian, P. and Tan, M. P. (2015). Barriers to the Acceptance of Percutaneous Endoscopic Gastrostomy among Healthcare Professionals: A Qualitative Study. Paper presented at 11<sup>th</sup> National Geriatric Conference, Kuala Lumpur, Malaysia.
- 9) Jaafar, M. H., Mahadeva, S., Morgan, K. and Tan, M. P. (2015). A Systematic Review of Qualitative and Quantitative Studies: Attitudes and Barriers to Percutaneous Endoscopic Gastrostomy Feeding. Paper presented at International Academy Nutrition and Aging, Barcelona, Spain.
- 10) Jaafar, M. H., Mahadeva, S., Morgan, K. and Tan, M. P. (2015). Perceptions and Barriers to Percutaneous Endoscopic Gastrostomy Feeding: A Systematic Review of Qualitative and Quantitative Studies. Paper presented at The 10<sup>th</sup> International Association of Gerontology and Geriatrics – Asia/Oceania 2015 Congress, Chiang Mai, Thailand.