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# Enteral Nutrition in the Community Setting

*By*

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**A thesis submitted for the degree of Doctor of Philosophy at the University of Dublin, Trinity College**

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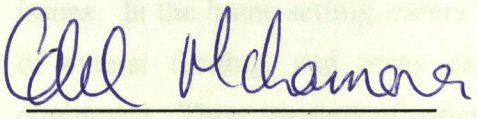
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**Edel McNamara**

## Summary

The practice of tube feeding patients outside the acute hospital setting has existed in Ireland for over a decade. Anecdotal evidence (mainly from hospital dietitians) suggested that the care services for these patients were inadequate and the subject of home enteral tube feeding required examination. A small pilot survey of patients on tube feeding in nursing homes in Dublin suggested that there was a lack of co-ordination and organisation of the practice of community-based enteral tube feeding. The aim of this work was to investigate enteral tube feeding in Dublin in the community setting from the perspective of patients' and the health care professions.

Initial surveys of health care professionals (hospital dietitians, general practitioners and nutritional company representatives) showed that hospital dietitians were mainly responsible for the preparation and aftercare of these patients, but they were generally dissatisfied with the services available to these patients in the community. Company representatives encountered problems in the community, which they felt under pressure to deal with, but they also recognised it was inappropriate for them to intervene. General practitioners encountered relatively few patients on home tube feeding.

A survey of 50 adult patients on tube feeding in the community highlighted a number of issues. In the home setting, carers had little faith in their general practitioners' knowledge of enteral feeding, and many experienced difficulties obtaining necessary feeds and equipment. Three quarters of patients surveyed had never been weighed in the community, and 26% of patients assessed were found to be undernourished. Twelve mothers of children on home tube feeding were surveyed. Such families experienced few major problems, and complications tended to be social and practical rather than physiological.

A study of the opinions and attitudes of Irish consultants in relation to tube feeding found that only a minority would want tube feeding for themselves in terminal or irreversible circumstances where tube feeding might be considered an option. Few were in favour of tube feeding terminal cancer patients, persistent vegetative state patients or patients with dementia.

Results of an investigation of the costs of home tube feeding in Ireland suggests that the provision of a community nutrition service would be viable. In conclusion, home enteral tube feeding requires coordination and management by the carer and health care teams, firstly in the hospital setting where careful preparation is necessary to ensure a smooth transfer of care from hospital to home. Secondly, the health care teams in the community (i.e. general practitioners, public health nurses and dietitians) need to act together to ensure that these patients are managed effectively and complications and hospital readmissions are minimised. At the moment in Ireland the community framework is not structured adequately to facilitate the effective monitoring of patients on home tube feeding. Locally organised community nutrition support services would help to achieve this.

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## Abbreviations

| | |
|---|---|
| ADA | American Dietetic Association |
| AIDS | Acquired Immune Deficiency Syndrome |
| AMC | Arm Muscle Circumference |
| ASPEN | American Society for Enteral and Parenteral Nutrition |
| BANS | British Artificial Nutrition Survey |
| BAPEN | British Association for Parenteral and Enteral Nutrition |
| BCSF | Biceps Skinfold |
| BDA | British Dietetic Association |
| BMI | Body Mass Index |
| BMR | Basal Metabolic Rate |
| CBA | Cost Benefit Analysis |
| CC | Calf Circumference |
| CEA | Cost Effectiveness Analysis |
| CF | Cystic Fibrosis |
| CMA | Cost Minimisation Analysis |
| CME | Continuing Medical Education |
| CNS | Central Nervous System |
| CP | Cerebral Palsy |
| CUA | Cost Utility Analysis |
| CRC | Central Remedial Clinic |
| DCC | Director of Community Care |
| DCSS | Drug Cost Subsidization Scheme |
| DoH | Department of Health |
| DoH&C | Department of Health & Children |
| EAR | Estimated Average Requirement |
| EHB | Eastern Health Board |
| EIG | Enteral Interest Group |
| ERHA | Eastern Regional Health Authority |
| EU | European Union |
| GDP | Gross Domestic Product |
| GI | Gastrointestinal |
| GMS | General Medical Services |
| GNP | Gross National Product |
| GP | General Practitioner |
| HETF | Home Enteral Tube Feeding |
| HEN | Home Enteral Nutrition |
| HPEN | Home Parenteral and Enteral Nutrition |
| HPHC | High Protein High Calorie |
| HPN | Home Parenteral Nutrition |
| ICGP | Irish College of General Practitioners |
| ICU | Intensive Care Unit |
| IEM | Inborn Errors of Metabolism |
| INDI | Irish Nutrition and Dietetic Institute |
| KH | Knee Height |
| LITRE | Looking Into The Requirements of Equipment |
| MAC | Mid Arm Circumference |
| MAMA | Mid Arm Muscle Area |
| MAMC | Mid Arm Muscle Circumference |

| | |
|---|---|
| MND | Motor Neurone Disease |
| MS | Multiple Sclerosis |
| NDS | Neurological Diseases of Swallowing |
| NHS | National Health Service |
| NST | Nutrition Support Team |
| OECD | Organisation for Economic Cooperation & Development |
| OASIS | Oley-ASPEN Information System |
| OPD | Out Patient Department |
| PEG | Percutaneous Endoscopic Gastrostomy |
| PEN | Parenteral and Enteral Nutrition |
| PHN | Public Health Nurse |
| PINNT | Patients on Intravenous and Nasogastric Nutrition Therapy |
| PVS | Persistent Vegetative State |
| SISF | Supra Iliac Skinfold |
| SPSS | Statistical Package for Social Sciences |
| SSSF | Subscapular Skinfold |
| TCST | Triceps Skinfold |
| US | United States |

# Chapter 1

# General Introduction

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## Introduction to Chapter 1

Nutrition support is increasingly used in the routine care of patients during their stay in hospital (Section 1.1). Nutritional assessment is an integral part of the evaluation of a patient before, during and after the use of enteral nutrition (Section 1.2). Increasingly, patients require enteral nutrition after leaving the acute hospital setting (Section 1.3 & 1.4), however, the appropriateness of long term tube feeding in certain patients has been questioned (Section 1.5). The cost of caring for patients in the community setting is increasingly important also, (Section 1.6), and poses challenges to the health services in ensuring adequate community-based services and follow-up (Section 1.7).

## 1.1 Nutrition support

### 1.1.1 Introduction

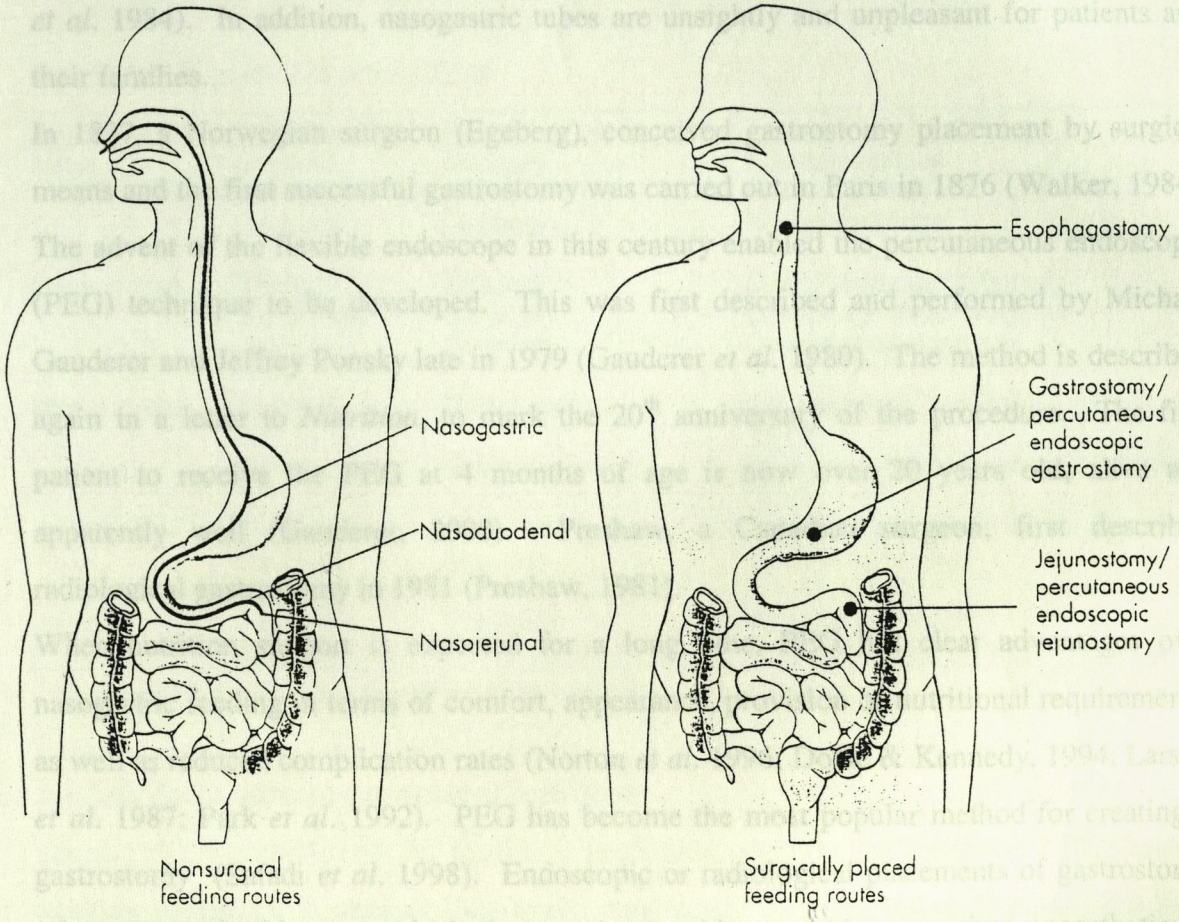
Nutrition support is defined as the provision of an adequate nutritional intake by means other than the eating of normal meals. Nutrition support can be given as oral supplements, enteral feeding or intravenous (parenteral) nutrition. Artificial nutrition refers to nutrition support administered via a tube, whether enteral feeding into the stomach or intestine, or parenteral feeding into the circulatory system.

### 1.1.2 Enteral tube feeding

Enteral nutrition may be defined as nutrition support given through the gut. It includes nutrition taken orally or administered by an enteral tube, though the term generally refers to the latter. An enteral tube may be passed via the *nasal* route into the stomach (nasogastrically), duodenum (nasoduodenally), or jejunum (nasojejunally). Enteral tubes may be passed into the stomach, duodenum or jejunum, via the *oesophagus* (oesophagostomy). Finally, enteral feeding can be provided via a tube placed into the stomach through the abdominal wall. When the latter method is used, *gastrostomy* tubes can be inserted radiologically (Percutaneous Radiologic Gastrostomy), endoscopically (Percutaneous Endoscopic Gastrostomy), or surgically into the stomach, and extension tubes can be used to extend the gastrostomy tube into the duodenum or the jejunum (see Figure 1.1). Direct percutaneous endoscopic jejunostomy is also possible, with a success rate of around 85% with minimal complications (Shike & Latkany, 1998).

Both wide bore and fine bore nasogastric tubes are available. The Ryles and Levines tubes are wide bore nasogastric tubes which are generally used for gastric decompression, but were used for feeding before fine bore nasogastric tubes became available. These tubes

**Figure 1.1 Types of feeding tubes**



are not normally used for feeding for more than a few days, but are necessary if bolus feeding (see Section 1.1.7) is required. Fine bore (diameter 1 to 2 mm) nasogastric tubes are made from polyvinyl chloride (for short term use) and polyurethane (for longer term feeding). Fine bore tubes are flexible and considerably more comfortable for patients (Silk *et al.* 1987), although they become blocked more easily than wide bore tubes. Enteral feeding via the nasal route should only be utilised for short periods of time. Long term nasogastric feeding can result in complications such as nasopharyngeal sepsis (Grossman *et al.* 1984). In addition, nasogastric tubes are unsightly and unpleasant for patients and their families.

In 1837, a Norwegian surgeon (Egeberg), conceived gastrostomy placement by surgical means and the first successful gastrostomy was carried out in Paris in 1876 (Walker, 1984). The advent of the flexible endoscope in this century enabled the percutaneous endoscopic (PEG) technique to be developed. This was first described and performed by Michael Gauderer and Jeffrey Ponsky late in 1979 (Gauderer *et al.* 1980). The method is described again in a letter to *Nutrition*, to mark the 20$^{th}$ anniversary of the procedure. The first patient to receive the PEG at 4 months of age is now over 20 years old, alive and apparently well (Gauderer, 2000). Preshaw, a Canadian surgeon, first described radiological gastrostomy in 1981 (Preshaw, 1981).

When nutrition support is expected for a long time, PEG has clear advantages over nasogastric feeding in terms of comfort, appearance, provision of nutritional requirements, as well as reduced complication rates (Norton *et al.* 1996; Doyle & Kennedy, 1994; Larson *et al.* 1987; Park *et al.* 1992). PEG has become the most popular method for creating a gastrostomy (Safadi *et al.* 1998). Endoscopic or radiological placements of gastrostomy tubes are preferable to surgical placement, as neither technique requires anaesthetic or laparotomy and are therefore cheaper and quicker to perform. PEG is safer, cheaper and results in fewer complications than the surgical method of tube placement (Wollman *et al.* 1995; Campos & Marchesini, 1999). Replacement gastrostomy tubes (Foley catheters, Mic-Key® buttons), which do not require endoscopic placement and can be inserted into the original stoma site are cheaper than conventional PEG tubes when replacement tubes are required (Kadakia *et al.* 1994).

Some claim that radiological placement of gastrostomy has a higher success rate, shorter procedure duration, and less conscious sedation requirements than PEG (Wollman & D'Agostino, 1997). Giulliano and colleagues (2000) found similar success with fluoroscopically guided placement of gastrostomy and gastrojejunostomy tubes and Righi

*et al.* (1998) have found radiological placement to be a valuable tool for establishing enteral nutrition in patients with head and neck cancer. Table 1.1 summarises the various types of feeding tubes that may be inserted. Wollman *et al.* (1995) found that surgical gastrostomy placement had the highest complication rate and radiological placement was associated with fewer major complications. Conversely Cosentini *et al.* (1998) and Barkmieier *et al.* (1998) have found no differences in complication rates between surgical and others methods of tube placement.

**Table 1.1** Types of feeding tube

| Access route | Tube position | Method of placement | Term given to tube |
|---|---|---|---|
| Nasal | Stomach | Manually | Nasogastric tube |
| | Duodenum | Manually | Nasoduodenal tube |
| | Jejunum | Manually | Nasojejunal tube |
| Oesophagus | Stomach | Surgically | Oesophago-gastroststomy |
| | Duodenum | Surgically | Oesophago-duodneostomy |
| | Jejunum | Surgically | Oesophago-jejunstomy |
| Stomach wall | Stomach | Radiologically | Percutaneous Radiologic Gastrostomy (PRG) |
| | Stomach | Endoscopically | Percutaneous Endoscopic Gastrostomy (PEG) |
| | Stomach | Surgically | Surgical gastrostomy |
| | Stomach | Manually | Gastrostomy tube* |
| Jejunum | Jejunum | Surgically | Surgical jejunostomy |
| | Jejunum | Endoscopically | Percutaneous endoscopic jejunostomy |

** i.e. replacement tubes, of which various types available*

### 1.1.3 Enteral versus parenteral nutrition

The use of the enteral route for feeding is preferable when the gastrointestinal (GI) tract is working because it is cheaper, has fewer complications, and is more physiological than parenteral nutrition (Bowling & Silk, 1994; Suchner, 1998). In cancer patients, enteral nutrition is always preferable in terms of physiological response, local and systemic competence, quality of life and cost (Mercadante, 1998). Prospective randomised comparisons of enteral and parenteral nutrition after oesophagogastric surgery have shown significantly fewer complications associated with enteral nutrition (Baigrie *et al.* 1996). In the perioperative period, parenteral nutrition is only indicated when major complications occur in association with intestinal failure (Silk & Green, 1998), and enteral nutrition can be commenced early in virtually all critically ill patients after major abdominal surgery (Sigurdsson, 1997). A recent review found enteral nutrition to be superior to parenteral nutrition in terms of reducing infectious complications in critically ill or injured patients (Minard & Kudsk, 1998).

While the usefulness and benefits of enteral over parenteral nutrition to patients in terms of morbidity and shorter in-patient admissions would appear to be undisputed; recently some authors have questioned the advantages of enteral feeding over parenteral nutrition in the clinical setting (Keith & Jeejeebhoy, 1998). One review of the literature comparing enteral and parenteral nutrition in terms of cost, safety, physiology, intestinal structure and function, bacterial translocation and outcome found that while enteral nutrition appears to be less expensive than parenteral nutrition, new economic analyses are necessary in view of newer aggressive access techniques for enteral nutrition (Lipman, 1998). According to Lipman (1998), with the exception of decreased cost and possible reduced septic morbidity in acute abdominal trauma, the current literature does not sustain the theory that enteral nutrition is better than parenteral nutrition in humans.

### 1.1.4 Candidates for PEG placement

Candidates for PEG feeding should need enteral nutrition for more than six to eight weeks, and those with rapidly progressing disease are better served with nasogastric or nasojejunal tube feedings. Patients should demonstrate potential for extended survival and must have functional GI tracts. Careful selection of patients for PEG feeding is fundamental. Once commenced, it commits the clinician towards long term feeding for all practical purposes (Raha & Woodhouse, 1993). The procedure should also be avoided in septic patients, patients with massive ascites or those undergoing peritoneal dialysis (Ponsky & Gauderer, 1989). Gastrostomy feeding should not be used in those patients who themselves or their next of kin object to this form of treatment (Lo & Dornbrand, 1989). When the decision is "to PEG or not to PEG" physicians should weigh issues such as the benefits, risks, quality of survival, and ethical considerations (Tham & Taitelbaum, 1997). Physical contraindications to PEG placement are outlined in Table 1.2.

**Table 1.2** Physical contraindications to PEG placement

1. Inability to bring the anterior wall of the stomach into apposition with the anterior abdominal wall (can occur in patients with previous sub-total gastrectomy, ascites, or marked hepatomegaly)
2. Distal gastrointestinal tract obstruction
3. Proximal small bowel fistula
4. Neoplastic and infiltrative diseases of the gastric wall
5. Obstructing oesphageal lesions
6. Irreversible abnormal coagulation defect

### 1.1.5 Indications for enteral feeding

#### 1.1.5 (i) Adults

Enteral nutrition may be used in numerous disease states. Generally though, patients require enteral nutrition because they cannot physically swallow food or liquids, or because they cannot eat sufficiently to meet their requirements. Inability to swallow will be due to either *neurological impairment* or a *physical obstruction*. The major indication for enteral feeding in the adult is neurological impairment (Ciocon *et al.* 1988; Quill, 1989; Hull *et al.* 1993; Panos *et al.* 1994; Raha & Woodhouse, 1994) especially stroke (O'Mahony & McIntyre, 1995), and to a lesser extent motor neurone disease (MND) (Scott & Austin, 1994), multiple sclerosis (MS), and Parkinson's disease as well as other neurological disorders of swallowing. Physical obstruction, such as inoperable oesophageal cancer also warrants enteral feeding (Bozzetti *et al.* 1998).

Many patients are unable to meet their nutritional requirements orally, and so benefit from enteral nutrition. The cachexia seen in cancer patients is one such further indication for enteral feeding, although the efficacy of nutritional therapy in patients with cancer has been questioned, and well designed prospective randomised control trials have been recommended to review this issue (Klein *et al.* 1997). Certain patients with cystic fibrosis (CF) (Williams *et al.* 1999), AIDS (Crotty *et al.* 1998) inflammatory bowel disease (Mahajan *et al.* 1997) and burn injury who are unable to meet their nutritional requirements orally may also require and benefit from enteral nutrition.

#### 1.1.5 (ii) Children

The general indications for enteral nutrition in children are similar to those in adult patients. A limited ability to eat will require tube feeding and the background may be *neurological*, as commonly seen in children with cerebral palsy (Rempel *et al.* 1988), or *physical,* such as in children with facial trauma. An inability to meet full nutritional requirements orally also necessitates tube feeding, seen in patients with CF (Courtney-Moore *et al.* 1986; Rosenfeld *et al.* 1999) AIDS (Miller *et al.* 1995) or congenital heart

disease (Schwarz *et al.* 1990). Finally, enteral nutrition is required in patients with altered absorption or metabolism of oral intake, for example in patients with short bowel syndrome or glycogen storage disease (Baker, 1997). Table 1.3 summaries the indications for enteral tube feeding in adults and children.

**Table 1.3** The indications for enteral tube feeding in adults and children.

| Indication for EN | Children | Adults |
|---|---|---|
| **Unable to swallow** | | |
| *Neurological cause* | e.g. Cerebral palsy, prematurity, suck-swallow dysfunction, congenital abnormalities etc. | e.g. Stroke, MND, MS, Parkinson's disease, Alzheimer's dementia, coma, cerebral palsy etc. |
| *Physical cause* | e.g. Facial trauma, oesphageal stricture etc. | e.g. Cancer of oesophagus, severe Barrett's oesophagus etc. |
| **Unable to meet nutritional requirements orally** | e.g. Burns, trauma, AIDS, CF, cancer, anorexia nervosa etc. | e.g. AIDS, cancer, anorexia nervosa, burns, trauma etc. |

### 1.1.6 Commercial feeds for tube feeding

Commercial feeds for enteral feeding are "nutritionally complete" products containing protein, fat, and carbohydrate, plus vitamins, minerals, and trace elements in appropriate amounts to meet most patient's daily requirements at a certain levels of intake. There are currently over 100 commercial enteral feeds on the market (Silk, 1999). The Scientific Committee for Food (European Committee) has suggested upper limits for the vitamin and mineral and trace elements in nutritionally complete foods (Scientific Committee for Food, 1997). However, many commercial feeds currently exceed this suggested upper limit of micronutrient content. Feeds range from the cheaper standard intact protein (polymeric) feeds to expensive disease-specific feeds that may contain crystalline amino acids or branched chain amino-acids. Physiological and clinical studies have clearly shown that only in patients with severe disease or with very short bowels, are there likely to be any rate limiting or absorptive problems with the cheaper standard feeds (Russell & Evans, 1987; McIntyre *et al.* 1986). A recent randomised, double blind trial comparing polymeric and elemental enteral feeds in the treatment of Crohn's disease found both types of feed to be equally effective (Verma *et al.* 2000). Similarly, a study comparing a semi-elemental and a non-elemental formula for patients with CF concluded that a non-elemental formula, (with enzyme replacement), is absorbed as well as a pre-digested formula in patients with CF

who have pancreatic insufficiency (Erskin *et al.* 1998). Other studies have shown that specific enteral diets such as those feeds enriched with branched chain amino acids for patients with hepatic encephalopathy may have substantial theoretical benefits, but when the treatments are examined in the environment of a randomised control trial, the clinical benefits do not necessarily equal the theoretical benefits (Brennan *et al.* 1986, Silk, 1988). The latest addition to the feeding formulas variety has been the immunonutrition range of products. These are enteral feeds that contain immune-enhancing ingredients, such as arginine, taurine and omega-3 fatty acids. Recent meta-analysis of studies shows that enteral immunonutrition has a significant effect on reducing infection rate, ventilator days, and hospital length of stay. There appears to be no effect on death rate however (Beale *et al.* 1999; Heys *et al.* 1999).

### 1.1.7 Methods of enteral feed delivery

Enteral feeds can be administered to the patient either as a bolus (intermittent) feed, a continuous infusion or a cyclical infusion, either with or without the use of a feeding pump. Pumps specifically designed for enteral feeding have been available since the late 1970s. Modern pumps have features such as touch panel controls, a wide range of flow rates, LED displays, audio and visual alarms. Most pumps are ± 10% accurate in their delivery of feeding (Torrence & Harrison, 1988). Small, mobile pumps are also available (see Figure 1.2). Plastic tubing (the giving set) connects the pump to a container holding the enteral feeding formula. Previously, formula was decanted into a special container; now "ready-to-hang" formulas are available which do not require decanting, and are thus less prone to bacterial contamination.

Bolus feeding is the delivery of up to 400mls of an enteral feed over a short period of time several times per day (4, 5 or 6 times is usual). A pump or large syringe (e.g. 50mls) may be used to administer the feed. This method of feeding resembles normal dietary habit and thus may promote a normal insulin response. Initially, bolus feeding can lead to complaints of abdominal discomfort, nausea and fullness, but generally individuals adapt to bolus feeds in time. Bolus feeding is also associated with an increased risk of abdominal distension, diarrhoea, constipation, and delayed gastric emptying (Jones *et al.* 1983).

Continuous infusion refers to the delivery as a constant infusion over 16 to 24 hours via a fine bore tube. This form of feeding is suitable for most patients, and is preferable to the technique of bolus feeding in terms of lower risk of gastric distension, aspiration and reflux (Hiebert *et al.* 1981; Parker *et al.* 1981, Coben *et al.* 1994). A potential advantage of this


Nutrison
Nutrison pack
Standard
Nutrison pack
Nutrison Concentrated LE

method of feeding is a smaller osmolar load on the GI tract compared with the bolus method. The smaller osmotic load may decrease the chance of gastric intolerance and aspiration by improving gastric motility. This method is also easier and less time consuming than bolus feeding in a nursing setting.

Cyclical infusion refers to the administration of feed for less than 16 hours per day and usually refers to feeding as a night time supplement. It is most suitable for ambulatory patients whose oral intake is insufficient because of poor appetite or increased nutritional requirements e.g. CF patients (Smith *et al.* 1994). It is an ideal method of feeding for children. The short delivery period decreases the risk of contamination and allows the patient to eat normally during the day and can help prevent the psychosocial problems associated with tube feeding (Holden *et al.* 1991).

### 1.1.8 Complications associated with enteral feeding

Complications associated with enteral feeding can be classified as *major or minor* and as *early or late*. Complications of enteral feeding also include access problems and microbial contamination of feeds. Most complications associated with enteral feeding are minor and can be easily avoided. Major early complications (i.e. soon after initiation of therapy) include gastric bleeding and haematoma. Major late complications include aspiration and diarrhoea. Minor early complications include wound infections and stoma leaks, while minor late complications include catheter displacement or rupture.

Access problems can include pressure necrosis, feeding tube displacement and migration, tube obstruction and leakage through stoma sites (Hamaoui & Kodsi, 1997). Obstruction of the feeding tube is one of the most common mechanical complications of enteral feeding. The incidence of tube blockage varies. The incidence of tube clogging from medications or nutrient solutions varies in the literature from 2% to 9% (Mathus-Vliegen *et al.* 1993; Crocker *et al.* 1982). Tube diameter, quality of nursing care, type of tube used (jejunostomy vs. gastrostomy) and the duration of tube placement have also been shown to affect the rate of tube obstruction. Patients on continuous feeding are three times more likely to have blocked tubes than patients on bolus feeding. Sucralfate and antacids have also been found to cause tube obstruction by precipitating with enteral feeds (Hamaoui & Kodsi, 1997).

Problems encountered during feeding include regurgitation, aspiration, and diarrhoea. Regurgitation of feed that cannot be absorbed or moved down the gut may lead to aspiration. Aspiration is an important complication associated with enteral feeding.

Documented mortality from aspiration varies from 17% to 62% (Kirby *et al.* 1995), while there is a reported incidence of aspiration ranging from less than 5 to 95% (Hamoui & Kodsi, 1997). In contrast to most findings, Mullan *et al.* (1992) reported a 4.4% incidence of aspiration events in 276 patients, with no excess mortality and little morbidity associated with aspiration. Kirby *et al.* (1995) have outlined issues that need consideration with respect to aspiration pneumonia. Patients lying in the supine position are at a greater risk of aspiration, as are patients fed with rapid bolus feeds. They conclude that more information is needed on the cause of aspiration (i.e. whether the source is oropharyngeal or gastric). Patients fed via the jejunal route appear to have a lower risk of aspiration pneumonia (Shike *et al.* 1996).

Incidence of enteral diarrhoea in enterally tube fed patients has been reported as low as 2.3% and as high as 68% (Cataldi-Betcher *et al.*1983; Kelly *et al.* 1983). Diarrhoea can cause considerable distress to both patient and carer, in addition to limiting the efficacy of the treatment (Bowling & Silk, 1998). A number of causes for enteral feeding related diarrhoea have been proposed, including antibiotic therapy, infected diets, hypoalbumineamia, lactose intolerance, and osmolality. Of the postulated causes, conclusive evidence exists for only antibiotic therapy, infected diets, and hypoalbuminaemia (Bowling, 1995). Incidence of diarrhoea in enterally tube-fed patients is much higher than in non-tube fed patients taking the same antibiotics (Keohane *et al.* 1984). Even controlling for those possible factors, diarrhoea still occurs in 15% of patients, suggesting that some other unknown mechanism is involved (Bowling & Silk, 1998). Complications associated with enteral feeding are summarised in Table 1.4.

Microbial contamination of enteral feeding solutions is an important complication of feeding that can lead to the development of nosocomial pneumonia in susceptible patients (Hamoui & Kodsi, 1997). Contamination risk is increased when feeding formulas are decanted into containers (Anderton & Aidoo, 1990). The design of the feeding system also plays a role (Aidoo & Anderton, 1988), as does non-aseptic manipulation of the feed by the patient or carer (Casewell & Phillips, 1977). Methods of prevention include using ready-to-hang formula (Eisenberg, 1993) and changing the delivery sets every 24 hours (Kohn, 1991).

**Table 1.4** Complications associated with enteral feeding

| Category | Complication |
|---|---|
| Access & mechanical problems | Pressure necrosis |
| | Feeding tube migration |
| | Feeding tube displacement |
| | Tube obstruction |
| | Leakage through stoma site |
| | Tube withdrawal |
| | Tube impaction |
| Gastrointestinal | Nausea & vomiting |
| | Diarrhoea |
| | Constipation |
| | Abdominal distension |
| | Regurgitation of feed |
| | Gastric bleeding and haematoma |
| Site or stoma related | Stoma infection |
| | Pain at stoma site |
| | Erythema at stoma site |
| | Nasal pressure necrosis |
| | Oesophageal pressure necrosis |
| Aspiration | Aspiration pneumonia |
| Microbial | Nosocomial infection |
| Metabolic | Hyperglycaemia |
| | Abnormal liver function tests |
| Other | Gastric perforation |
| | Gastric bleeding |
| | Haematoma |
| | Peritonitis |

### 1.1.9 Medication use and enteral feeding

Problems can occur when medications are administered via the enteral feeding tube. These can arise from poor absorption of the drug leading to a reduced efficacy of the drug therapy, or tube blockage and diarrhoea. It is important that the formula feed does not interact with the drug and cause a decreased absorption of the drug, especially for drugs with a narrow therapeutic range (e.g., phenytoin, warfarin, theophylline, penicillins, quinolones and tetracyclines (see Table 1.5). One study showed an immediate and significant loss of fluoroquinolone when mixed with Ensure (Ross Products Division, Abbott Laboratories) (Wright *et al.* 2000).

The chances of a feeding tube becoming blocked are decreased if the medications are administered correctly and carefully as outlined by a number of authors (Adams, 1994; Estoup, 1994; Smith, 1997). For example, flushing the tube with about 30mls of water before and after medication administration ensures that the tube is clear before administration and that the full dose of medication has been delivered to the

stomach/jejunum and does not remain in the tube. Enteric-coated, sustained release or sublingual drugs should never be crushed and administered via an enteral tube (Kochevar, 2000).

When drugs are administered directly into the jejunum, they bypass the stomach, so it is necessary in these instances to ensure that the drug in question is sufficiently absorbed in the jejunum to therapeutic levels. Liquid drug preparations are problematic when administered directly into the jejunum, and can cause diarrhoea. Firstly, because the hyperosmolar solutions can cause osmotic diarrhoea, but also because the sorbitol content of many liquid medications has a laxative effect and can cause bloating and cramps. Liquid preparations that can cause cramps are ranitidine syrup, metclopropramide solution, and most antibiotic syrups (Estoup, 1994).

**Table 1.5** Drug nutrient interactions (Smith, 1997)

| Drug | Interaction |
|---|---|
| **Phenytoin** | Interaction well established. Amount of phenytoin can be reduced by 75% |
| **Warfarin** | There have been several case reports of enteral feeds interfering with the anticoagulation effect of Warfarin, due to their Vitamin K content |
| **Theophylline** | Interaction with enteral feeds is unpredictable. Has been shown to interact with enteral feeds and it's absorption can be decreased by two thirds, although three have also been reports of increased absorption |
| **Penicillins** | It is recommended that phenyoxymethylpenicillin and flucloxacillin should be taken an hour before meals or on an empty stomach. Larger doses of the drug may be given to counteract any reduced absorption, or alternatively, amoxycillin may be used |
| **Quinolones** | The absorption of ciprofloxacin can be reduced by 25% in the presence of antacids and enteral feeds containing calcium, magnesium or iron.. Larger doses may be used to counteract the problem |
| **Tetracyclines** | The amount of tetracycline absorbed can be reduced by 70 to 80% in the presence of milk or other dairy products. Therefore, another antibiotic would be preferable, and it essential to have a gap of at least one hour between giving the tetracycline and starting the enteral feed |

## 1.2 The assessment of nutritional status

### 1.2.1 Introduction

Assessing of the nutritional status of an individual is a dynamic process that involves investigating a number of parameters, including review of medical data, evaluation of social and medical histories, measurement of anthropometric and laboratory data, and finally, clinical evaluation. There is no "gold standard" for determining nutritional status, and no single body composition measurement has been shown to consistently predict clinical outcome.

Anthropometry is an impartial, inexpensive, quick, easy and reasonably non-invasive method of measuring overall body size and composition. There are a number of equations which allow calculation of percentage body fat from a variety of anthropometric measurements. Anthropometric measurements are usually compared to age and sex matched reference data, which has been collected from "normal healthy" populations.

Potential problems that exist in making anthropometric measurements including errors made resulting from examiner inexperience, inaccurate or badly calibrated equipment or the reference standards used may be inappropriate. Improper anthropometric techniques can produce poor estimates of nutritional status, or overestimates or underestimates of the effect of nutritional intervention in the elderly (Chumlea, 1991). Certain anthropometric parameters may be altered by some disease conditions e.g. height and weight are affected in osteoporosis or oedema. This section describes the anthropometric assessment of nutritional status in greater detail.

### 1.2.2 Weight

Body weight is a simple and practical measure of total body components. Body weight and assessment of weight loss are the parameters most commonly used in the assessment of nutritional status. Weight is a good index of nutritional status at the extremes of protein-energy malnutrition in ambulant elderly patients (Manson & Shea, 1991). As a sole indicator of nutritional status, it is less reliable in mild to moderate cases. The rate of weight loss is as important as the amount lost, and smaller degrees of weight loss in the elderly may assume a higher clinical significance. Generally, a weight loss of less than 5% of usual weight is considered small, between 5% and 10% potentially significant, and more than 10% definitely significant (Detsky & Smalley, 1994). Longitudinal studies have shown that weight decreases gradually with increasing age (Steen *et al.* 1988).

### Measuring weight

For those patients who cannot stand up to be weighed, sit down scales are available. All equipment used for weighing must be calibrated regularly. Alternatively, weight can be estimated from other anthropometric measurements. The necessary measurements are calf circumference (CC) knee height (KH), mid arm circumference (MAC) and subscapular skinfold thickness (SSSF). The equations for estimating weight are outlined below, and have a 95% probability of estimating the weight of an elderly man or woman to within plus or minus 8.96kg or 7.6kg respectively (Chumlea *et al.* 1998)

Body weight for men: (0.098 x CC) + (1.16 x KH) + (1.72 x MAC) + (0.37 x SSSF) – 81.69
Body weight for women: (1.27 x CC) + (0.87 x KH) + (0.98x MAC) + (0.4 x SSSF) – 62.35

The CC measurement can be used in the estimation of the height of an individual. The left knee should be bent to a 90° angle. The maximum circumference of the calf is measured in a plane perpendicular to the shaft of the tibia. The calf circumference can also be taken with the participant supine (Chumlea, 1991).

KH is the distance from the sole of the foot to the anterior surface of the thigh, with the ankle and knee flexed to a 90° angle (Chumlea, 1991).

To measure MAC, the left elbow is bent to a 90° angle, and the left forearm placed palm down across the middle of the body. The midpoint of the distance between the left acromion and olecranon processes is located and marked. The left arm is then extended alongside the body with the palm of the hand facing upwards. The circumference of the upper arm is measured at its midpoint, perpendicular to the long axis of the upper arm. The MAC measurement can also be taken with the participant supine. To accurately measure this circumference, the upper arm must be supported off the surface of the bed (Chumlea, 1991).

### 1.2.3 Height

To measure the stature of an individual, the person should be able to stand upright, without assistance, with bare heels close together, legs straight, arms at the sides, shoulders relaxed, and wearing minimal clothing so that posture can be clearly seen (Chumlea, 1991). In elderly subjects, accurate measurement of stature is often difficult. Alternative methods are available to estimate stature. For elderly or recumbent individuals who may not be able

to be measured in the conventional manner, height can be estimated from measurements of KH, sex and age (Chumlea, 1985).

KH does not change with age and is highly correlated with stature. The knee height measurement should be taken in centimeters (cm), age is rounded to the nearest whole year, and the resulting value is stature in cm. The 90% error bound for estimates of height are about 6cm for both men and women. Accurate measurement of height is essential if body mass index (BMI) is to be ascertained.

Height for men: (2.02 x KH) – (0.04 x Age ) + 64.19

Height for women: (1.83 x KH) – (0.24 x Age ) + 84.88

### 1.2.4 Body Mass Index (BMI)

BMI is a simple anthropometric index that correlates well with body fat content, and hence provides a measure of body energy stores. A BMI of less than 18.5 constitutes chronic energy deficiency, and a BMI of less than 17 constitutes a substantial health risk. BMI may not be completely useful in some elderly persons, because of deceases in stature with age, and because associations between weight and present stature are problematic depending upon the degree of spinal curvature (Chumlea, 1991)

Body mass index: weight (Kg) ÷ by height ($m^2$)

### 1.2.5 Skinfolds thickness

Skinfold measurements and calculation of muscle area derived from them have been used in assessing fat and muscle stores in healthy populations. The skinfold measurements generally used are from four sites, namely, biceps (BCSF), triceps (TCSF), subscapular (SSSF), and suprailiac (SISF). For assessing skinfold measurements at least 3 measurements should be taken and the final value taken as the average of the results. The skinfold measurement is based on two assumptions (neither of which have been proven to be true). Firstly that the thickness of the subcutaneous adipose tissue reflects a constant proportion of the total body fat, and secondly, that the sites selected for measurement represent the average thickness of the subcutaneous tissue (Lukaski, 1987).

In the clinical setting, the TCSF measurement is the most frequently used for the estimation of fat stores, as it is a relatively inexpensive, easily performed test. Arm muscle circumference (AMC) can be calculated from TCSF measurements and gives an estimation

of muscle reserve. The measurement obtained may then be compared with standard reference values for the general population. Interpretation of skinfold measurements in the elderly is complicated, due to the natural changes that occur with aging (i.e., changes in distribution of body fat, skinfold thickness' and skin compressibility) (Charney, 1995). The validity of skinfold thickness measurements in the elderly has been questioned (Fischer & Johnson, 1990). Both males and females show an increase in the percentage of body fat, as well as redistribution of body fat with increasing age, where fat appears to move from the extremities onto the trunk. Skinfold thickness measurements on the trunk i.e., SISF and SSSF in males and TCSF and BCSF in females have been postulated as being the most accurate in the elderly (Morley, 1988). TCSF and SSSF thickness measurements can be taken in recumbent patients. These measurements are collected with the person lying on the right side. The right arm should be extended at a 45° angle relative to the trunk. The trunk should be in a straight line, and the legs bent at the knees, and tucked up slightly under the trunk. The subjects left arm should rest palm down along the trunk. A line across the acromial process should be perpendicular to the surface of the bed and the vertebral column. The triceps skinfold thickness is taken on the back of the left arm, over the triceps muscle at the level marked as the midpoint of the circumference measurement. Values of repeated TCSF measurements can vary if they are measured at different sites. SSSF thickness is measured just posterior to the inferior angle of the left scapula (Chumlea, 1991).

### 1.2.6 Arm Muscle Circumference

The AMC provides a good estimate of an individuals muscle reserve and can be calculated from the TCSF and MAC using the following formula:

$$\text{AMC (cm)} = \text{MAC (cm)} - 0.3142 \times \text{TSSF (mm)}$$

This formula can also be used with recumbent measurements of MAC and TCSF because of the absence of significant systematic differences between corresponding standing and recumbent measures.

### 1.2.7 Muscle Function Status

Muscle function status may be assessed in a number of ways, for example, by voluntary hand grip, by electrical stimulation of the addicator pollices muscle, or by pulmonary

function testing. Voluntary hand grip has been found to be more sensitive than body composition measurements in the prediction of post operative complications and mortality (Kliajan, 1980). Hand grip can be measured using hand grip dynamometers, which like other anthropometric equipment, should be calibrated regularly.

### 1.2.8 Recumbent anthropometry for the non-ambulatory elderly

There are five anthropometric measurements when assessing the anthropometric nutritional assessment of an immobile elderly patient, namely, KH, CC, MAC, TSSF, and SSSF, which have all been described above. Ideally, measurements should be taken from the left side, because in the formulation of standards, measurements were taken on the left side. However, measurements can be taken from the right side, because the difference between measurements taken from both sides of the body has been shown to be insignificant (Martorell *et al.* 1988).

### 1.2.9 Standard Values

Normal values for stature and body mass derived from large representative samples are available for the young adult population. The most commonly used standard reference values for adults are those devised by Jelliffe and Frisancho. Jelliffes values are derived from measurements of European military men and low-income women (Jelliffe, 1966). Frisanchos values are based on the measurements of white males and females who participated in the 1971-74 US health and nutrition survey (Frisancho, 1981). Many studies have shown that between 20% and 30% of healthy control subjects would be considerably malnourished on the basis of these standards (Hames, 1982; Thuluvath, 1995). However, values below the 5$^{th}$ percentile are often associated with poor clinical outcome. Anthropometric norms representing very large groups of the elderly population are not as common. One set of references used for person's over 75 years are those developed by Burr and Phillips. Burr conducted an anthropometric survey of 1500 people over the age of 75 years in South Wales. There are standards available from this survey for BMI, MAC, skinfold thickness' and AMC for both males and females in a range of age groups from 65 to 85 years and over (Burr & Phillips, 1984). Chumlea *et al.* have also produced sex specific means, standard deviations, and percentiles for BMI for ages 65, 70, 75, 80, 85, and 90 (Chumlea *et al.* 1986). Ideally, reference data needs to be age, sex and geographically specific from a large and representative sample to account for the diversity within the group (WHO, 1995). A recent anthropometric study of elderly Irish males and

females by Clare Corish (*unpublished data, personal communication*) should soon provide appropriate references data for the elderly in the Irish population.

## 1.3 Enteral tube feeding in the community setting

### 1.3.1 Introduction

Many patients require nutrition support beyond the point where their primary disease is stabilised and continued hospitalisation is feasible. The practice of feeding patients by artificial means outside the hospital setting has existed for many years and home enteral tube feeding (HETF) is now well recognised as an important therapeutic procedure. The origins of HETF are much older than those of home parenteral nutrition (HPN) and date back centuries. One of the first records of tube feeding was in ancient Greek and Egyptian times where physicians used rectal tube devices to provide food to patients who were unable to swallow, the foods they used included milk, grain, broths and whey. The provision of oro-gastric feeding was described as early as the 12$^{th}$ century, and by the mid 17$^{th}$ century physicians were using flexible leather catheters to administer feeds nasogastrically (McCamish *et al.* 1997).

In westernised countries, the practice of enteral feeding in the community (in the home as well as in other residential institutions in the community) has increased over the last number of years as result of a number of factors. Firstly, the introduction of the endoscopic procedure for placing gastrostomy tubes without general anaesthesia in 1980 (Gauderer *et al.* 1980) meant the number of gastrostomy tubes placements increased considerably. In fact, the originator of the PEG has said "because of its simplicity and low complication rate, this minimally invasive procedure also lends itself to over utilisation" (Gauderer, 2000). With continually rising hospital costs, the emphasis on home care and returning patients to the primary care setting has also led to an increase in the number patients on tube feeding outside the hospital setting. Lastly, continuing improvements in the design of the equipment necessary for enteral feed infusion and the availability of formula feeds means a return to the community is more feasible for a greater number of patients.

A number of terms and abbreviations describe the use of enteral tube feeding outside the hospital setting, for example, *home enteral tube feeding* (HETF), *home enteral nutrition* (HEN) *home parenteral and enteral nutrition* (HPEN), *tube feeding in the community*, *enteral tube feeding in the community setting* etc. Most authors describe the use of all enteral tube feeding outside the acute hospital as *home enteral tube feeding* (HETF), that is, including both enteral nutrition in the domicile as well as in institutional settings in the community. While the phrase *tube feeding in the community setting* is the most accurate as it describes all tube feeding outside the acute hospital, for the purposes of this thesis, both "HETF" as well as "tube feeding in the community setting" are used interchangeably.

### 1.3.2 Prevalence and growth of home enteral tube feeding

In 1995 Elia described how the extent of HETF in a country can be related to on the expenditure on health in that country, or on the percentage of gross domestic product (GDP) expended on health (Elia, 1995). For example, Western European countries expend approximately 6-9% of their GDP on health care, in the US, it's about 11-12%, but in poorer Asian countries (e.g. India) expenditure on health is only 4-5% of GDP.

The distinction between prevalence and incidence is important. The *incidence* of HETF can be defined as the number of new cases per unit of time (one year), divided by the total number at risk in the beginning of this time period. The *prevalence* of HETF is defined as the number of persons on HETF divided by the number of persons in the population at risk at a particular point in time. This is also known as point prevalence, but more generally just referred to as "prevalence".

#### 1.3.2 (i) United Kingdom

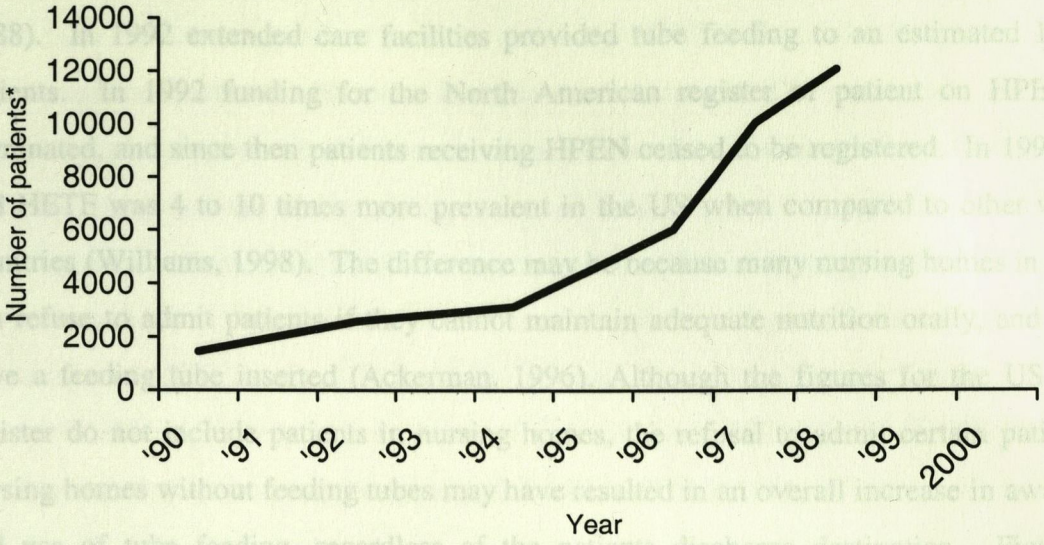
The precise number of patients currently receiving home enteral nutrition in the UK is not known. In 1992, the estimated prevalence of HETF in the UK was between 2000 and 2500 patients (approximately 33-42 per million of the total population). This national figure was based on a combination of industrial estimates, and on extrapolation of survey results from a number of individual districts and regions. In 1994, the estimated prevalence of patients on HETF had increased to between 3000 and 4000 patients (Micklewright, 1996). This constituted a growth rate of more than 25% from 1992 to 1994. In 1996, the annual report of the British Artificial Nutrition Survey (BANS) reported that there were approximately 6000 patients on HETF in Britain. This figure was based on 3 things. Firstly, independent surveys of HETF that were carried out in East Anglia and extrapolated to the whole of the UK, secondly, on industrial estimates, and lastly, on extrapolated BANS data taking into account the types of hospitals taking part in the survey and their bed distribution (i.e. acute and non-acute beds) (Elia *et al.* 1996). In 1998, the annual BANS report stated that there might be as many as 10,000 patients on HETF in the UK, an increase of 25% on the previous years figures (Elia *et al.* 1998). The incidence of HETF may be two or three times greater than the above figures, as during the course of a year, many new patients will start on HETF, while others may die and others will return to normal eating (Elia, 1995).

In 1999, the prevalence of enteral feeding in hospital in the UK was 2.8% (i.e. at any time 2.8% of hospital beds accommodated patients who were enterally fed). The total number of hospital beds in the UK is approximately 325,000, with an occupancy rate of 85%

(approximately 276,000 patients in hospital at any one time). Thus, approximately 7728 patients are on tube feeds in hospital at any one time. This figure was less than the estimated point prevalence of HETF at 12,000 patients in 1999, and therefore, more patients were tube fed outside the hospital setting than in hospital at any one point in time (Elia *et al.* 1999). Recently, however, there has been a reduction in the rate of increase of HETF discharges, at both a local level (Litchfield *et al.* 1998) and at a national level (Elia, 1998).

The reason for the gradual increase over the past few years may in part be due to a general increase in the number of PEG tubes inserted annually (Elia, 1995) as well as a progressive improvement in the support for patients on HETF. Inevitably there is a stage at which the number of patients discharged will reach a plateau or saturation point. At the British Association for Parenteral and Enteral Nutrition (BAPEN) annual meeting in 1998, Marinos Elia, (then president of BAPEN) suggested that the saturation point might be close to being achieved (Elia, 1998). However, the number of patients on home tube feeding at that time (200 per million of the population) in the UK, was lower than the number per million (515) of the population in the US in 1992 (see 1.3.2). Figure 1.3 outlines the increasing numbers of patients on HETF in the UK from the years 1992 to 2000.

**Figure 1.3** Trends in HETF in the UK. 1990-2000




**Figures taken from BANS data*

### 1.3.2 (ii) United States

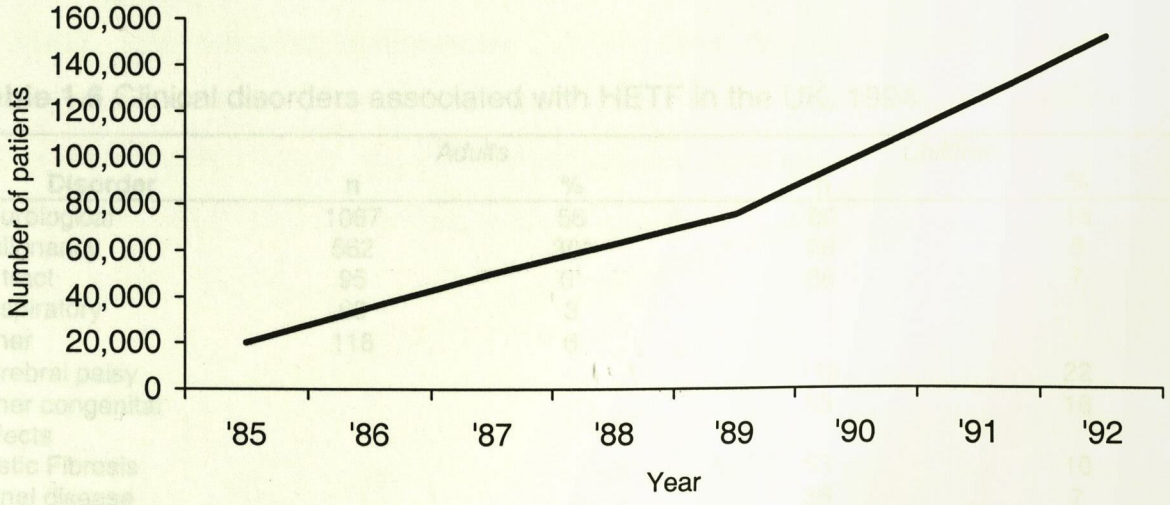
Much of the initial interest in HETF began in the United States. In 1984, when it became apparent that the number of patients requiring HETF was increasing, the North American "Home Parenteral and Enteral Nutrition Patient Registry" was started. The registration of patients receiving home enteral or home parenteral nutrition was not mandatory however, and therefore, the precise number of patients in North America receiving home nutrition was never known. Approximately 15-20,000 patients (~58-77 per million population) were receiving HETF in 1985. At that time, it was estimated that HETF was one of the fastest growing home care therapies. The annual growth rate was 25-30% (Elia, 1994a) and by 1987, around 50,000 patients were receiving HETF.

Indirect measurements are made to estimate the number of patients receiving HETF in the US. The number of registered patients who are Medicare beneficiaries is known, as is the money spent by Medicare annually on home parenteral and enteral nutrition (HPEN), therefore by extraction the approximate number of patients on HETF can be calculated. In 1992, there were 148,000 patients on HETF in the US (Howard *et al.* 1998). This represents a growth rate of 25% per year, which means that about 230,000 patients (about 800 per million population) may have received HETF in 1994 (Elia, 1995).

If the above trend were to have continued, an estimated 280,000 patients would have received HETF in the US in 1996. The figures do not include patients on HETF in extended care facilities, such as nursing homes (Howard, 1993). In 1985, a national

nursing home survey found that 2% of all nursing home residents (or approximately 26,000 patients) were receiving artificial nutrition support mainly as enteral tube feeding (Maslow, 1988). In 1992 extended care facilities provided tube feeding to an estimated 150,000 patients. In 1992 funding for the North American register of patient on HPEN was terminated, and since then patients receiving HPEN ceased to be registered. In 1992 HPN and HETF was 4 to 10 times more prevalent in the US when compared to other western countries (Williams, 1998). The difference may be because many nursing homes in the US can refuse to admit patients if they cannot maintain adequate nutrition orally, and do not have a feeding tube inserted (Ackerman, 1996). Although the figures for the US HETF register do not include patients in nursing homes, the refusal to admit certain patients to nursing homes without feeding tubes may have resulted in an overall increase in awareness and use of tube feeding, regardless of the patients discharge destination. Figure 1.4 outlines the trend in HETF in the US between the years 1985 and 1992, when the North American HPEN Patient Registry, also known as OASIS (Oley-ASPEN Information System) was in use.

**Figure 1.4** Trends in HETF in the US. 1985-1992



### 1.3.2 (iii) Ireland

The number of patients discharged on tube feeding from hospitals in Ireland, is not known. There is no national register of patients receiving HETF in Ireland. Efforts to establish such a register by the Irish Nutrition and Dietetic Institute (INDI) were made, with a view to providing information about patient profiles and numbers discharged into the community annually. However, the interest group involved in setting up the register was disbanded after 3 years of efforts to establish the register, as insufficient funding was secured to meet the projected cost of establishing and maintaining such a register. Since the estimated prevalence of HETF in the UK is 12,000 patients, an extrapolation of these figures for Ireland would predict a point prevalence of approximately 730 patients on HETF with the population estimated to be approximately 3.6 million (CSO, 1996).

### 1.3.3 Indications for HETF

### 1.3.3 (i) United Kingdom: Indications for HETF

In 1990, the Parenteral and Enteral Group (PEN group) of the British Dietetic Association (BDA) established a national register of HETF patients. In 1994, analysis of the register showed that patient's clinical conditions were recorded in 2422 (77%) of records (Micklewright, 1996).

**Table 1.6** Clinical disorders associated with HETF in the UK, 1994

| | *Adults* | | *Children* | |
|---|---|---|---|---|
| **Disorder** | **n** | **%** | **n** | **%** |
| Neurological | 1067 | 56 | 80 | 15 |
| Malignancy | 562 | 30* | 26 | 5 |
| GI tract | 95 | 5† | 36 | 7 |
| Respiratory | 60 | 3 | | |
| Other | 118 | 6 | | |
| Cerebral palsy | | | 112 | 22 |
| Other congenital defects | | | 83 | 16 |
| Cystic Fibrosis | | | 53 | 10 |
| Renal disease | | | 36 | 7 |
| Metabolic | | | 23 | 4 |
| Other | | | 68 | 13 |
| HIV/AIDS | | | 2 | 1 |
| **Total** | **1902** | **100%** | **519** | **100%** |

*(83% of upper GI tract)
† (54% Crohns disease)

Fifty six percent of patients on HETF suffered from a neurological disorder (*n* 1067). Of these patients, a diagnosis of stroke was most common at 52%, MND followed at 14.5%, MS accounted for 11%, brain injury for 6.5% and other diagnoses were 16%. Eighty three

percent of patients with malignancies suffered from malignancies of the upper GI tract. The majority, (54%) of those with non-malignant disorders of the GI tract suffered from Crohns disease. This report showed that the children's group (up to 15 years) exhibited a wide range of conditions requiring HETF (see Table 1.6).

In 1996, the first BANS report (Elia *et al.* 1996) was published and described those patients registered between January and October 1996. The indications for HETF reported in this survey were similar to those in published in the PEN report of 1994. While the categorisation of indications for feeding is somewhat different, swallowing disorders remain the primary indication for feeding in adults (84.5%) and failure to thrive in children (50.7%).

A survey to establish the profile of patients receiving HETF in East Anglia was carried out in 1993. One hundred and ninety-one patients were surveyed in detail; this included 117 adults and 74 children (Parker *et al.* 1996). Sixty-four percent of adults and 38% of children were suffering from neurological diseases, while 11% of adults and 23% of the children required HETF due to diseases of the GI tract. A number of single unit surveys and audits have been published which describe the indications requiring HETF in centres, for example, Hull *et al.* (1992) have presented an audit of 22 patient years of home enteral nutrition using PEG, found 32% of adults required HETF following stroke, 28% as a result of MND, 15% following malignancies. While these reports are useful, the most comprehensive overview of the indications for HETF is found in the annual BANS report. The BANS report (Elia *et al.* 1999) described the distribution of diagnosis among registered patients on HETF according to age (see Table 1.7).

**Table 1.7** BANS 1999: Distribution of diagnosis among registered patients on HETF

| | 0-15y (*n* 2832) % | 16-54y (*n* 2379) % | 55-64y (*n* 1197) % | 65-74y (*n* 1990) % | >75y (*n* 2448) % |
|---|---|---|---|---|---|
| Cerebral Palsy | 19 | 7 | 0 | 0 | 0 |
| Congenital handicap | 13 | 3 | 1 | 0 | 0 |
| Cystic fibrosis | 9 | 7 | 0 | 0 | 0 |
| Congenital malformation | 5 | 0 | 0 | 0 | 0 |
| IEM* | 4 | 0 | 0 | 0 | 0 |
| Cerebral trauma | 2 | 8 | 3 | 3 | 1 |
| Failure to thrive | 2 | 0 | 0 | 0 | 0 |
| Stroke | 1 | 6 | 24 | 44 | 65 |
| Cancer: oesphageal | 0 | 9 | 18 | 14 | 4 |
| Oropharyngeal | 0 | 3 | 9 | 4 | 2 |
| Gastric | 0 | 1 | 1 | 1 | 0 |
| Head & neck | 0 | 1 | 1 | 1 | 0 |
| Other | 1 | 1 | 1 | 2 | 1 |
| MS | 0 | 20 | 8 | 2 | 2 |
| MND | 0 | 3 | 7 | 6 | 4 |
| Parkinson's disease | 0 | 0 | 4 | 4 | 1 |
| Dementia | 0 | 0 | 1 | 2 | 4 |

**Inborn errors of metabolism*

### 1.3.3 (ii) US: Indications for HETF

The use of HETF for patients with malignant disease is higher in the US and accounts for the main difference in the indications for HETF between the UK and the US (Elia, 1995) (see Table 1.8). In 1986, Nelson *et al.* published a report documenting the results of a pilot home enteral nutrition support programme from the Mayo Clinic in Minnesota (Nelson *et al.* 1986). One hundred and forty four patients had been referred to the programme in 1985. In this particular centre, malignant disease accounted for almost half of the patients discharged on HETF, while neurological impairment resulting in dysphagia or alteration in GI motility accounted for 40% of the group. Between the years 1985 to 1992, 3931 patients were reported to the American HETF register. Patients with cancer and those with neuromuscular swallow disorders made up the majority of patients at 42% and 29% respectively. Of the remaining 29% of patients 21% had nutritional depletion from other causes, and the remaining 8% suffered from small bowel malabsorption.

Other surveys in the US have also documented malignancy as a more common indication for HETF than neurological diseases (Howard *et al.* 1986). Malignant disease of sites other than those causing GI obstruction are treated with HETF as often (Elia, 1994a), unlike in the UK, where in 1994, Micklewright reported 83% of those patients on HETF with malignant disease to be suffering from malignancies of the GI tract (Micklewright, 1996). The precise differences in diagnostic indications for HETF between the US and the UK are difficulty to ascertain because of the different classification of patient disease states in the registers in each country, however, there is a distinct difference in terms of

proportions of patients on HETF with malignancies. The reason for the differences in diagnostic indications for HETF in the UK and US are unclear, but may be due to different attitudes about selection criteria for HETF in the two countries (Elia, 1994a). There is, perhaps a more aggressive attitude toward the treatment of cancer in the US. In many European countries, there appears to be a greater reluctance to use enteral tube feeding for older patients suffering from malignancy. The difference may also be due to different registration criteria, as patients in long term care were not included in the US register, the proportion of US patients seen to require HETF due to cancers may be falsely raised.

**Table 1.8** Comparison of indications for HETF in the US and the UK

| **Indication for HETF** | ***US (1985-1992)** *% Adults & Children* | **UK † (East Anglia, 1995)** *% Adults & Children* |
|---|---|---|
| *Cancer* | 42 | 14 |
| Head & neck | (15) | --- |
| Oesophageal | (8) | 13 |
| Gastric | (5) | --- |
| Other GI tumours | (5) | 1 |
| Leukaemia, lymphoma | (2) | --- |
| Other tumours | (7) | --- |
| *Neuromuscular disorder* | 29 | 53 |
| Stroke | --- | (9) |
| Other neurological disorders | --- | (45) |
| Small bowel malabsorption | 8 | 4 |
| Nutritional depletion, other causes | 21 | 15 |
| Total number studied | ***3931*** | ***191*** |

* Howard *et al.*, 1998
† Parker *et al.*, 1996

### 1.3.3 (iii) Ireland: Indications for HETF

No information is available in the literature regarding the indications for HETF in Ireland. In a pilot study to examine enteral tube feeding in nursing homes in the Eastern Health Board (EHB) region, 80% of those surveyed suffered from stroke, and the remainder from other neurological diseases affecting swallow processes (O'Connor, 1996). A report of the results of PEG insertion from a single Irish unit series found that 39.5% of the first 44 PEGs inserted in the hospital were inserted following stroke, 34.4% following brain tumours or head injury, and the remainder as a result of dementia (9%) and other indications (18.4%) (Pender *et al.* 1993).

### 1.3.3 (iv) Indications for HETF in other countries

The main indication for HETF in Austria and Germany is reported to be neurological disorders of swallowing, which account for 90% or more of the patients there. Malignant disease is an uncommon indication for HETF in these particular countries. In contrast 60% of all Italian patients on HETF suffer from malignant disease (Gaggiotti *et al.* 1995), and in Switzerland the proportion of patients on home enteral tube feeding who suffer from malignant disease of the upper GI tract is 70% (Weberhofer, 1996). In Spain, home enteral nutrition is used more frequently in patients with cancer (39%) than in patients with neurological disease (33%) (Gomez Candela *et al.* 1999).

While countries may vary in the proportions of patients of particular types who receive HETF, the main diagnostic categories remain the same, stroke and malignant disease in adult patients, and neurological diseases in children.

### 1.3.4 Demographics and functional status

In 1996, the annual BANS report stated that 28% of the patients registered between January and October 1996 were children (<16 years), 33% were aged between 16 and 65 and 39% were over 65 years of age (Elia *et al.* 1996). Information on gender distribution was not given in this report, but in 1998 the distribution was 52.4% males and 47.6% females (*personal communication, Doug Scott, BANS*). In 1997 the percentage of children in the group of patients registered had appeared to fall to 17% and in 1998 it had dropped to 13.4% (Elia *et al.* 1998). The actual number (prevalence) of children receiving HETF over the 3 years increased, from 2026 children in 1996 to 2832 in 1998. However BANS only reports on patients registered and not all patients are registered, although, the number of participating centres and patient registrations have grown over the three years. In terms of the prevalence numbers, the BANS data collection system relies on reporters correctly updating the database when the patient discontinues HETF or changes status. While most centres are very good at this a few are not, which can skew the reports (*personal communication with Doug Scott, BANS*). The proportion of patients discharged on tube feeding to extended care facilities (special schools for the disabled and nursing homes) was 14% in a study carried out in East Anglia (Parker *et al.* 1996).

Information on 1015 patients referred to the Mayo Clinic (US) programme from 1983 through to 1988 showed that 56% of the patients were male, and 44% female. The majority of patients (51%) were aged 61-80 years. Only 6% of patients were aged 0-20 years, in contrast to British data. Thirty three percent of US HETF patients were aged

between 20 and 60 years, while only 24% of UK patients on HETF came into this age range (Nelson & Fleming, 1990). The proportion of patients on community tube feeding that live in nursing home in the US is approximately 54% of the total, with 8.9% of all nursing home residents in New York State receiving tube feeding (Howard *et al.* 1998). The reasons for the difference in the age distribution of patients on HETF is in the US and the UK are not certain, but may be due to different selection criteria for patients in the 2 countries (Elia, 1996).

The main indications for home feeding in adults, stroke and cancer, suggest that adult patients are older, debilitated, or suffering from terminal disease. A survey of patients (*n* 191) in East Anglia found that speech was normal in only 29%, 38% required 24 hour aid and 9% were totally house bound. Only 1% of the sample worked full time and 14% attended school or adult education (Parker *et al.* 1996). The 1994 report on the British HETF register found that only 20% of patients whose status was recorded were able to carry out normal activities of life (Micklewright, 1996). Twenty six percent of the sample were confined to their house, and needed assistance with their HETF. Eleven percent of the sample was confined to bed, and 4.5% were either semiconscious or totally unconscious. The BANS report of 1996 showed similar results with respect to patient profiles. Only 14.6% of adults were capable of full normal activity, although 40% of children were capable of the same. Forty-five percent of adults were either house bound or bed bound, as opposed to 29% of children (Elia, 1996).

In conclusion, patients on HETF tend to be either very young or very old and many live in care facilities and suffer from debilitating diseases.

### 1.3.5 HETF patient outcomes

The *outcome* of patients on tube feeding outside the acute hospital can be examined in terms of survival rate or length of time spent on the treatment, changes in nutritional status, complication rates experienced and quality of life.

### 1.3.5 (i) Patient Survival Rate

After discharge from the acute hospital setting, patients on tube feeding either remain on the tube feed until death or resume oral feeding after a period of time and have the tube removed electively. In their study of patients on HETF in East Anglia, Parker *et al.* (1996) found that during the one year study period, 110 patients were receiving HETF at any one time, but that over the course of the year, twice as many patients (220) had received HETF. This is because during the year, some patients resumed oral feeding, others died, while some patients continued to be supported on HETF and others commenced on HETF for the first time. Because twice as many patients received HETF over the year than the actual number on HETF at any one time, the average length of time on feeding was 6 months. Unfortunately, this particular study was too short to extrapolate survival rates in different groups of patients.

In a two year prospective study of home artificial nutrition support in Cambridge Weekes *et. al.* (1992) found that over the course of the two years, 46% of the HETF patients died, 27% returned to their normal eating pattern, and 27% continued on HETF at the end of the study period. In a further audit of the outcome of adult patients in the same district, Dewit (1999) described how the overall mortality while on HETF is highest in patients with cancer of the oesphagus/oropharynx. Return to full oral feeding is unlikely in patients with MND and MS, whereas in patients with stroke it occurs in an increasing proportion of patients.

Raha and Woodhouse (1994) followed 161 elderly patients who had a PEG inserted either until death or until the gastrostomy tube was no longer required. The main indication for PEG was stroke (81%). Only 12% of tubes were removed electively after a mean of 99 days (45-365 days) as these patients had regained their swallow. The 3-month fatality rate in this group of elderly patients (mean age 79 years) was 39%. Wanklyn *et al.* (1995) reviewed the medical records of all stroke patients who had required a PEG in 4 hospitals in West Yorkshire over a 30-month period. Thirty-seven records were obtained. The median survival rate from the time of PEG insertion was 53 days (range 2-528 days) with only 12 patients (32%) surviving more than 3 months.

In 1993, the Oley Foundation report (US) reported a high mortality rate for HETF patients, which depended highly on the severity of the underlying condition. They reported a 70% mortality rate at one year for patients with neoplasm, and a 45% mortality rate at one year for patients with the neurological disorders of swallowing. Only 15-25% of patients were found to resume oral nutrition 6 months (Oley Foundation, 1993). In 1993, it was reported that only 32% of cancer patients survived one year on HETF compared to 60% of patients with neurological diseases of swallowing (Howard, 1993).

In 1997, Howard and Malone investigated the clinical outcome of geriatric patients in the US receiving home parenteral and enteral nutrition. They found that geriatric patients with swallowing disorders had a poorer outcome than younger patients after a one-year follow up in terms of lower survival and fewer patients resumed oral feeding (Howard & Malone, 1997).

There is little data on the length of time spent by children on HETF, however one study of children on HETF in the West of Scotland found that over the course of one-year 43 patients (out of a total of 156 patients) discontinued HETF. Nine children had died, 30 no longer required feeding and 4 children were transferred to other centres. The mean length of time spent by these children on HETF is not stated however (McCarey *et al.* 1996).

A comprehensive study of the long-term outcome of patients on home tube feeding was presented at the American Society for Parenteral and Enteral Nutrition Meeting 2000 by Hebuterne *et al.* (2000). They described the outcome of 417 patients who were discharged from an Italian hospital between 1990-1996. Probabilities of being alive at one and five years were 41.7% and 25% respectively. The 5-year survival rate for children was 80.8%, for patients aged 16-70 it was 34.3% and for patients over 70 years it was only 10.7%. After a follow up of 24 to 103 months, 300 of the 417 patients had died (72%), 109 (26%) were alive and 2% had been lost to follow up. Twenty percent of patients died during the first month of home tube feeding.

In the 1999 BANS report, details of patient status following discharge on HETF were outlined. The results are summarised in Table 1.9.

**Table 1.9** Patient status at 1 year after starting HETF (BANS 1999)

| Diagnosis | N | Died | Withdrew/ refused HETF | Returned to oral diet | Continued on HETF |
|---|---|---|---|---|---|
| | | % | % | % | % |
| All | 8832 | 22.4 | 2.0 | 13.6 | 62.0 |
| Stroke | 2466 | 27.8 | 1.1 | 13.9 | 57.2 |
| MND | 393 | **59.7** | 1.7 | 0.3 | 38.3 |
| MS | 369 | 11.0 | 0.6 | 3.4 | 85.0 |
| Parkinson's disease | 143 | 37.4 | 2.2 | 6.6 | 53.8 |
| Dementia | 129 | 38.0 | 1.4 | 15.5 | 45.1 |
| Cancer | | | | | |
| Oesophageal cancer | 1086 | 39.5 | 3.7 | 25.1 | 31.7 |
| Oropharyngeal cancer | 188 | 21.6 | 2.0 | **29.4** | 47.0 |
| Gastric cancer | 87 | 55.1 | **5.8** | 20.3 | 18.8 |
| Cerebral palsy | 451 | 5.0 | 0.6 | 4.7 | 89.7 |
| Cerebral trauma | 257 | 11.2 | 0.5 | 9.2 | 79.1 |
| Congenital malformation | 112 | 8.8 | 3.3 | 12.1 | 75.8 |
| Congenital handicap | 281 | 4.4 | 1.3 | 1.8 | **92.5** |
| Crohn's disease | 216 | 2.3 | 3.5 | 29.1 | 65.1 |
| Cystic fibrosis | 324 | 5.4 | 1.1 | 5.4 | 88.1 |

*Highest percentages highlighted in bold*

Table 1.9 shows that over half of the patients on HETF with MND and gastric cancer have died before completing 1 year on therapy. Nearly 30% of patients with Crohn's disease and oropharyngeal cancer return to oral diet, and over 90% of patients with congenital handicap are still receiving HETF after 1 year on therapy.

### 1.3.5 (ii) Nutritional status of HETF patients

#### Nutritional status of adults on HETF

Studies of adult patients with CF on HETF have shown improved nutritional status in terms of weight gain, improved lean body mass and composition, increased activity and stabilisation of pulmonary function, plus improved sense of well being (Smith *et al.* 1994). In adults with diseases of the GI tract, increases in weight have been found, as well as increases in lean body mass in adults (Heymesfield, 1983). In adults with HIV, PEG feeding can lead to increased weight gain and subsequent improvements in quality of life (Crotty *et al.* 1998). Newmark *et al.* (1981) found that in a group of 23 patients on HETF (most with malignancies) 20 gained an average of 3.2kg body weight and their serum albumin increased by a mean of 0.6gm / dl over a period of about 2 months whilst being tube fed at home.

The poor functional status of many adult patients on HETF with neurological impairment (for example following stroke or as a result of MND or MS) has already been described (see 1.3.5). The difficulties in nutritionally assessing this group of patients have been

described by Bannerman *et al.* (1999). In a study of 46 nursing home residents Kaw and Sekas (1994) found no improvement in either functional or nutritional status in patients with PEGs (93% of the survey group required PEG due to neurological cause). In contrast, Park *et al.* (1992) found a mean increase in weight of 3.4kg from baseline in patients with persisting neurological dysphagia, in addition to improvements in TSSF and MAC. Similarly, Britton *et al.* (1997) found a mean weight increase of 9kg following PEG insertion in patients with neurological disease. In the pilot study to examine the current status of HETF in the Dublin region, O'Connor found that 80% of those patients assessed were receiving their minimal nutritional requirements, while 20% were not receiving their minimal nutritional requirements in their feed. Forty-two percent of the sample assessed was underweight, 25% were overweight, and 33% were within their ideal body weight range, as determined by desirable BMI range for sex (O'Connor, 1996).

### Nutritional status of children on HETF

Holden *et al.* (1991) looked at the acceptability and safety of nasogastric feeding for children at home. The nutritional status of the children involved in the study was measured at the start and at the end of the period on HETF. They reported an improvement in the nutritional state (in terms of weight for age centile, MAC centile and AMA) in all patients (*n* 70) after HETF. The indications for nutritional support in this group was varied, and included chronic renal failure, cardiac disease, cerebral palsy, liver disease and Crohn's disease.

Other authors have found similar improvement in catch up growth in children on enteral feeding (Kang *et al.* 1998). Papadopoulou (1995) has found HETF to be an effective method of nutrition support for a variety of medical conditions in children, provided there concurrent advice from a nutrition care team is available. Other studies report improved nutritional status in terms of weight gain, improved lean body mass and composition, increased activity and stabilisation of pulmonary function, plus improved sense of well being in paediatric CF patients on HETF (Courtney Moore *et al.* 1988; Levy *et al.* 1985; Boland *et al.* 1986). In patients on HETF with diseases of the GI tract, weight gain has been reported, as well as increases in lean body mass in children (Morin *et al.* 1980). Rempel *et al.* (1988) found that gastrostomy feeding in children severely affected by cerebral palsy can improve nutritional status but does not eliminate growth retardation. An American study showed that for neurologically impaired children with gastrostomy tubes,

TSSF may be a more sensitive clinical indicator of nutritional status change after tube placement rather than weight and height measurements (Isaacs *et al.* 1994).

### Micronutrient status of patients on HETF

McWhirter *et al.* (1994) found that patients receiving nutrition support at home may be at risk of protein energy malnutrition and regardless of their indication for HETF, anthropometric measurements or duration of feeding, are at risk of developing vitamin or trace element deficiency. In 1994, Tamura *et al.* described a patient on long term enteral tube feeding who developed neutropenia due to copper deficiency. It has been reported that patients receiving long-term HETF show sub-optimal circulating concentrations of vitamins D and C (Baldwin *et al.*, 1997). In a study of 55 patients (32 still feeding via the PEG and 23 who had resumed oral intake) Bannerman *et al.* (1999) found that 53% of individuals on HETF presented with biochemical evidence of micronutrient deficiency (magnesium, selenium, copper, zinc vitamins A, D, E were measured). Conversely, a more recent survey of 28 disabled patients on long term feeding has found that no patients were deficient in circulating concentrations of vitamins D, C and thiamine (Dewit, 1999a).

## 1.3.5 (iii) HETF complication rates

### HETF complication rates in adults

Major complications associated with HETF are rare. A survey of adults on home tube feeding in the US found that all patients had experienced access problems (e.g. tube blockages, tube dislocation, equipment malfunction etc.). Fifty two percent of these problems were resolved in the home; the remainder required more extensive attention. Similarly, all patients reported experiencing tolerance problems (e.g. constipation, nausea and fullness), however 85% of these problems were treated in the home (Nelson *et al.* 1986). Six years later, a study of 97 patients on HETF in Minnesota found that 20% experienced wound infection in the community, and the most common complication was tube dislodgement, with 41% of patients experiencing this problem (Taylor *et al.* 1992). A recent Spanish study over 2760 patient days on HETF found that GI complications were more prevalent in patients fed via gastrostomy, and tube blockage and dislocation were more common in nasogastrically fed patients. Only 1 major complication was noted (Candela *et al.* 2000).

A study of 19 patients on HETF in Cambridge over a 2-year study period found 62 instances of patho-physiological disturbances (fullness, flatulence, constipation etc.) and 10

instances of tube blockage (Wilcock *et al.* 1991). Parker *et al.* (1996) found that the incidence of tube feeding related complications in the community was directly related to the number of dietitians (per million of the population) working in the hospitals where the HETF was initiated and co-ordinated. In the areas with most dietitians there was a higher proportion of patients home tube feeding, and a lower proportion of patients whose feeding tubes became blocked. There were also a lower proportion of patients with blocked tubes who required medical attention in hospital.

In 1996, O'Connor found that 52% of a sample (n = 25) of HETF patients in Dublin had experienced trouble with their stoma site, 48% had experienced diarrhoea, and 44% had experienced blocked tubes. Thirty six percent of the sample required a hospital visit to deal with the problems encountered during feeding (O'Connor, 1996). Similarly, in the North of Ireland, problems with tube blockages were reported by 59% of patients (although patients and or carers had a good knowledge of how to clear blockages) and diarrhoea was a problem for 44%. A very high proportion of the sample (70%) reported experiencing irritation around the stoma site (L'Estrange, 1997).

### HETF complication rates in children

Holden *et al.* (1991) reported finding no incidences of major complications such as aspiration, hypoglycaemia after feeding, or entanglement of tubing after 11,041 days of home enteral nutrition in 70 paediatric patients. Other studies of paediatric patients have found tube feeding to be successful with low complication rates in a number of different patient types such as cancer (Pedersen *et al.* 1999), CF (Levy *et al.* 1985; Rosenfeld *et al.* 1999; Williams *et al.* 1999), cerebral palsy (Sanders *et al.* 1990), Crohns disease (Aiges *et al.* 1989; Cosgrove & Jenkins 1997), neurologically impaired children (Sulaeman *et al.* 1998), and ureamic children (Strife *et al.* 1986) as well as a mix of diagnostic indications (Holden *et al.* 1991; Popadopoulou *et al.* 1995; Behrens *et al.* 1997; Kang *et al.* 1998). Conversely, some authors have found that PEG in paediatric practice is associated with significant morbidity, and should be considered a major undertaking (Khattak *et al.* 1998), while others have found that paediatric patients with cancer or AIDS are at risk of complications after endoscopic gastrostomy regardless of weight or nutritional status (Fox *et al.* 1997).

In conclusion, it is generally well accepted that HETF is a safe therapy, in which some minor, but few serious complications are encountered. Successful HETF will depend

highly on the pre-discharge planning and education of the suitable candidate and on the post-discharge management of patients on HETF (see 1.3.8 & 1.3.9).

### 1.3.5 (iv) Quality of Life on HETF

Quality of life encompasses a broad range of physical and psychological characteristics and limitations that describe a person's ability to function and acquire satisfaction in doing so.

#### Adults: Quality of Life on HETF

Park *et al.* investigated the practical aspects and patient compliance of long-term home enteral nutrition and concluded that most patients (the majority of whom had Crohn's disease) had an improvement or stabilisation in their lifestyle when on HETF (Park *et al.* 1988). Nelson *et al.* (1990) looked at the quality of life experienced by a group of HETF patients in Minnesota (*n* 53). Most of these patients suffered from malignancies or progressive deteriorating diseases. Forty-one patients (77%) reported that their quality of life was poor prior to initiation of HETF. Over half (*n* 27) reported that HETF improved their quality of life; while 39% of patients (*n* 21) stated that it maintained their quality of life. Patients felt that home feeding allowed return of a more normal lifestyle, despite the demands that the therapy placed on their daily routine. Twelve percent reported that HETF resulted in a deterioration in their quality of life. The demands of tube feeding appeared to offset the benefits of treatment in these patients.

Despite the reported improvements in quality of life in patients on tube feeding as outlined above, the profile of adult patients on HETF shows that the majority are elderly, with chronic debilitating illnesses, and a very limited physical capacity. Fifty-three percent of adult patients on HETF require total help, while only 17% are independent (Elia *et al.* 1996). The mortality of this group is high; at least 1 in 3 of these patients die within 1 year of starting such treatment, as illustrated in Table 1.9. Bannerman *et al.* (1998) highlighted the difficulties in trying to assess the quality of life of adult PEG patients using a standardised health related quality of life index. In a prospective study to examine health related quality of life and nutritional outcomes after PEG, at one month 73% of patients felt that they could cope with the PEG, and at 6 months all patients felt they could cope and were confident with the care of the PEG (Bannerman *et al.* (1999a).

In a retrospective review of 25 patients who had undergone PEG, a questionnaire was administered to patients, or in the majority of cases, the primary carer. Of the 21 surrogates interviewed, 33% were uncertain that proceeding to nutritional support via PEG had been the right decision. The authors conclude that the findings indicate a need to improve the

process by which decisions to treat with PEG are made, ideally, including better prognostic information (Van Rosendaal *et al.* 1997).

Howard and Malone (1997) investigated the clinical outcome of geriatric patients in the US receiving home parenteral and enteral nutrition. They found that geriatric patients with swallowing disorders had a poorer outcome than other patients in terms of poorer rehabilitation after a one-year follow up. Raha and Woodhouse (1994) found a 3-month fatality rate of 39% in a group of elderly patients. While the authors recognise that the outcome in their group of frail patients was poor, they believe that providing them with a route of hydration and nutrition that is comfortable significantly improved their quality of life in their last weeks and made their nursing care much easier. Wanklyn *et al.* reviewed the medical records of stroke patients who had required a PEG. Only 32% of patients survived more than 3 months. The six patients who were still alive at the time of the study were assessed and all but one of these patients were severely disabled. Again, the authors recognise the poor outcome of their patients and ask, "if the majority of stroke patients do not have prolonged survival after PEG, are there any reasons for continuing to use this method of treatment?" The conclude however, that PEG in these patients is justified, as it can ease the concerns of carers and ward staff, provide relief from hunger, and improve the nutritional state to allow for rehabilitation and increased function (Wankyln *et al.* 1995).

In a pilot survey carried out to investigate the current practices with respect to HETF in nursing homes in Ireland carers (n = 25) were asked, "Do you think the patient has a good quality of life on HETF?" Eighty four percent of carers responded "yes", 12% responded "no", and 4% preferred not to comment on the issue (O'Connor, 1996).

The ethical issues involves in tube feeding particular types of patients are outlined in greater detail in Section 1.5

### Children: Quality of Life on HETF

In contrast to adult patients on HETF, 69% of children (under 16 years) on HETF have either full (40%) or limited (19%) physical activity level. Only 2.1% of paediatric patients are unconscious and 8.2 % bed-bound (Elia, 1996). Borowitz *et al.* (1997) found that all parents *(n* 19) in a survey would recommend PEG to families with disabled children, and Tawfik *et al.* (1997) found out of a sample of 29 parents of neurologically impaired children, only one regretted the gastrostomy insertion. In fact, Moukarzel *et al.* (1994) have stated that a period of as short as 10 days justifies the time and expense of setting up home enteral feeding, due to its social, emotional and financial benefits over tube feeding in the hospital environment. In terms of improving the quality of life of children on home

tube feeding, Firth *et al.* (2000) showed, not surprisingly, that a ambulatory pump with a long battery life and a shorter recharge time significantly improved the overall quality of the child's life on home tube feeding, by allowing more independence than static shorter battery life pumps.

### 1.3.6 Selection of candidates for HETF

The decision to provide tube feeding outside the hospital setting should be carefully considered. Prolonging the life of terminally ill patients who are suffering, for example, may not be appropriate (see Section 1.5). Oral intake should be insufficient to meet patient's requirements (generally accepted to be the persistent consumption of less than 1000kcals and 30gms of protein daily) and the clinical state should be sufficiently stable for HETF. The treatment should be likely to be required for a sufficiently long period to justify its use (about 2 to 3 months). There must be consent by patients (and/or relatives if necessary) to this form of treatment, and patients and/or caregivers must agree to undertake HETF and demonstrate ability to perform necessary procedures to acceptably high standards. The patient's home environment should be suitable for the purposes of HETF, and the use of HETF should be likely to produce benefit or prevent deterioration (Elia, 1995). Callahan *et al.* (1999) provide an insight into the complexity of the decision making process regarding the use of PEG amongst older adults. They document a decision-making environment characterised by uncertainty, and a societal norm of the presumed obvious benefit of the procedure. They conclude that the climate of decision making for PEG is unlikely to change without clear and compelling evidence that particular groups of patients either do not benefit from the procedure or are actually harmed by the procedure.

The suitability of the home environment for HETF needs to be discussed with the patient and carers before the patient is discharged. A home visit may be organised in some centres before discharge. The general requirements for successful HETF are a clean sink and work surface area, a well positioned electrical socket for the pump plug, a telephone, a storage area for the feed and equipment away from direct sunlight and extremes of heat (Arrowsmith, 1994).

While screening patients for discharge, the physical facilities and the attitudes and availability of caretakers must be evaluated. If a supportive home environment is not available, successful management of the patient becomes more difficult (Bloch, 1994). Often, assessment of the home environment can lead to changes being made in the feeding regimen to suit the lifestyle of the patient and/or carers (Elia, 1994b).

### 1.3.7 Psychological aspects of tube feeding

Mothers caring for children with disabilities who require a gastrostomy tube have described how they spent enormous time and energy seeking confirmation of the feeding problem and devising extraordinary practices to ensure the child's survival before "giving in" to the gastrostomy tube. After tube insertion, they initially feel "relief" and "disappointment" before customising feeding and moving on (Spalding & McKeever, 1998). An American study found that mothers of children requiring tube feeding experienced greater stress than mothers of children who did not require tube feeding, and lack of free time was mentioned as one of the greatest stresses (Adams *et al.* 1999). Michaelis *et al.* (1992) found that the problems identified by parents of children on home tube feeding as most common and difficult were often in the social rather than the medical realm. A study of children with cerebral palsy found that 86% of carers would have started tube feeding earlier had they known the beneficial effects. The authors also noted that it was their (unqualified) impression that the children of unsatisfied caregivers were at a higher functional level with fewer reasons for tube feeding (Smith *et al.* 1999).

Children need to be psychologically prepared for enteral feeding. Dolls and teddies with enteral feeding tubes attached, photos of other children receiving enteral feeds, coloured booklets, reward stickers and certificates are helpful in making enteral feeding a more acceptable process (Holden, 1990). Other authors have suggested that children should be encouraged to sit at the family meal table when taking enteral nutrition (Sidney & Torbet, 1995). A survey that examined the psychological preparation for nasogastric feeding in children found that detailed psychological preparation of families takes time. Children aged between 7 and 16 years who received detailed psychological preparation were better prepared for enteral feeding at hospital and at home and the passing of nasogastric tubes - although unpleasant - was significantly less distressing to them than those children who received standard formal preparation (Holden *et al.* 1997).

In a survey of 70 families with children on nasogastric feeding in the home 34 families reported that their child appeared happier and more active on tube feeding. A similar number reported that HETF gave them a new sense of freedom (mostly due to a reduction in the time spent on trying to get the child to eat). Older children were self conscious and inhibited about going out. Many reported being teased by their peers. This problem was prevented by teaching them to pass their own tubes at night time and remove them in the morning (Holden *et al.* 1991).

### 1.3.8 Microbial aspects of HETF

Enteral feeds prepared in the home environment can be contaminated in a similar way and by similar routes to other foods prepared in the home. Enteral feeds are nutritionally complete, and therefore support microbial growth. Feeding in a warm home environment provides the conditions necessary for the rapid proliferation of contaminating organisms. Bacteria can then multiply to levels that are hazardous to compromised patients and children. A pilot study on HETF carried out by Shaw *et al.* (1997) found that not all hygienic procedures for administrating feed were followed by patients and carers, and that the type and extent of bacterial contamination of feed occur in the giving set, with bacterial counts similar to those observed in the hospital setting (Kohn, 1991). It is important that both patients and their carers understand the potential sources of microbial contamination and take precautions to minimise them. The microbial aspects of HETF should be made clear to patients and carers during their education before their discharge into the community (Anderton, 1990). The basic hygienic precautions that should be followed when preparing feeds are described in Table 1.10.

**Table 1.10** Basic hygienic precautions in the preparation of enteral feeds*

| | |
|---|---|
| **Selection and handling of feeding solutions and feeding systems** | 1. Disposable giving sets should only be used once, and the design selected should be one that requires minimum manipulation during the assembly and administration of the feed. |
| | 2. Pre-packed, sterile, ready-to-use feeds requiring minimal manipulation should be used in preference to feeds requiring reconstitution, dilution, additions, or decanting. |
| | 3. If feeds must be decanted, the outsides of the can or bottle should be wiped clean and disinfected prior to opening. |
| | 4. A delay between the preparation and the administration of feeds should be minimized; and unused feed in open containers should be covered and stored in the top shelf in the refrigerator at less than or equal to 5 degrees Celsius for a maximum of 24hours and feeds should never be stored below products such as raw or thawing meat or fish, because blood may drip onto the feed container. |
| **Personal and environmental hygiene** | 5. Raw foods such as meat, eggs, fish, should never be handled in close proximity to enteral feeding solutions or feeding systems. |
| | 6. Waste water from flower vases, aquaria, and nappy buckets, should be disposed of down the toilet, and not down the kitchen sink. |
| | 7. Pets and insects should not be allowed access to the feeding solutions or systems. |
| | 8. The sink, taps, and work surfaces should be cleaned and disinfected prior to preparing and handling the feeding systems, particular care should be taken to use the concentration recommended by the manufacturer. |
| **Anderton (1990)* | 9. Where possible, disposable gloves should be worn when preparing feeds, and assembling and manipulating systems, but if this is not practicable, hands should be thoroughly washed and disinfected. |

### 1.3.9 Organisations involved in HETF

In response to the growing needs of HETF patients, support groups for patients and their carers have developed, especially in those countries where the number of patients is large.

### 1.3.9 (i) BAPEN: The British Association for Parenteral and Enteral Nutrition

BAPEN is a registered English charity, which was set up by a group of health professionals in 1992 as a result of recommendations made by the Kings Fund Report "*A Positive Approach to Nutrition as Treatment*" (Lennard-Jones, 1992). BAPEN's aim is to improve the nutritional treatment of all sufferers from illness who have become, or are likely to become malnourished, and who are unable to consume or absorb normal foods in quantities necessary to effect recovery. In achieving their aims, BAPEN set standards of clinical practice in nutrition support; they educate and train health care workers, patients and policy makers in the prevention of malnutrition during illness. BAPEN have developed standards of practice in the area of HETF (Elia *et al.* 1994b). Disappointingly, Whittingham (1996) audited 9 hospitals in the West Midlands and found an overall conformance of less than

50% to the BAPEN standards, however Hughes & Lloyd (1998) found a 94% conformance in a health district in Wales. BAPEN promote research and has a number of sub-groups or working parties, one of which is involved in enteral and parenteral nutrition in the community.

### 1.3.9 (ii) **BANS**: British Artificial Nutrition Survey

BAPEN established a multidisciplinary working group that launched the British Artificial Nutrition Survey in early 1996. The overall aim of BANS is to audit and research nutritional care in hospitals and in the community in order to improve the quality of nutritional support for patients at risk of disease related malnutrition. The BANS group produce reports on the information received regarding HETF received from various Health Trusts who partake in the survey.

### 1.3.9 (iii) **PINNT**: Patients on Intravenous and Nasogastric Nutrition Therapy

When first formed, PINNT was predominantly a group for patients on intravenous therapy, where patients on home parenteral nutrition made up the majority of its full members. However, the number of patients on home enteral nutrition who are members of the group is steadily increasing (Carter, 1993).

### 1.3.9 (iv) **LITRE**: Looking Into The Requirements of Equipment

This group is a committee, which was originally a subgroup of PINNT, but became a working party of BAPEN in April 1994. Since then, its members have continued to identify problems with equipment that patients are experiencing and have been striving to find ways to resolve these issues. The work involves looking at the needs of patients on intravenous and gastrostomy feeding, with respect to the equipment necessary for these therapies i.e. pumps, clamps, stands and so forth.

## 1.3.10 Standards of care for patients on HETF

Standards are professionally developed statements that indicate the acceptable level of performance for health care. Standards will form the basis of a quality assurance programme and are vital in helping health care workers in identifying, monitoring, and evaluating the elements of optimal care unique to the community environment. Standards are essential in that they assist the health care professional in attaining the goal of providing quality patient care through internal review mechanisms. As home enteral tube

feeding increased, a number of organisations developed standards of care, in order to improve the organisation and the management of HETF.

In 1994, the working party of BAPEN concerned with enteral and parenteral nutrition in the community produced standards of care and procedural guidelines for patients on HETF, to ensure that patients received satisfactory training and quality of care before their home nutrition support commenced, and that the quality of care is maintained throughout their treatment. The guidelines include standards of care and learning goals for patients, and cover the following topics; training programmes, discharge planning, instruction manuals, equipment, management of feeding at home, plus checklists on what the patient/carer should know on their discharge and what the patient/carer will be able to do after discharge (Elia, 1994b).

ASPEN produced their third set of American guidelines for home enteral nutrition in 1992 (ASPEN 1992). Their standards are more detailed than the British, and include sections on organisational standards, patient selection standards, treatment standards, implementation standards, patient monitoring standards and finally termination of therapy standards. The most recent Standards were published in 1999 (ASPEN Board of Directors, 1999). The American Dietetic Association (ADA) has periodically produced "position" papers on the role of the dietitian in the care of patients on HETF. The most recent position paper was published in 1994 and stated "it is the position of the American Dietetic Association that the registered dietitian assume a key role in the medical nutrition therapy for patients receiving home parenteral and enteral nutrition support to provide appropriate and cost effective nutrition care" (ADA, 1994).

## 1.4 Practicalities of managing tube feeding in the community

### 1.4.1 The education and discharge of patients on HETF

To provide a smooth transition from hospital to the community, a multidisciplinary approach to the discharge, planning, and teaching of HETF is necessary, and teaching should begin as early as possible. A co-ordinated effort among the patient, caregivers, and health care team is essential for the successful discharge and management of these patients (Klein *et al.* 1998). While it is desirable to have as much notice as possible that the patient is to be discharged into the community on HETF, and while ideally 5 to 7 days should be allowed for education and preparation, it has been reported that patients can be educated in 3 to 5 days (Adams & Wirsching, 1984). The length of time necessary for education will depend on the length of time the patient has been enterally fed during their hospital stay and the cognitive ability of the patient and/or carer. Patients may be intimidated or overwhelmed by the thought of going home with enteral feeds. Some will have been tube fed in hospital, and may be quite familiar with the feeding system, while others may only have started feeding 1 or 2 days prior to discharge, and will not have had much opportunity to master the technique fully (Bloch, 1994).

Due to demands on hospital beds, patients due to start HETF are often discharged before adequate training has been completed. This can lead to an increased risk of hospital readmission (Elia *et al.* 1994b). Standards of patient training may vary within a hospital. This is because the training may be undertaken by a number of independent health professionals, including, dietitians, ward nurses and clinicians. These professionals may have variable standards and variable time available for instruction (Wilcock *et al.* 1991). Before the patient is discharged on HETF, his or her general practitioner (GP) should be informed regarding all aspects of the patients feeding regimen as well as anthropometric data. The local public health nurse (PHN) should also be informed, if s/he is to be involved in the patients care. The services of a paediatric nutrition nurse specialist can provide an important link between hospital and community (by facilitating home care, improving quality of patient care and alleviating pressure on the surgical team) (Abel *et al.* 1996). The patient's local pharmacy should be contacted to ensure that they will be able to provide the feed and equipment necessary for HETF (some companies will deliver the feeds and equipment directly to the patients home).

Follow up care is not always undertaken by the same health professional that prepared the patient for their discharge. This obviously leads to a lack of continuity and confusion for patients concerning whom to contact when problems arise. Therefore patients should be

clear about follow up arrangements before discharge into the community, and should be given contact telephone numbers to ring when or if a problem arises (Elia, 1994b). A summary of an ideal pathway in the discharge of the HETF patient is outlined in Figure 1.5.

**Figure 1.5** The home tube feeding discharge process

**Patient in hospital on enteral nutrition**

↓

**Multidisciplinary assessment**

| Medical | Nutritional | Social | Financial |
|---|---|---|---|
| Is patient medically stable? | Are nutritional requirements being met? | Family support at home? Is home environment suitable? | Medical card, VHI/BUPA, Long-term illness card? |

↓

**Contact company supplying pump**

↓

**Patient & family education re HETF**

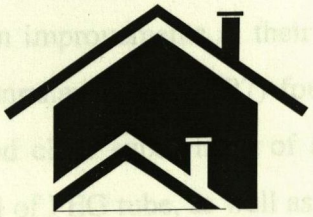
| Introduction | Equipment | Logistics | Complication | Tube care | Contact |
|---|---|---|---|---|---|
| Introduce patient / carer to home tube feeding | How to use & care for pump and delivery system, microbial aspects | Inform where to obtain feeds & equipment in the community | Teach how to deal with minor complications | How to care for and change tubes (if necessary) Medication use | Names, tel. numbers etc |

↓

**Inform GP, PHN & pharmacist of patient's discharge**

↓

**Patient discharged home**



### 1.4.2 Post-discharge management of patients on HETF

Careful monitoring of patients on HETF is essential to prevent the occurrence of complications and side effects of the treatment. In 1992 ASPEN devised guidelines for monitoring patients on HETF. These stated that patients should be monitored for review of the efficacy of the treatment, adverse effects of the treatment and clinical changes that may influence specialised nutritional support. Protocols should be developed for the periodic review of the patients clinical and biochemical status. Routine monitoring of the patient should include assessment of nutrient intake, review of current medications and signs of intolerance to therapy. Weight changes, biochemical data, haematological data and clinical signs of nutritional deficiencies and excesses should be observed. Periodic appraisal of adjustment to therapy, changes in lifestyle, psychosocial problems and changes in the home environment should be made. Periodically, it is necessary to assess the patient's major organ function and psychosocial aspects of the patient/caregiver (ASPEN, 1992). In some centres in the US, patients are seen 2 to 4 weeks after their discharge into the community, depending on their stability. The patient brings a record of temperatures, weights, urine checks for glucose, and fluid balance records to the clinic, as well as a 3-day food record intake when appropriate. The various members of the health care team will then evaluate the patient at each visit to the clinic (Davey-McCrae, 1994).

The BAPEN standards of care for patients on HETF state that there should be a post discharge monitoring protocol, which will be established by the nutrition team (or equivalent) in each centre. Monitoring of the patient in the community will be performed by a designated health professional (as defined by the protocol). The patient should always be aware of the follow up arrangements (Elia, 1994b). Riordan *et al.* (1999) have highlighted the changing needs of patients on HETF, and that regular multidisciplinary review is necessary in the years post insertion of a PEG. On follow-up, they found that 75% of their patients were not following dysphagia recommendations following discharge from hospital, and 13 had shown improvements in their swallow. In a small pilot study carried out in Bournemouth, Hanrahan *et al.* (1997) found that a gastrostomy clinic for stroke patients on HETF allowed close supervision of a return to oral intake whenever possible, and the earliest removal of PEG tube, as well as facilitating regular monitoring of swallow, nutritional status and local complications relating to the PEG site.

### 1.4.3 Approaches to managing patients on HETF

The practicalities of managing patients on HETF requires examination at this point, as there are a number of possible approaches to managing patients of this type. Since there is little information in the literature regarding such practices, for this section it was necessary to personally contact various dietetic departments to learn how these patients are managed nutritionally when they leave the hospital setting.

Departments were selected through personal knowledge of practices or through publications and/or presentations at scientific meetings (other departments may have provided different points of view on HETF, but it was felt that these 3 diverse departments would provide a good general overview of different ways of managing patients on HETF)) One staff member in each centre who was requested to forward any written information available (e.g. policy documents etc.) concerning their practices with respect to patients on home tube feeding. On receipt and examination of written data the individual was contacted again by telephone or face-to-face interview if possible to clarify points and to seek any additional outstanding information. Three dietetic departments were contacted. These were 2 community services (one in Northern Ireland and one in Wirral, Liverpool) and a hospital dietetic department in Dublin, where a pilot "hospital to home scheme" with a nutritional company was in place. Their practices are outlined and discussed below.

### 1.4.4 Managing patients on tube feeding in the community in Belfast

The first nutrition service is a community nutrition service in the Belfast area of Northern Ireland, which serves a population of around 664,200 people, and has approximately 140 patients on home tube feeding (children make up a small proportion of the total caseload in the service). There are 5.8 whole time equivalent (WTE) dietetic staff in the community dietetic department, and 1.3 WTE who are involved with patients on home tube feeding only. The community department provides its services to patients discharged from 8 acute hospitals. The geographical area that the dietitian covers is approximately the size of the Eastern Regional Health Authority (ERHA) area. The community nutrition department have published a report of their findings in the community (L'Estrange, 1997).

In the UK and Northern Ireland, the GPs budget (provided by the Government through each regional health authority) covers all costs of the care for patients in the community, including medicines and dietetic services. Therefore, referral of the patient in the community to the community dietetic service must come from the patients GP. If a GP fails to refer the patient to the community service, the *hospital* dietitian who prepared the

patient for discharge will contact the GP to enquire the reason for non-referral and restart the referral process if necessary. If the patient is still not referred, then the hospital dietitian will write to the GP (the letter will be countersigned by the patients consultant), confirming the patients discharge of nutritional care and reiterating the necessity for immediate referral process. GPs do not generally refuse to refer patients to the community service, but in 1998, 38 patients were discharged from hospital and were not referred to the community service by their GP, for a variety of reasons (e.g. the patient preferred to remain in close contact with the hospital dietitian).

Few patients are actually initiated on tube feeding in the community, but this does happen periodically, especially in the nursing home setting. Patients may be admitted for tube insertion on an out-patient basis, and are therefore not referred to the hospital dietetic service. On return to the nursing home, the community dietitian is then contacted to deal with the patient. Company representatives will educate patients in the hospital or community only if necessary. The company will arrange for the delivery of plastic disposables to the patients home, feeds are not delivered however.

### Belfast: Hospital procedure

The hospital dietitian establishes the need for enteral nutrition, assesses the nutritional status, calculates requirements, formulates appropriate regimen and monitors the patient during hospital stay. Before discharge, the patient is provided with accurate, comprehensive and current written information regarding the feeding regimen and administration system, as well as relevant telephone numbers should complications arise. The patient is provided with all necessary equipment to facilitate home tube feeding and all relevant individuals are educated sufficiently to implement feeding. Patients are given written information regarding their actual feeding regimen. All patients discharged on tube feeding are registered with BANS by the hospital dietitian who update the information when appropriate. The hospital dietitian will also telephone the patients GP to inform him/her of the patients pending discharge on tube feeding and request onward referral of the patient to the community dietitian. The hospital dietitian will forward information to the community dietitian regarding the patients age, weight, height, tube type and the date it was inserted as well as feeding regimen details, current oral intake, problems experienced on the feed as well as any available biochemistry details.

### Belfast: Community procedure

When patients are discharged into the community, they will only be seen by the community nutrition service on receipt of a written referral from the patients GP. If urgent, the GP can request the service by telephone and forward the referral letter to the service as soon as possible. Where priority status of the patient is not evident in the referral letter, the community dietitians will contact the patient/carer within 5 working days of receipt of the referral to establish priority and arrange the initial visit. Patients priority for visits is determined as outlined in Table 1.11. On the initial visit from the community dietitian, patients nutritional requirements are assessed, feeding formula and regimen are checked for their suitability with the patients lifestyle. The patient is provided with the dietitians contact name and number in writing. The patients GP and district nurse (if applicable) are informed of the visit by a standard letter. A copy of this letter is sent to the hospital dietitian. Patients who have commenced enteral nutrition in the community are registered with BANS, otherwise the care of the patient in terms of BANS registration is transferred from the hospital to the community. A letter confirming the transfer of BANS registration from hospital to community reporter will be sent to the hospital dietitian by the community dietitian.

After the initial visit, the community dietitian ensures that the patient receives follow-up telephone calls and where necessary, a visit in person if extra advice and/or support is required. All patients are reviewed every 6 months to assess if their feeding regimen is meeting their nutritional requirements. Again, the GP and district nurse (*if necessary*) is informed, by standard letter of any visits to the patient. The community dietitian is also responsible for the education of district nurses and GPs with respect to enteral nutrition. The approach of the dietitian with the patient is not "hands on" as yet, in terms of handling and fixing tubes if necessary, but this approach is evolving. Currently however, the district nurse is called in to deal with tube related problems.

Although the cost effectiveness of providing the service has never been evaluated one community dietitian responsible for patients on home tube feeding feels that the service has resulted in cost savings in terms of a reduction in acute admissions to hospital. Instead, planned admissions (which are cheaper than acute admissions) are organised for tube maintenance and service. In addition, patients tubes can be repaired in the community setting, avoiding admission to hospital entirely.

**Table 1.11** Priority criteria for reviewing patients on home tube feeding

| Criteria | Reasons | Patient seen |
|---|---|---|
| **Urgent** | Patient commenced on tube feeding in the community<br>Patient has complications that require urgent input from a dietitian<br>Referral received within 5 days* of patients discharge from hospital | Within 5 days* |
| **Non Urgent - High Priority** | Patients on home tube feeding not meeting criteria of urgent or non standard priority | Within 2 weeks |
| **Non Urgent Standard Priority** | Patients on tube feeding discharged to nursing homes where the community dietitian has confirmed with the nursing home that there are no problems. The community dietitians will leave her name and contact number with the nursing home should problems arise. | Within 8 weeks |

** working days*

### 1.4.5 Managing patients on tube feeding in the community in Dublin

In Ireland, there are no nationally defined standards for monitoring patients on HETF. Monitoring of patients is not routine, and the designation of a health professional with responsibility for patients on HETF in the community is not usual practice. Anecdotal evidence suggests that patients contact hospital dietitians by telephone if problems arise after their discharge or if possible, patients may attend the out patient department (OPD) for review of their feeding regimen. However, this is often difficult as many patients on HETF are housebound or bed-bound elderly patients, who may live in nursing homes, and trips to hospital for review of feeding may not be feasible. Problems with the feeding regimen may be discovered by the nutritional company representative, when on visit to manage problems relating to the pump. Similarly, GPs or PHNs may encounter problems with patients feeding and they may also contact the hospital dietitian to discuss the problem. Since there are no health care professionals with appropriate training to monitor many of the patients on home tube feeding for whom return to hospital for review is difficult, patients may return to hospital to deal with complications that may be treated in the community setting.

Our second case therefore, is that of an acute hospital in Dublin where a pilot scheme for the Abbott Hospital to Home Service was carried out (Abbott Laboratories Ireland Ltd.). The pilot was set up in 1998 in the hospital but has since been introduced to the whole country. It was decided to investigate the practices relating to patients on HETF in this hospital as the scheme had been carried out for a sufficient length of time for the

department to become familiar with the system. The payment for feeds, equipment etc. in the Republic of Ireland has also been described in Section 1.4.5.

### Dublin : Hospital procedure

The are currently 11 WTE dietitians in the hospital. The hospital dietitian establishes the need for enteral nutrition, assesses the nutritional status, calculates requirements, formulates appropriate regimen and monitors the patient during hospital stay. The hospital dietitian prepares and educates patients who are to be discharged on home tube feeding. Before discharge, the patient is provided with accurate, comprehensive and current written formation regarding the feeding regimen and administration system, as well as relevant telephone numbers should complications arise. The patient is provided with all necessary equipment to facilitate home tube feeding and all relevant individuals are educated sufficiently to implement feeding (patients are given a pump and 7 days supply of feed and disposables on their discharge from hospital). Preparation may or may not include teaching on the use of the feeding pump, depending on ward practice. The dietitian will write to or telephone the patients local chemist, GP, PHN and local Director of Community Care to explain the patients treatment requirements (feed, giving set, syringes etc.) and also to explain the *Abbott* hospital to home scheme. A standard form developed by *Abbott* Laboratories is filled out in triplicate and faxed to *Abbott Laboratories* to inform them of the patients discharge. The patient is given a copy of the form, and a copy is retained by the hospital dietitian. Arrangements for follow up are made but may vary depending on the patient type etc. After discharge, patients may be seen in the out-patients department, but for immobile or poorly mobile patients, review must be over the telephone (*if at all*). Patients are not seen in the community setting by the hospital dietitian, and as mentioned above there are no community dietitians in Dublin who are responsible for the after discharge care of patients on home tube feeding.

### Dublin: Community procedure

The hospital to home service is designed to simplify the transfer of patients on *Abbott* tube feeds from hospital to home. The service ensures that patients receive exactly what has been prescribed by the dietitian in the discharging hospital. After receiving the fax from the hospital dietitian which contains details of the patients feed and requirements the service coordinator contacts the patients at home and explains the delivery service. The company arrange to deliver enteral feed and giving sets to the patients home at a certain

time every month. The coordinator of the service telephones the patient approximately 1 week after the patients discharge to arrange delivery of feed and equipment. Following this the coordinator telephones the patient 3 weeks after the delivery to check the patients stock of feed and supplies and consequently how much is required for the following delivery. Enteral feeds are giving sets are delivered to the home (monthly) by a courier. The company also maintains and services the feeding pump. Patients are provided with a "Tube Feeding at Home Booklet" and instructions on pump operation. The company representatives will not visit the patient in the home unless requested to do so.

The service alleviates the burden on patients and carers who do not have to collect feeds and equipment themselves. Regular contact is kept with the patient, therefore deaths or discontinuation of feeding may be noted by the service coordinator and the hospital dietitian may then be informed. The company do not, however, provide a nutritional monitoring service to patients who must return to the hospital setting for nutritional review. Anecdotally, some patients problems have been noticed by the service coordinator and the hospital dietitian has been informed, although this is not a function of the service *per se.* Nutritional companies in the US often provide the services of physicians and dietitians to care for patients on HETF (Elia, 1994), but the numbers of patients on home tube feeding in Ireland is obviously too small for such a service to be cost effective to a commercial company.

A competitive market dictates that in time, other companies in Ireland which are involved in home tube feeding are likely to provide the same or similar service to the *Abbott* hospital to home scheme. The service provides a more standard and accurate delivery service which theoretically may lead to less wastage of feed and equipment. Certain problems may be picked up when the monthly telephone call is made by the service coordinator. Finally, however, the most notable benefit of the scheme is in it's assistance to the patient/carer.

### 1.4.6 Managing patients on tube feeding in the community in Liverpool

The last case study is that of a community nutrition service in the Wirral area of Liverpool, England, which serves a population of around 350,000 people, and has approximately 120 patients on home tube feeding (children make up a proportion of the total caseload in the service). There are 3.6 WTE dietetic staff in the community dietetic department, and 1 WTE who is involved with patients on home tube feeding only. The community department provides its services to patients discharged from 1 acute hospital principally, but from 3 other hospitals as well.

### Liverpool: Hospital procedure

The hospital procedure in this area is similar to the first 2 cases, i.e. the hospital dietitian establishes the need for enteral nutrition, assesses the nutritional status, calculates requirements, formulates appropriate regimen and monitors the patient during hospital stay. The patient is provided with accurate, comprehensive and current written formation regarding the feeding regimen and administration system, as well as relevant telephone numbers should complications arise.

### Liverpool: Community procedure

In general, patients are referred to the community dietitians by the discharging dietitian in the hospital, or if they fail to refer, the district nurses or nursing home will contact the community dietitians. Following discharge from hospital, all patients are contacted within 3 working days and all patients seen in their own home within 7 working days of discharge from hospital. On the initial visit, written and verbal advice is given to the patient/carer regarding the care of feeding tube, the use of feeding pump and equipment. A copy of the feeding regimen is given as well as information on the home delivery company and emergency contact numbers. Following the initial and subsequent visits to the home, records are kept in accordance with British Dietetic Association standards for record keeping.

Where possible the patient's weight, BMI and Bioelectrical Impedance are calculated and recorded. A dietetic carer is identified and his/her contact number given to the patient or carer. A nutritional care plan is devised, which incorporates nutritional aims, nutritional treatment and methods of monitoring. If the patient has a balloon replacement tube *in situ*, patients or carers are given 18Fr Foley catheter, plus advice regarding method of tube replacement and contact numbers to use if required. Finally, written notification is sent to the patient's GP and other relevant healthcare professionals (e.g. district nurse).

The patients are initially prescribed feeds by the discharging dietitian (unless the community dietitian specifically requests a feed/system that they think is better for the patient). Following discharge, the patients are placed on the system used in the community dietetic department, irrespective of the hospital system. In addition, the feeding regimen may be changed after the patients discharge from the hospital. Enteral feeds are funded by the patients GP, and the community nutrition service has a budget to fund the ancillary items. The community nutrition service therefore decides what feeds and system will be

used by patients in their area on home enteral feeding. The advantages of using a system such as this include greater flexibility over stock control, the availability of extensive supplies, 24hr pump replacement, and greater flexibility in terms of feeds and equipment utilised. In addition, the community dietitian has control over how much a patients orders, because nothing is delivered to patients without approval from the community dietitian. The service in the Wirral is currently under review by internal audit to determine if they are cost effective. Results were not available at time of writing the thesis.

## 1.5 Ethical dilemmas in tube feeding

### 1.5.1 Introduction

It is over twenty years since the first successful PEG was inserted. The originator of the PEG tube has recently expressed concern about over utilisation of PEG feeding, stating that more consideration should be given to the ethical aspects associated with long term feeding in the future (Gauderer, 2000). The appropriateness of PEG in certain types of patients has been questioned. In particular this relates to 3 patient types: the demented patient, the patient in a persistent vegetative state (PVS), and the terminally ill cancer patient (terminally ill implies a life expectancy of 3 months or less (McCann *et al.* 1994)).

### 1.5.2 Clinical evidence for tube feeding in dementia

When feeding becomes difficult in the patient with dementia, tube feeding is sometimes initiated to overcome these difficulties. Factors affecting food intake in patients with dementia are outlined in Table 1.12. In the US, a retrospective cohort study of over 7000 patients found that approximately 30% of gastrostomy tubes inserted in older people were inserted in patients with dementia (Rabeneck *et al.* 1996). In the UK, about 3% of the patients registered as receiving home tube feeding over the age of 65 were categorised as having dementia. However, around 58% of this group required tube-feeding following stroke; but the presence or absence of dementia in stroke patients is not reported (Elia *et al.* 1999).

Tube feeding became widely used as the treatment for the weight loss that occurs in aging and dementia due to the simplicity and convenience of tube feeding and to the fear of allegations of neglect if tube feeding is not employed (Sheiman & Pomerantz, 1998). Recently, however, the clinical evidence for tube feeding severely demented patients has been challenged. In their review of the clinical evidence for tube feeding patients with advanced dementia, Finucane and colleagues found no data to suggest that tube feeding reduces the risk of pressure sores or infection, improves functional status, improves comfort, prevents aspiration pneumonia or improves survival. They conclude that tube feeding severely demented patients should be discouraged on purely clinical grounds (Finucane *et al.* 1999). An extensive review of the use of tube feeding to prevent aspiration pneumonia concluded that no data show conclusively that it reduces the risk of aspiration pneumonia in neurogenic dysphagia, but rather that data exists on the contrary (Finucane & Bynum, 1996). Peck *et al.* (1990) found the incidence of aspiration pneumonia and decubitus ulcers to be greater in tube fed patients compared to non-tube fed

elderly demented patients. Furthermore, physical restraints were used more frequently in the tube fed group. Other studies report the use of restraints to keep nasogastric tubes in situ, ironically, where the feeding tube was often used to improve patient comfort (Quill, 1989). Three review papers have found no evidence to suggest that tube feeding can improve pressure sore outcome in these patients (Finucane, 1995; Berlowitz *et al.* 1996; Berlowitz *et al.* 1997). Kaw & Sekas (1994) found no improvement in either functional status or nutritional status after a long term follow up of a group of nursing home patients, the majority of whom had a feeding tube placed as a result of dementia.

Prospective randomised controlled trials to examine whether there are any differences in life expectancy between tube-fed and non-tube-fed demented patients are difficult to conduct from an ethical and practical point of view, but one study on the risk factors and impact on survival of tube feeding in nursing home residents with severe cognitive impairment found that even after adjusting for independent risk factors, the presence of a feeding tube had no survival benefit (Mitchell *et al.* 1997). More recently, however, Rudberg *et al.* (2000) have shown that patients with feeding tubes are *less likely* to die than comparable residents of nursing homes without feeding tubes, even if the gain in life in not substantial. Rudberg *et al.* conclude that the difference between their findings and those of Mitchell *et al.* were due to the fact that Mitchell *et al.* did not condition their sample selection on whether or not a patient had total eating dependence *and* a swallowing disorder (but just a swallow disorder). Many of those without feeding tubes had milder eating disorders and hence better health.

**Table 1.12** Factors affecting food intake in patients with dementia

| |
|---|
| **Reduced food intake** |
| 1. Patient may be distracted from eating |
| 2. Patient may refuse to eat |
| 3. Agnosia |
| 4. Decreased olfactory function |
| 5. Apraxia of eating |
| 6. Patient may not want to eat due to depression (this is reversible) |
| 7. Patient may have a reduced appetite |
| **Impaired swallow** |
| 1. Abnormal chewing movements |
| 2. Absent chewing movements |
| 3. Abnormal tongue and jaw movements |
| 4. Coughing |
| 5. Choking |
| 6. Delayed swallow when eating |

### 1.5.3 Tube feeding in PVS

Vegetative state is defined as a complete unawareness of self or the environment and an inability to interact with others, though in every case unawareness has to be judged on the best evidence available by those who observe and care for the person. Recovery is unusual when this state persists for longer than 12 months after trauma, or 3-6 months after an anoxic episode, when a description of "persistent" may be applied to the state (Lennard-Jones, 1998). In such patients, the only benefit that can be achieved from tube feeding is the maintenance of physiological function, as the minimal functioning of these patients eliminates the possibility for experiences and activities that make human life possible, that is, they cannot experience any quality of life (Rabeneck *et al.* 1997). Persistent vegetative state is uncommon. The numbers of patients on PVS in Ireland are not known, but extrapolation for m UK data (Institute of Medical Ethics, 1991) would suggest that there are about 100 patients in this state in Ireland, although a dietitian working in a long term care institution estimates that a number of 30-40 patients in PVS is more likely (*personal communication, Michelle Hurley*).

The focus of the debate surrounding these patients is on the morality of withholding or withdrawing nutrition and fluids. While individual doctors, institutions and judges believe that the withholding of nutrition and fluid from PVS patients would be murder, every professional medical group, and every court of final jurisdiction (including the US supreme court) have decided that where evidence exists to suggest that a patient would not want such treatment, withdrawal is accepted medical practice (Paris, 1993).

### 1.5.4 Enteral tube feeding in the terminal cancer patient

Whether a terminally ill cancer patient should be actively fed or simply hydrated through subcutaneous or intravenous infusion of isotonic fluids is a matter of ongoing controversy among clinicians involved in the care of these patients. Terminally ill cancer patients do not generally experience hunger and those who do need only small portions of food to alleviate it, and complaints of thirst and dry mouth are relieved by sips of water (much less than is needed to prevent dehydration) (McCann *et al.* 1994). In the final stages of cancer, near death, removing or withholding fluid from patients results in a further depression of their consciousness and coma, but observers have noted that this period does not appear to cause pain, indeed, evidence exists for impaired thirst in neurological impairment, and for the endogenous production of natural analgesia (Arhronheim & Gasner, 1990). A committee of experts (under the auspices of the European Association for Palliative Care) have developed guidelines to help clinicians make a reasonable decision on what type of nutritional support should be provided to patients (on a case-by-case basis). The committee recognise that part of the debate is related to the definition of the "terminal cancer patient". This was seen to be heterogeneous group of patients with different needs, expectations, and potential for a medical intervention. The committee have outlined that there are huge difficulties in predicting the life expectancy and the patient's likely response to aggressive nutritional support. In an attempt to reach a decision on the type of treatment support (artificial nutrition vs. hydration) which would best meet the needs and expectations of the patient, the committee proposed a three-step process (see Table 1.13) (Bozzetti *et al.* 1996).

**Table 1.13** Process to reach a decision on treatment of terminal cancer patients

Step 1: **Define the eight key elements necessary to reach a decision**

Involves assessing the patient concerning the following:

1. oncological/clinical condition
2. symptoms
3. expected length of survival
4. hydration and nutritional status
5. spontaneous or voluntary nutrient intake
6. psychological profile
7. gut function and potential route of administration
8. need for special services based on type of nutritional support prescribed.

Step II: **Make the decision**

Involves the overall assessment of pros and cons, based on information determined in Step I, in order to reach an appropriate decision based on a well-defined end point (i.e., improvement of quality of life; maintaining patient survival; attaining rehydration).

Step III: **Reevaluate the patient and the proposed treatment at specified intervals.**

Involves the periodic reevaluation of the decision made in Step II based on the proposed goal and the attained result

### 1.5.5 Patient preferences for tube feeding

By the time tube feeding becomes an option for the demented patient with feeding difficulties or the patient in a PVS, the patient will clearly be unable to express their wishes concerning the use of the treatment. A number of studies have examined people's opinions about life-sustaining treatments. Gerdingen *et al.* (1999) surveyed 84 cognitively normal American men and women over 65 years and found that most did not desire life-sustaining treatment with any degree of dementia. The proportion of those not wanting such treatments increased with the progressing severity of the dementia. Only 4% said that they would desire tube feeding if they could not communicate and care for themselves. Only 22% of an Israeli population group would choose tube feeding with an irreversible condition of severe mental impairment, and only 28% would want tube feeding if they had metastatic cancer (Carmel, 1999). A postal questionnaire survey of 218 community living Americans by Reilly *et al.* (1994) found that 43% of persons aged between 60 and 87 years of age would want to be tube fed if in a state of moderately advanced Alzheimer's disease, 28% wished for tube feeding if in a coma, and 29% wanted tube feeding if they had metastatic terminal cancer. A lower preference for tube feeding in Alzheimer's disease was found by Emanuel *et al.* (1991) who studied the treatment preferences for patients of all ages in the Boston area. Only 11% wanted tube feeding in the case of dementia and 80% did not want to be fed if in a PVS. A predominantly male American nursing home

population studied by Gerety *et al.* (1993) found that only 25% would accept tube feeding in a PVS.

The preferences for treatment appears conflicting based on the studies outlined above. However comparisons between studies are difficult, as the populations studied differed in terms of age, sex, race, cultural factors, education status, health status and functional status, all of which are factors which may influence peoples decisions about life-sustaining treatments (Garrett *et al.* 1993). Possibly more importantly, the questions and scenarios posed to participants differed. Use of a scenario to examine preference for treatment may be limited to the precise scenario described (Reilly *et al.* 1994). In addition, the patient's knowledge about tube feeding will affect their preference for it under particular circumstances (Krynski *et al.* 1994). Evidence regarding the consistency in life sustaining opinions of elderly subjects is conflicting; Kellogg *et al.* (1992) found that older persons opinions on the use of life sustaining treatments (including tube feeding), are not always consistent when re-assessed at a later date. Conversely, Carmel & Mutran (1999) found older persons preference for the prolongation of life was stable after 1 and 2-year intervals. The disparity in results is again, probably due differences in the populations studied.

### 1.5.6 Opinions of health professionals

As they are frequently the primary decision makers in the matter of feeding tube insertion in elderly demented patients, the opinions of physicians and other health professionals are important regarding the use of tube feeding in controversial situations. In a study of 339 doctors in Israel, physicians were found to use more life sustaining treatments more frequently than an elderly population had reported they would want (Carmel, 1999). A study of the attitudes American internists to tube feeding showed that 84% were generally *opposed* to tube feeding a nursing home resident with irreversible dementia that had lost interest in eating and 80% favoured withdrawing a tube feed from a patient in a PVS (Hodges *et al.* 1994). A Welsh study found that just under half (47%) of the geriatricians surveyed felt that PEG feeding was indicated in dementia with rejection of food. Speech therapists and dietitians held similar views (Hasan *et al.* 1995). A survey of 141 American physicians found that cognition and life expectancy were relatively minor influences on physician decisions regarding tube feeding of nursing home residents (Von Preyss-Friedman, 1992). Conversely, Watts *et al.* (1986) found that the mental status of the patient significantly influenced physicians (*n* 124) preferences for tube feeding patients. Younger

patients tended to be given higher preferences for tube feeding, and the happiness of the patient was the strongest and most significant influence upon their preference. Hasan *et al.* (1995) found that 57% of nurses were in favour of tube feeding a patient with dementia who had rejected food. An international study of nurse's attitudes to tube feeding severely demented patients found clear differences between nurses in different countries. Australian, Canadian and Swedish nurses most often chose not to tube feed a severely demented patient, whereas all of the Chinese nurses (*n* 10) and 90% of the Israeli nurses chose to feed such a patient. Nurses choosing not to feed the patient tended to stress the ethical principal of beneficence, the most common justification for those choosing to feed the patient were related to the ethical principles of sanctity of life and beneficence (Norberg *et al.* 1994). Clearly racial influences play a part in the decision making process regarding the use of life sustaining treatments. Mebane *et al.* (1999) found that a physician's race influenced their preferences for end of life treatment, with black physicians favouring the use of life sustaining treatments more frequently than white doctors for themselves and for patients.

### 1.5.7 Decision-making

Severely demented patients and patients in a PVS are unable to take part in the decision making process regarding the use of tube feeding. The physician and family members often make the decision in the absence of an advanced care directive by the patient, although medical decision-making in general may be dominated by physicians (Van Rosendaal *et al.* 1999). Advanced directives are decisions about how one will be cared for in the future when one may be incapable of making an informed decision. There are two types of advanced directive; firstly the living will, a signed statement of medical treatment preferences and secondly, the appointment of a durable power of attorney, a trusted individual who will make decisions based on knowledge of the individuals wishes. Both have their limitations, for example, the appointment of a durable power of attorney does not guarantee that the wishes of the patient will be carried out, it merely means that he or she will be represented and living wills apply only to terminal illness (Reilly *et al.* 1994). One study found medical treatment to be consistent with advanced directives in 75% of cases, however, inconsistencies occurred more frequently in nursing homes where the patients were incompetent, where delivery of the advanced directive to the hospital setting was achieved in only 35% of cases (Danis *et al.* 1991). In a study of the decision makers for cognitively impaired older patients who were tube fed, less than half felt confident that

their patients would have chosen to have a feeding tube inserted if they were capable of expressing themselves. Only 1 decision maker (out of 94) was aware of previously expressed wishes regarding tube feeding (*the patient didn't want it*) (Mitchell *et al.* 2000). Others have concluded that while proxy decision makers may make incorrect judgments, they tend to not methodically err in either withholding or providing treatment (Gerety *et al.* 1993).

Advanced directives are not common practice in either Ireland or the UK. Their use in the US is increasing, but still only 9.8% of patients near the end of life have completed a living will (Hanson & Rodgman, 1996), although a survey of physicians found that 51% of older physicians had a living will or an advanced care directive (Mebane *et al.* 1999). The goal of decision-making is to make the choice that the patient would have made if they were in a position to make an informed decision (Myers & Grodin, 1991). Not surprisingly, the time at which a decision to insert a feeding tube must be made can be emotional and difficult, and many carers may make decisions without adequate information and with an overly hopeful view of the future clinical course (Van Rosendaal *et al.* 1999). Physicians (*n* 82) responding to a postal questionnaire survey reported a significant amount of conflict between healthcare staff and family members regarding the decision making process to proceed or defer gastrostomy. The perception amongst responders was that the decision to have a tube inserted was sometimes driven by concern for the burden to caregivers of providing oral feeding to the patient (Callahan, 1999).

Surrogate decision makers have reported to have been told that "improved nutritional status" was the most common benefit to be expected from feeding tube insertion, and early complications post-insertion were the most frequently quoted negative expectations (Callahan, 1999). In contrast, a Canadian study of surrogate decision makers found that prevention of aspiration and the maintenance of life were the medical benefits most often cited as indications for tube feeding. Just over half of the surrogate decision makers in this study felt that they had received adequate support from the heath care professionals in making their decision regarding tube feeding (Mitchell & Lawson, 1999). In addition, a further study found that of 73 surrogates and patients undergoing PEG found that 24% of patients and 61% of surrogates said that they were not asked their opinions about PEG insertion and 26% of surrogates said that they felt their opinions were not respected. In 22% of the patients with poor prognosis (including severely demented patients), conflicting messages regarding the anticipated outcome were given by different health care professionals on the medical team (Van Rosendaal *et al.* 1999). Having made the decision

to have a feeding tube inserted into a family member, 33% of surrogates are reported to have felt unsure that proceeding to nutrition support was the right decision (Van Rosendaal *et al.* 1997). A survey of family members of severely demented nursing home patients who were not tube-fed examined the surrogate decision-makers preferences for life sustaining treatment. Tube feeding was the second least accepted life sustaining therapy, with only 36.4% accepting it for their family member (Cogen *et al.* 1992). In conclusion, it appears that the decision making process is difficult for both doctors and surrogate decision makers. Meyers & Grodin (1991) advise that "the challenge for the decision making process is to facilitate communication, respect the ethical principals of respect for autonomy and beneficence, tolerate a plurality of belief systems, and yet safeguard vulnerable patients". Within this framework, physicians and other health professionals must preserve their own professional and personal ethic.

### 1.5.8 Loss of autonomy

Deciding how to care for a demented patient who is not dying, but has stopped eating, or a PVS patient poses a difficult challenge for everyone involved their care. The process of deciding whether to tube feed or to withhold tube feeding from a dementia patient is extremely emotionally charged and poses enormous moral dilemmas. The primary ethical issue in the case of the demented or PVS patient is the loss of autonomy, which is an inevitable consequence of the decline in the cognitive abilities of the demented patient (Watson, 1994), and the consciousness' of the PVS patient. Fundamentally, autonomy means that a person has the right to determine his or her own destiny, and has the right to choose, the right to know and the right not to be harmed (MacFie, 1996). Advanced directives may be used in an effort to help maintain autonomy. In Ireland, the question of how enforceable an advanced directive would be if it contravened the ethical principles of an institution or healthcare provider is an issue of serious doubt (Cusack, 2000). However, people with mild dementia may often answer rationally to questions relating to their wishes regarding life-sustaining treatments. Therefore before autonomy is lost permanently, early and ongoing communication with patients and families can help to prevent conflict, disagreement and distress later on (Post & Whitehouse, 1995).

### 1.5.9 Tube feeding: medical or ordinary treatment?

The question of whether tube feeding is *ordinary treatment* (i.e. the simple provision of food and water, albeit in an alternative fashion) or a *medical treatment* is also central to the

debate regarding tube feeding in the non-autonomous patient. Fluids and nutrition, in whatever form, have a symbolic nature, in that they represent the core of life, nurturing and care-giving (Cranford & Ashley, 1986), and are thus often set apart from other forms of life sustaining treatments such as ventilators, antibiotics etc. However, the prevailing consensus amongst medical ethicists is the tube feeding is a medical intervention and as such, is subject to the same considerations of risk versus benefit that preside over other medical decisions (Goldstein & Fuller, 1994). A useful distinction between oral and tube feeding is in the concept of "volitional" versus "non-volitional" feeding. Volitional feeding is eating "normally", placing food in our mouths, chewing and swallowing, deriving in the process the pleasure and sensations that go along with that. Normal human beings would never forcibly prevent volitional feeding. Non-volitional feeding, such as the provision of food and fluids via a feeding tube, does not provide the pleasure and sensations associated with volitional feeding; so withdrawing or withholding it is not as peculiar a concept for us (Lipman, 1996).

### 1.5.10 Demented patients: maintaining nutritional status

The weight of evidence seems to suggest that tube feeding is unwarranted in most patients with eating difficulties caused by dementia. But if tube feeding is not used in a severely demented patient with eating difficulties, then how can their nutritional status be maintained? One physician has described several experiences involving withholding tube feeding from demented elderly with inadequate oral intake despite efforts at hand feeding. He described how withholding nutrition lead to a slow death with development of decubitus ulcers, and that this has lead him to have a substantially more aggressive approach to nutritional support for these patients (Mehr, 1984). On the other hand, a longitudinal cohort study of weight changes, length of survival and energy requirements of long term care residents with dementia found that dementia is not necessarily associated with chronic weight loss during institutional care, and that, without the use of tube feeding, nursing staff are able to sustain the weight and survival of patients for long periods, even in very demented cases (Wang *et al.* 1997). Oral intake can be maintained by numerous practices, such as skillful feeding techniques, altered consistency in dysphagic patients, providing enough time for feeding, and taking advantage of the midday meal when cognitive abilities are at their peak (Suski & Neilsen, 1989). Treatment of depression, providing access to favourite foods, finger foods, strong flavours, calorie and protein enriched foods and reminding patients with apraxia of swallow to swallow after eating can

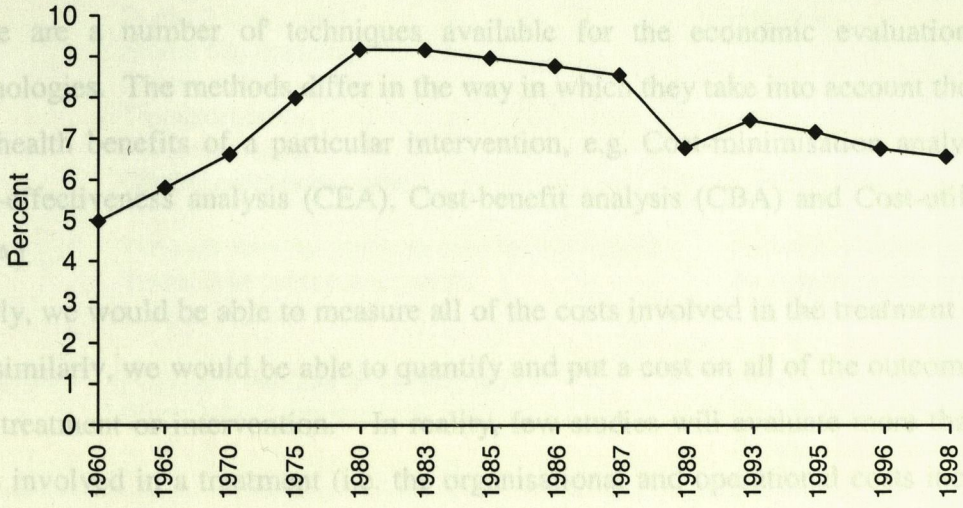
also help (Morley, 1996) as well as altering the feeding environment (Finucane *et al.* 1999). Inevitably, however, tube feeding will be necessary for a small minority of patients with dementia.

## 1.6 The cost of enteral tube feeding in the community

### 1.6.1 Introduction

In the developed world between 1960 and 1980, there was a large increase in expenditure on healthcare where practically all OECD (Organisation for Economic Cooperation and Development) countries exceeded Gross National Product (GNP) growth quite substantially. Expenditure on health increased from 3.8 to 7.0 as a percentage of GNP over the period in these countries. In 1970 in Ireland, for example, total health expenditure as a percentage of the GNP was 6.6% and in 1983 it was 9.2% (see Figure 1.6).

**Figure 1.6** Trends in health expenditure in Ireland as a % of GNP




After 1980, it became apparent that sufficiently better outcomes were unlikely to be achieved through any further growth in health expenditure, and since then there has been a greater restraint on health expenditure (Selby-Smith, 1993). Nonetheless, expenditure on health care is still growing in practically all industrial countries and the search for more cost effective uses of finite resources is universal (OECD, 1990). Ireland, however is one of the few OECD countries that has experienced a reduction in the share of GNP devoted to health - taking private and public expenditure together, in the period 1980 to 1996. Only 3 European Union (EU) countries show a reduction in the allocation of expenditure to health in the years 1980-1996. Ireland has by far the biggest reduction at 20%, followed by Sweden at 9% and Denmark at 8% (Wiley, 1998). As a result, the share of GNP devoted to health has fallen markedly, from amongst the highest to the lowest, reaching 7.2% in 1995. Since 1993 the economy has grown at an unprecedented fast rate, so that in 1996, the share of GNP had fallen to 6.8%, the lowest since 1980 (OECD, 1998). While the share of GNP devoted to health expenditure has shown a decline over the 1990s as a

whole, because of the growth in the economy, this expenditure has actually been increasing in real terms, and is likely to continue to increase for the foreseeable future (Wiley, 1998).

### 1.6.2 Health economic evaluation techniques

Health care economics can be broadly defined as the application of basic economic principles to the problem of allocation of healthcare resources. Many advances have been made in the development of methods of economic evaluation to assist in decision-making regarding the allocation of scarce health resources (Robinson, 1993). As new medical treatments and strategies emerge, they are increasingly subject to evaluations of economic efficiency, as individuals who are responsible for the allocation of healthcare resources need information on the relative value for money offered by the alternative treatments.

There are a number of techniques available for the economic evaluation of health technologies. The methods differ in the way in which they take into account the health and non-health benefits of a particular intervention, e.g. Cost-minimisation analysis (CMA), Cost-effectiveness analysis (CEA), Cost-benefit analysis (CBA) and Cost-utility analysis (CUA).

Ideally, we would be able to measure all of the costs involved in the treatment of a patient, and similarly, we would be able to quantify and put a cost on all of the outcomes measures of a treatment or intervention. In reality, few studies will evaluate more than the direct costs involved in a treatment (i.e. the organisational and operational costs incurred in the provision of health care). Intangible (i.e. outcome measures that cannot be assigned a monetary value, such as pain or happiness), or humanistic costs as they are also called are obviously more difficult to put values on (McCabe, 1997). Unfortunately, in many economic evaluation studies there is rarely concrete information available regarding life years gained. It will often be necessary to *estimate* future outcomes, using results from other surveys or trials with as much accuracy and as least subjectivity as possible. When evaluating or comparing the costs of interventions or treatments, it is essential to recognise that different groups (e.g. patients, health professionals, and hospital managers) may vary in their perspective towards cost and benefits. Potential conflicts of interest should be avoided, and the most general outlook should be taken when carrying out an economic evaluation.

### 1.6.3 Costs involved in HETF

The costs and benefits of HETF may be categorised as direct, indirect and intangible. Direct costs are the obvious costs involved and include the costs of the formula feeds and

giving sets; direct benefits include the reduction in hospital costs as a result of the patient being discharged into community care. Indirect costs include the costs to relatives, who may need to take time from work to take care of the patient; an indirect benefit could be the patient returning to the work environment. Intangible costs are pain and worry that may be experienced by the patient on HETF; alternatively intangible benefits include feelings of being more independent and being in familiar environment. Table 1.14 while not an exhaustive list, outlines other costs and benefits of HETF (Goff, 1998).

**Table 1.14** Examples of items in cost-benefit categories for home enteral nutrition

| Category | Cost | Benefit |
|---|---|---|
| **Direct** | Nutritional product<br>Giving sets<br>Pump & Drip stand<br>Stoma site dressings<br>Nurse-visits<br>Transport costs<br>Personnel costs<br>Clinical procedure costs | Reduction in hospital costs<br>Reduced risk of nosocomial infections |
| **Indirect** | Time off work for family to care for the patient<br>Travel time for follow-up visits<br>Loss of income | Patients or family member may be able to return to work |
| **Intangible** | Pain from disease or feeding tube<br>Worry (about prognosis or work) | Patient is in familiar environment<br>Patient feels more independent<br>Patients has more control over daily activities |

### 1.6.4 Cost analysis of HETF

In 1995 Pironi & Tognoni (1995) recommended the implementation of CEA and CBA studies with respect to HETF, and in 1997 Baldwin *et al.* recommended that the benefits, detriments and cost-effectiveness of HETF in patients with cerebral palsy and stroke required formal and urgent investigation (Baldwin *et al.* 1997). However, cost effectiveness studies in the area of nutrition support are still limited, particularly on the subject of HETF (Goff, 1998). The cost of HPN has been analysed to a greater extent than that of home enteral nutrition, perhaps due to the higher cost involved on a per patient basis. For example an Italian study found that HETF is 43% the cost of HPN (when the costs of the nutrition support team are taken into account) and 30% the cost of HETF when the fixed direct costs only are considered (Pironi *et al.* 1997). It is difficult to find studies that examine the cost reduction or cost benefit analysis of enteral nutrition by itself (Goff, 1998), and variations between countries with respect to the different methods of payment

and reimbursement for HETF makes comparative analysis difficult. However, due to the current increase in the practice of HETF and the relatively large number of these patients, the cost of community tube feeding is likely to become a more important issue in the future. An American study estimated the costs of HETF conservatively at $18,000 (range $5,000 to $50,000) per patient per year (Reedy & Malone, 1998). The cost of feeding a patient in the UK has been estimated at over stg£3,500 per patient per year (Wilson, 1998). It has also been reported that HETF provides a cost saving of 75% in comparison to feeding in hospital in the US (Howard *et al.* 1986), and 70% in the UK (Elia *et al.* 1994). More recently, a study presented at ASPEN (2000) concluded that home enteral nutrition permitted savings in the range of 91% when compared to hospital therapy (Dias Gonca *et al.* 2000). Clearly, tube feeding in the home environment rather than the hospital environment saves money. The cost saving involved in feeding patients in the community in Ireland instead of the hospital setting is not known.

### 1.6.5 Payment for HETF in Ireland

Irish patients can avail of a number of schemes to pay for HETF. Formula feeds are obtainable under the General Medical Services (GMS) scheme for patients who are eligible for a medical card (eligibility is dependent on family income etc.). For those patients who are ineligible for a medical card, a drug cost subsidization scheme (DCSS) exists whereby patients are reimbursed for all monies over £90 spent on drugs over a 3 month period. Disposable plastics, such as giving sets, are not available under the GMS scheme and funding for these is sought for each patient separately from fund holders in the community (Directors of Community Care). The decision to provide funding is at the discretion of the fund-holder, although refusal to provide funding is unusual. The type of giving set used by the patient is dependent on the contract used by the discharging hospital. Thus a number of different companies are involved in the community enteral nutrition market.

### 1.6.6 Payment for HETF in the UK

At present in the UK, the organisation and financial arrangements for nutrition support in hospitals and in the community differ considerably, and this is found to be partly due to the emergence of the independent National Health Service (NHS) trusts. It is also evident that some confusion exists regarding the financial arrangements for HETF in the UK. The BANS survey found that problems arose for 21% of their respondents (health professionals) because of difficulties in financial arrangements, and 54% said that

problems arose "sometimes" due to difficulties in the financial arrangements for patients (Elia *et al.* 1996).

The family doctor (GP) currently provides the prescription for the feeds required for HETF. Hospital clinicians provide prescriptions for equipment. The direct payment for equipment for HETF (giving sets etc.) varies, and can be provided by a number of units, (e.g. community services, individual wards or pharmacy or dietetic departments). In some centres in the UK, one company is given the contract for the provision of giving sets in the community, thus reducing the costs to the payer. Problems regarding funding can arise therefore, when a patient is transferred from one district to another. Ultimately, however, the NHS is financially responsible for HETF in the UK (Elia, 1994).

### 1.6.7 Payment for HETF in the US

Home Nutrition Support companies feature prominently in the provision of HETF in the US. These companies provide a wide variety of services and products to patients on HETF. The company will deliver products to the patients own home, offer to rent or purchase equipment, will service equipment in 24 hours, and offer a 7 days per week, 24 hour emergency telephone contact. The company will also arrange for the coverage of costs with the patient's medical insurance company. Many of the companies employ health care professionals, such as dietitians, nurses, pharmacists, and physician consultants. The aim of many of the home care companies is to facilitate the provision of the physicians prescribed treatment in the comfort, privacy, and convenience of the patients own home. Obviously, as the number of these companies increases, the selection of an appropriate company becomes more important. Some may provide a better service to certain types of patients.

Funding for HETF in the US has changed somewhat since the procedure began in the seventies. The Medicare home reimbursement scheme was introduced in 1981. In 1983 it became financially more beneficial for hospitals to discharge patients home, as a new procedure for the reimbursement of hospitals was introduced that meant they would be reimbursed, not on the length of hospital stay, but on the basis of patient diagnosis and procedures undertaken while the patient is in hospital.

In 1984, the US congress introduced a national reimbursement scheme. According to this scheme, the maximum reimbursement possible was based on the 25$^{th}$ centile of expenditure for the items necessary for HETF (formulas, pump, giving sets etc.). Medicare now base their reimbursement, not only on the diagnosis of the patients (as they did in the past) but also on the functional effects of the condition (e.g. on swallowing). For example, it is not

enough to document that a person has suffered a stroke, it must also be stated that a patient cannot swallow. Also, before Medicare will reimburse the cost of renting or purchasing a pump, they require a statement from the patient's physician stating that the patient has a physiological intolerance to gravity feeding. The cost of feeding more than 2000 kcals daily will not be covered unless special reasons are provided (Elia, 1994).

### 1.6.8 Recommendations

A report by the Irish Commission on Health Funding recommended that formal studies be undertaken to quantify the relative cost-effectiveness of the various para-medical services in Ireland and alternative methods of delivering them (DoH, 1989). There has been a consistent trend since the early 1980's in reducing the share of health expenditure allocated to hospital services and increasing the investment in the community care area (Wiley, 1998). Expenditure has increased to over 12% annually in contrast to a 9% annual increase in the hospital care programme (OECD, 1998). Many patients in the community now receive services from many para-medical personnel (e.g. physiotherapists, speech and language therapists), however, there are currently no dietitians in the community in Ireland with responsibility for the care of patients on HETF. The cost feasibility of providing such a service has never been investigated.

The current emphasis on shifting patient care from the costly hospital setting to the community care setting is likely to continue. For such practice to succeed and be of real value to patients, the relevant structures need to be in place in the community, this includes the appropriate provision of relevant support staff for the GP, the "key ingredient" of primary care.

## 1.7 The health services in Ireland

### 1.7.1 Introduction

Health services may be defined as those services under which public authorities arrange for the diagnosis, prevention, and treatment of human illness (Hensey, 1988). The Irish health care system has a unique structure in that it is a combination of a universal health service, free at the point of consumption, and a fee based private system where individuals have to subscribe to insurance if they wish to be covered for their medical expenses. The government funds approximately 75% of the health care system, and the remaining 25% is funded through voluntary health insurance premiums. Over 36% of the population are entitled to free health services, based on means testing of income (O'Hara, 1998). There are currently over 66,000 staff working in the Irish health care services (DoH&C, 1999). In 1970, the Health Act established an administrative system that lead to the establishment of 8 health boards in the country. Figure 1.7 broadly illustrates the current administration of the health services in Ireland. The shaded areas are mainly concerned with the broad questions of health policy of the scope of the services and how they should be organised. The main burden of work of the health services is laid on the health boards (Hensey, 1988). In March 2000, the largest (in terms of population size) health board area (the Eastern Health Board) changed its administrative structure dramatically, and became the Eastern Regional Health Authority (ERHA). It is planned that the new ERHA will facilitate a more integrated approach to planning, delivery and evaluation of health and personal social services in the eastern part of the country.

### 1.7.2 The Department of Health and Children

On taking office in July 1997, the Government renamed the previously titled Department of Health as the Department of Health & Children (DoH&C). One of the key roles of the DoH&C is to support the Minister for Health in the formulation, development and evaluation of health policy. Over the last decade the Department has published strategy statements outlining their objectives and targets for the health services. In 1994 "Shaping a Healthier Future: A strategy for effective health care in the 1990s" was published, which was followed in May 1997 by the publication of "Working for Health and Well-being", which intended to build on the first document (DoH, 1994, DoH, 1997). The main aims of the Department is, in partnership with the providers of healthcare, and in co-operation with other government departments, statutory and non-statutory bodies, to protect, promote and restore the health and well-being of people by ensuring that health and personal services

are planned, managed and delivered to achieve measurable health and social gain and provide the optimum return on resources invested. The Department is currently undergoing repositioning which involves internal reorganization measures to strengthen the Departments strategic role, to end the direct funding by the Department of voluntary hospitals and certain mental handicap agencies, to devolve executive work to other agencies and to redefine the Departments relationship with the agencies it funds.

The transfer to the health boards of the funding of voluntary mental handicap agencies and voluntary hospitals is a major component of the DoH&C strategy over the next few years. The transfer of funding of the voluntary hospitals and agencies with in the Eastern region took place with the establishment of the ERHA.

### 1.7.3 Health Boards

The role of the health boards is to identify the priority needs of their area, and to measure the impact of the service that they provide, in addition to managing services across a wide range of programmes (O'Dwyer, 1998). The Minister for health specifies the membership of each health board. Memberships of the boards include elected representatives, ministerial nominees and delegates of consumer and health professional organisations. They have statutory responsibility for administering the services provided for in health legislation and by order from the Minister for health (O'Hara, 1998). The populations served by these boards range from 200,000 (Midland Health Board) to 1.3 million (ERHA), with annual budgets ranging from IR£100 million to IR399 million in 1997 (OECD, 1998). An outline of the Health Board management structure is given in Figure 1.8.

**Figure 1.7** Administration of the heath services in Ireland.

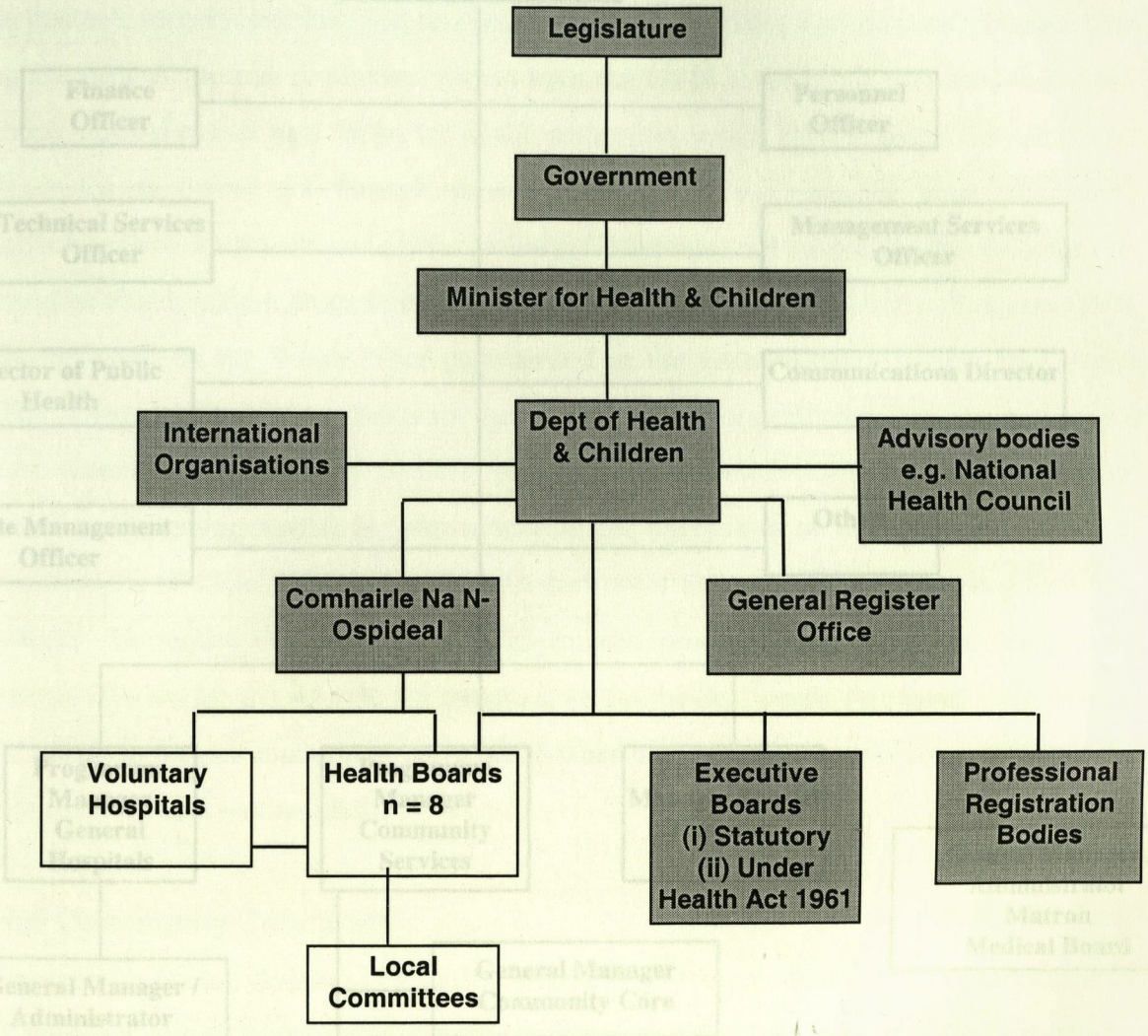
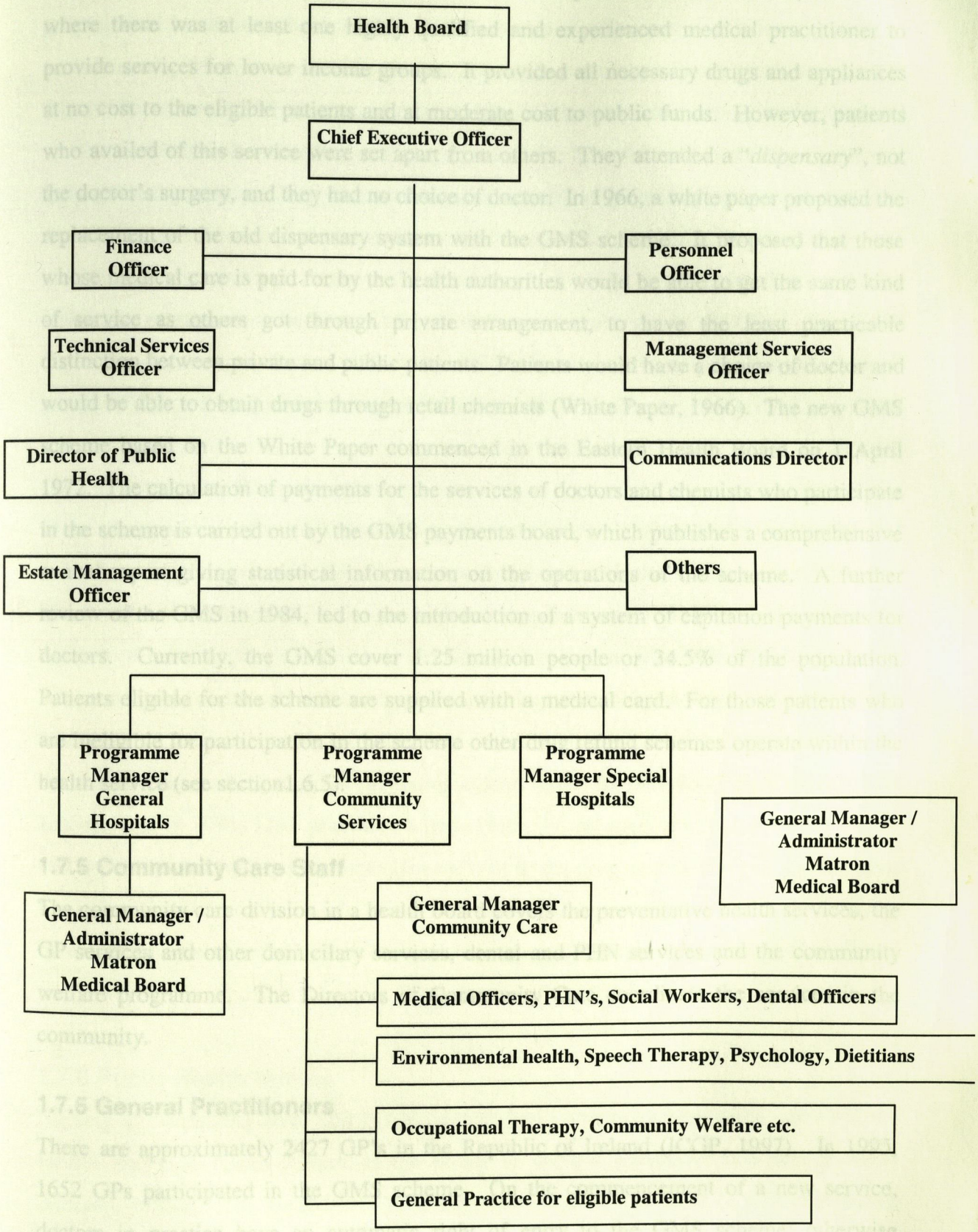


**Figure 1.8** The health board management structure (O'Hara, 1998)



### 1.7.4 The General Medical Services Scheme

Prior to 1972, a so called "*Dispensing System*" was in place for over a century in Ireland where there was at least one highly qualified and experienced medical practitioner to provide services for lower income groups. It provided all necessary drugs and appliances at no cost to the eligible patients and at moderate cost to public funds. However, patients who availed of this service were set apart from others. They attended a "*dispensary*", not the doctor's surgery, and they had no choice of doctor. In 1966, a white paper proposed the replacement of the old dispensary system with the GMS scheme. It proposed that those whose medical care is paid for by the health authorities would be able to get the same kind of service as others got through private arrangement, to have the least practicable distinction between private and public patients. Patients would have a choice of doctor and would be able to obtain drugs through retail chemists (White Paper, 1966). The new GMS scheme based on the White Paper commenced in the Eastern Health Board on 1 April 1972. The calculation of payments for the services of doctors and chemists who participate in the scheme is carried out by the GMS payments board, which publishes a comprehensive annual report giving statistical information on the operations of the scheme. A further review of the GMS in 1984, led to the introduction of a system of capitation payments for doctors. Currently, the GMS cover 1.25 million people or 34.5% of the population. Patients eligible for the scheme are supplied with a medical card. For those patients who are ineligible for participation in the scheme other drug refund schemes operate within the health service (see section1.6.5).

### 1.7.5 Community Care Staff

The community care division in a health board covers the preventative health services, the GP services and other domicilary services, dental and PHN services and the community welfare programme. The Directors of Community Care coordinate the services in the community.

### 1.7.6 General Practitioners

There are approximately 2427 GP's in the Republic of Ireland (ICGP, 1997). In 1995, 1652 GPs participated in the GMS scheme. On the commencement of a new service, doctors in practice have an automatic right of entry to the GMS scheme; otherwise admission to is on the basis of open competition. GPs are obliged to provide certain services to patients (e.g. adequate surgery and waiting room facilities). They are also

obliged to be indiscriminate between public and private patients. GP's receive a variable capitation payment for their GMS eligible patients, dependent on the age, sex and geographical location of their patients. GPs are also eligible for out-of-hours payment as well as money for practice development etc. In 1995, over 91 million pounds was paid to GPs in the scheme (GMS Payment Board, 1995). Unless a patient is admitted to hospital via the accident and emergency department, access to hospital care is usually by referral from general practice. GP's thus perform and important "gate keeping" role in terms of secondary care. There is little information on how powerful the Irish GP gate keeping role is. There is no central registration of GP's in Ireland, although the majority (approximately 85%) are members of the Irish College of General Practitioners (ICGP). The ICGP organises Continuing Medical Education (CME) through a national network of small groups of GPs led by practitioner tutors (Murphy, 1998).

### 1.7.7 Community Pharmacists

There are approximately 1600 pharmacists working in the retail sector in the Republic of Ireland. All pharmacists in Ireland must be registered with the Pharmaceutical Society. The Pharmaceutical Society is the professional organisation for pharmacy and works in a number of different ways to promote development of higher standards of practice and to safeguard public health. The Pharmaceutical Society is responsible also for enforcing the law on retail sale and supply of medicines. Retail pharmacies are the main suppliers of drugs and other medical supplies (including enteral feeds) for patients eligible for the GMS scheme, and in 1995, 1151 pharmacies participated in the scheme (GMS Payment Board, 1995). The pharmacist is reimbursed for the cost of the drug, and is also paid a dispensing fee by the GMS Payment Board. The prices and terms for supply to pharmacists of drugs by manufacturers and wholesalers are governed by an agreement made by the Department of Health with the Federation of Irish Chemical Industries (Hensey, 1988b).

### 1.7.8 Public Health Nurses

Nursing at community level was first established by voluntary organisation. In 1947 the Health Act gave health authorities the power to appoint nurses for community duties (Hensey, 1988b). The number of PHNs employed in1996 was 1222 (An Bord Altranis, 1998). PHNs are required to have a higher diploma in public health nursing provided by National University of Ireland Dublin or National University of Ireland Cork. Those applying to enter these programmes must be registered general nurses and midwives and

also have at least two years work experience. In past times, the PHN role was seen as encompassing all aspects of need within a family setting. At present, the role of the PHN is still quite broad and includes the provision of personalised nursing care to patients who have been discharged to the home from hospital. A recent report of the Commission for Nursing in Ireland advised a community nursing education programme to develop the community skills of each nursing discipline, in order to facilitate nurses to progress by specialising in the care of particular client groups in the community. In the future, therefore we will see an increase in sub-specialisation in community nursing (An Bord Altranis, 1998a).

### 1.7.9 Dietitians

In 1999 there were approximately 125 dietitians working in the health services in Ireland. The vast majority of these dietitians were working in the acute hospital environment. The number of dietitians working in the community has increased over the last decade and approximately 10 were employed in June 2000. These community-based dietitians are primarily involved in health promotion activities (*personal communication*), but some are also involved in administering advice to patients in GP surgeries. The is no statutory registration of dietitians in Ireland, however, dietitians wishing to work in the Irish health system who have *not* qualified in Ireland must have their qualification validated by the DoH&C (*personal communication, DoH&C*). Table 1.15 summaries the organisation of community health personnel in Ireland.

**Table 1.15** Community Health Personnel in Ireland

| Group | Approx n | Registration body | Professional body |
|---|---|---|---|
| Dietitians | 10 | INDI / DoH&C | INDI |
| GP's | 2427 | Medical Council | ICGP |
| PHN's | 1222 | An Bord Altranais | An Bord Altranais |
| Pharmacists | 1600 | Pharmaceutical Society of Ireland | Pharmaceutical Society of Ireland |

## 1.8 Questionnaire design

### 1.8.1 Introduction

A questionnaire is essentially a vehicle for human communication (Stone, 1993). Much of the clinical research undertaken by the medical and allied professions utilises a questionnaire (Fallowfield, 1995). Often, the use of questionnaire is the only way to obtain certain types of data. Designing a questionnaire is a difficult task and one which requires careful attention if the aims and objectives of a survey are to be met. Questionnaires should be appropriate, intelligible, unambiguous, unbiased, omnicompetent, piloted before use, and finally, questionnaires should be ethical (Stone, 1993).

### 1.8.2 Types of questionnaires

The design of a questionnaire depends heavily on who will complete the questionnaire. The questionnaire may be *administered* by a researcher, or may be *self-administered* by the respondent. In an administered questionnaire, questions are read out by an interviewer, to which the respondent replies orally, and the response is noted by the interviewer. Administered questionnaire may be "standardised" or "unstandardised". Un-standardised questionnaires involve re-wording questions to suit individuals respondents, also, the order of questions can be changed to conform with the respondents spontaneous flow of thought, and questions or probes can be introduced when it is felt that further useful information may be found. The greater adaptability of the un-standardised procedure might produce more authentic information than a standardised questionnaire, as it allows a more equal level of apparent understanding. The interviewer can record items and introduce prompts to try and ensure that the respondent has correctly understood what information is required. However, this method, allows greater opportunity for the interviewer to introduce their own personal views and attitudes, and therefore, to introduce an potential source of bias into the data. For most purposes, the standard procedure is preferred. In a standardised technique, the interviewer is allowed no initiative with regard to the introduction of addition prompts; their role is limited to the content of the questionnaire only (Abrahamson, 1974). Self administered questionnaires are completed by the respondent, without the assistance of an interviewer. When using a self-administered questionnaire, it is important to bear in mind who will be answering the questionnaire (i.e. this is especially important if children are to answer the questionnaire).

### 1.8.3 Types of questions

There are a number of different ways in which questionnaire can be posed in a questionnaire. The format of the questions depends largely on how the survey will be carried out (e.g. administered or self-administered). Questions may be *open* or *closed.* Open questions do not suggest any specific response e.g. how do you feel today? Open questions require the respondent to frame his or her own response using their own words, thus allowing the expression of individual experience. However, responses can be long, varied, difficult to compare with others, and difficult to handle statistically (Bennet & Ritchie, 1975).

Closed questions require the respondent to choose his or her answer from a given limited selection. There are a number of different formats of responses to closed questions. Closed questions may either be dichotomous or multiple choice. If questions are clear and unambiguous, simple dichotomous answers may be given e.g. do you drink tea? Yes/No. Categorical scales provide more choice for answers e.g. how do you travel to work? Walk/Bus/Train/Car/Other.

For certain questions, simple categorical or dichotomous answers are unsuitable, e.g. when seeking an opinion or feeling. Response formats which permit continuous judgment include adjectival, Likert, visual analogue, semantic differential and Guttman scales (Fallowfield, 1995). Likert scales consist of a statement to which the respondent ticks his or her response from a scale, usually of 1 –5 of answers such as "strongly agree, agree, uncertain, disagree, strongly disagree".

Ambiguity in questions must be avoided at all costs. Questions must be easily understood by the respondent, only one question should be asked at a time, and the question should not be open to interpretation. Piloting of the questionnaire on sufficient numbers of relevant individuals should enable such questions to be noted and removed before the survey is carried out.

Questionnaires which contain a variety of question types are less likely to bore respondents and may improve response and the quality of the data (Bennet & Ritchie, 1975)

### 1.8.4 Bias

Bias is defined as the intrusion of any unplanned or unwanted influence (Kahn & Cannell, 1957). Bias may be introduced by the use of *leading* questions or *loaded* words, which should be avoided. Use of jargon must be avoided when constructing questionnaire for use by lay populations (Fallowfield, 1995). The *respondent* will also be biased in the direction of his or her own self interest.

### 1.8.5 Questionnaire layout

The layout of a questionnaire is important, as the visual impact on the respondent may either arouse interest or alternatively, discourage them from participating. The questionnaire should be easy to follow and attractively set out (Fitzpatrick, 1991). Questionnaires should begin with an introduction, explaining the aims of the survey, and instructions on how the questionnaire should be completed. The introduction should be very general in its nature, otherwise it may introduce bias (Bennet & Ritchie, 1975). The initial portion of the questionnaire should be neutral, but interesting, and the more sensitive questions should come later. Multiple, branching questions should be avoided (Stone, 1993). Statements of confidentiality are important, and require only a simple explanation of how the information gathered in the survey will be processed and analysed (Fitzpatrick, 1991). Cooperation may decline if there are too many items or questions included (Fallowfield, 1995), particularly in self administered questionnaires. The respondent should always be thanked for filling out the questionnaire (Stone, 1993).

### 1.8.6 Piloting of questionnaires

Before a questionnaire can be used in a survey, it needs to be pilot tested for a number of reasons. Piloting will allow several potential problems to be caught before the real survey is carried out. If respondent are given space for open ended comments, additional items or issues not included in the first draft of the questionnaire may emerge (Fitzpatrick, 1991). Piloting should be carried out on a small sample (not necessarily taken at random) (Stone, 1993). The responses to the pilot questionnaire must then be evaluated to assess the questionnaires *validity* and *reliability*. A good questionnaire is one that works, i.e. it should be self-validating (Stone, 1993). Validity, in terms of questionnaires means the extent to which a measuring instrument measures what it is supposed to measure. Validity may be assessed by comparing results to a "gold standard", although this is often difficult, as there may not be a gold standard, a(s this may be the reason why the research is being carried out in the first place). Validity can be viewed in terms of relevance, completeness and accuracy i.e. *does it obtain the type of information it was designed to obtain? Does it collect all the relevant information? Can one rely on the responses to each question?* Reliability means the how well the questionnaire can perform in terms of obtaining the same answer from the same person at a different occasion (Stone, 1993). No questionnaire will be perfectly valid or reliable, but the extent to which it is will provide the means of predicting its potential usefulness (Bennet & Ritchie, 1975). Also it must also be borne in mind that often, questionnaires are designed by some researchers to find

out answers to specific questions about practice or treatment, and those researchers may not be particularly interested in producing a reliable validated test, which will be standardised for use in medicine (Fallowfield, 1995).

### 1.8.7 User attitudes to questionnaires

Respondent acceptance of a questionnaire is important in terms of their motivation to complete the questionnaire. A negative attitude may result in low motivation and carelessness, enhancing the number of false answers or unanswered questions (Mellner, 1970). There are a few factors which will influence an individuals decision to complete a questionnaire. Reasons for a poor GP response to postal surveys have been investigated and include insufficient involvement with the subject being researched, qualms about encroachment of confidentiality and resentment to the interference to his or her work (McAvoy, 1996). Respondents are more likely to respond if given assurances about the importance of the survey, confidentiality of the information given, and if there is a lack of moral judgment on the part of the researcher with regard to the responses (Pomeroy, 1963).

# Chapter 2

# A survey of adult patients on tube feeding in the community in the Dublin area

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their functional status, nutritional status, indications for feeding, feeding practices, complications experienced, and any problems they had experienced whilst on home tube feeding.

## 2.3 Methods

### 2.3.1 Sample Selection

Methods of sampling were considered at the project planning stage. Initially, it was hoped to identify patients receiving home tube feeds in the community through EHB/GMS dispensing records, but this did not prove to be feasible. Subsequently, it was considered to identify patients on discharge from hospital. Ethical approval to survey patients on home tube feeding was sought and granted by two ethics committees, the Federated Voluntary Hospitals and St. James's Hospital ethics committee, and the Irish College of General Practitioners ethics committee.

The dietetic notes of patients who have been discharged into the community on enteral feeding from St. James's Hospital are filed separately from other patient notes in the department of clinical nutrition in St. James's Hospital. Also, as each patient is discharged on tube feeding, a standard form is completed for the INDI, in preparation for a proposed national register of patients on tube feeding in the community (see Chapter 1). At the start of the recruitment phase, all available patient register forms and patient dietetic notes were examined. A letter seeking permission to review patients medical records, visit and survey them in the community was written to each patients consultant.

If the patient was living at *home* since their discharge from hospital, their GP was contacted by letter before an attempt was made to contact the patient, to avoid causing distress to the patients family if the patient was deceased. Each GP was subsequently contacted by telephone to inquire if the patient was still alive. If the patient had died, a date of death (if known by the GP) was established. If the patient was still alive, they were contacted at home by telephone, the survey was explained to them (or to their carer), and arrangements were made to visit the patient in their home to carry out the survey.

If the patient was discharged from hospital to a nursing home or other institution, then the individual in charge of the institution was contacted by letter, and permission was sought to visit the home and discuss the patients feed with a member of the staff who was closely involved in their care. The letter was followed with a telephone call, and again, if the patient had died, a date of death was ascertained if possible. Otherwise, appointments were made to visit the patient in the home. Patients who were discharged from St. James's

hospital to areas outside the EHB region were not included in the survey, as it was not logistically feasible to visit these patients.

Basic information (i.e. age, sex, indications for tube feeding, geographical discharge destination, discharge destination, feeding regimen, route of feeding, length of time spent on tube feeding in the community until death or discontinuation of feeding) was collated on all patients discharged from St. James's Hospital in order to provide a profile of the patients that had been discharged from the hospital over the previous 6 years. Information gathered was that which was accessible in patients dietetic and medical notes.

Following the first stage of the survey, when the initial patients on tube feeding in the community had been surveyed, regular visits were made to the dietetic department in St. James's hospital to recruit new patients discharged on tube feeding. Dietitians in the department of clinical nutrition were also asked to contact the researcher, should any patients in their care be discharged on enteral feeding.

### 2.3.2 Questionnaire Design

A questionnaire was designed (see Appendix 1). Almost all of the questions in the questionnaire were of the "closed" variety, with a choice of answers. The questionnaire used in this survey could be classified as being semi-standardised. Un-standardised questionnaires involve re-wording questions to suit individuals respondents, also, the order of questions can be changed to conform with the respondents spontaneous flow of thought, and questions or probes can be introduced when it is felt that further useful information may be found. The greater adaptability of the un-standardised procedure might produce more authentic information than a standardised questionnaire, as it allows a more equal level of apparent understanding. The interviewer can record items and introduce prompts to try and ensure that the respondent has correctly understood what information is required. However, this method, allows greater opportunity for the interviewer to introduce their own personal views and attitudes, and therefore, to introduce an potential source of bias into the data. For most purposes, the standard procedure is preferred. However, for this particular survey, where the same questionnaire was administered to both nursing staff and non-medical patients and carers, a "semi-standardised" method was deemed most appropriate, i.e. while maintaining a standardised structure, additional sub-questions were included at the discretion of the interviewer (Abrahamson, 1974). The questionnaire took between 45 minutes and 1 hour to administer.

### 2.3.3 Questionnaire content

The questionnaire was divided into 13 sections (see Table 2.1).

**Table 2.1** Topics included in the patient questionnaire

| |
|---|
| 1. Patient details |
| 2. Primary carer/Nursing home/Institution details |
| 3. Feeding regimen details |
| 4. Nutritional review of patients in the community |
| 5. Medical information |
| 6. Physiological and other problems |
| 7. Education re home enteral nutrition |
| 8. Payment methods |
| 9. Miscellaneous data |
| 10. Length of time on tube feeding in the community and readmission data |
| 11. Anthropometry |
| 12. Barthel Index* |
| 13. Norton Scale** |

** Mahoney, F & Barthel, D (1965)*
*** Norton D (1996)*

Questionnaire content was decided on the basis of findings of the pilot study (Aoibheann O'Connor) and other studies that have been carried out on similar subjects (Parker *et al.* 1996). The pilot study carried out by Aoibheann O'Connor (student dietitian), looked at basic details such as demographics, diagnosis, logistics, feeding schedules and anthropometric data in 25 nursing home patients. These details were also sought in this questionnaire. The questionnaire contained a huge range of question's and covers all aspects of enteral tube feeding in the home. The questionnaire was pilot tested on 2 patients who were in-patients in St. James Hospital, but who had lived at home on tube feeding before hospital admission. The patients carers were interviewed. Following the pilot, the questionnaire was modified appropriately. All of the changes made to the questionnaire at this stage were simple re-wording and re-structuring of the layout to allow for better flow of the questions in the interview. No new questions were added, and none were deleted.

#### The Barthel Index

This measurement of functional ability was developed by Mahoney and Barthel in 1965 (Mahoney & Barthel, 1965). It was originally developed to observe functional ability before and after intervention treatments, and to quantify the amount of nursing care required. It was previously used for patients who were in hospital for long periods of time, with neuromuscular and musculo-skeletal disorders, however, but it has used more generally since. Patients score zero when they are unable to carry out particular daily

functions (e.g. dressing, bathing, toilet use), therefore the score reflects the amount of time needed to assist a patient in the activities of daily living. This scale does not take psychological status into account, nor is it a complete measure of functioning, as many aspects of daily living are omitted, e.g. domestic and social functioning. The Barthel index is a simple scale, yet because of it's simplicity, it has obvious but acknowledged limitations. There is, however, an increasing number of references recommending its use with groups of patients with neurological disability (Collin *et al.* 1988, Wade & Collin, 1988). Recently, the Barthel index has been used in a number of studies to assess the functional status of patients following stroke (Resnick & Daly, 1997; Wyeller *et al.* 1997) and also for patients with Parkinson's Disease (Martinez-Martin & Garcia-Urra, 1997). Validity tests have been carried out on the Barthel index, comparing it with other rating scales and have found it to have a good predictive value (Mattison *et al.* 1991, Granger *et al.* 1979, Wylie & White, 1964). A reappraisal of reliability and validity studies in stroke found that the Barthel Index was the most reliable disability scale (D'Olhaberriague *et al.* 1996).

### Norton Scale

The Norton/Modified Norton Scale, has traditionally been used by nurses as a predictor of the risk of development of decubitus ulcers in elderly patients (Norton, 1996; Bassett, 1993; Hodge *et al.* 1990). It is a simple scale that takes about 30 seconds to complete. The scale has also been utilised in nutritional studies with geriatric patients (Unosson, *et al.* 1991, Olin *et al.* 1996) to assess functional status.

## 2.3.4 The Interview/Questionnaire Administration

Arrangements were made to visit the patient's home, nursing home or institution. Every effort was made to visit at a convenient time for the patient and carer in order to ensure full co-operation and attention of the interviewee(s). A patient information leaflet was given to each patient/carer, and a consent form was signed before the questionnaire was administered. The anthropometric assessment was carried out after the questionnaire was administered. Oral food consumption was measured using a combination of 24 hour recall and diet history. The patient's medical records were reviewed to verify dates, medical procedures etc., as many of the nurses and carers may not have been fully aware of procedures carried out on the patients in hospital. Questionnaires were then coded and entered into a computer database for analysis.

### 2.3.5 Anthropometry

Nutritional status was evaluated by carrying out an anthropometric assessment where possible, using established methods (Chumlea *et al.* 1987). Patients weight, height, and skinfold thickness were measured, in addition to hand grip dynamometry. Where patients' weight and height could not be measured using standard techniques, they were estimated using other anthropometric parameters, such as knee-height (See section 1.2) (Chumlea *et al.* 1988). Anthropometric measurements were interpreted using the appropriate reference data. The Bishop Tables were used if the patients was <65 y (Bishop *et al.* 1981) and the Burr Tables were used for patients >65 y (Burr & Philips 1984). Basal metabolic rate (BMR) were estimated using the Schofield equation, (Schofield, 1985) and a combined activity and thermogenesis factor was added to establish patients' estimated average daily requirements (Elia, 1990). Weights were recorded to the nearest 0.1 kg using an electronic scales (model "Soehnle"). Skinfold thickness' were measured with a pinch calipers (model "Holtain") to ± 0.01mm.

### 2.3.6 Statistical analysis

As well as the usual descriptive analysis (mean, median, standard deviation, range, sum, inter-quartile range, minimum, maximum), Chi squared tests (Crosstabs), and 2 sample and independent t tests were carried out to investigate relationships between a wide range of variables. The Statistical Package for Social Sciences (SPSS for Windows, V.6.0) was used to analyse data. A small sub-sample of data was hand analysed to check for errors in the computer analysis.

## 2.4 Results

One hundred and seventy patients who were discharged on tube feeding between July 1991 and July 1998 were identified both retrospectively (*n* 126) and prospectively (*n* 44) from hospital dietetic records. The number of patients discharged from the hospital over the 6 years increased yearly, for example there was a 24% increase in discharges between 1995 and 1997 (see Figure 2.1). The darker shaded portion in 1998 refers to the numbers of patients that would have been discharged if the trend had continued for the rest of the year as it did from January to March.

The dietetic and medical notes (where possible) of these patients were examined and basic information regarding the patients was collated (see Table 2.2). Twenty eight percent were discharged to rural areas and were thus excluded due to logistical and financial constraints of the survey. When the Dublin and rural groups were compared, it was found that patients discharged to areas outside Dublin were slightly younger on average (67.1 years, SD 12.8) than patients in the Dublin area (71.9 years, SD 14.7), probably due to the fact that a greater percentage of the patients outside the Dublin area required tube feeding due to cancer. This because a greater proportion of patients from rural areas are treated in St. James's Hospital for cancer than for stroke or other neurological disorders (St. James's Hospital is a tertiary referral centre for the treatment of cancer).

**Figure 2.1.** Numbers of patients discharged on tube feeding- 1992-1998

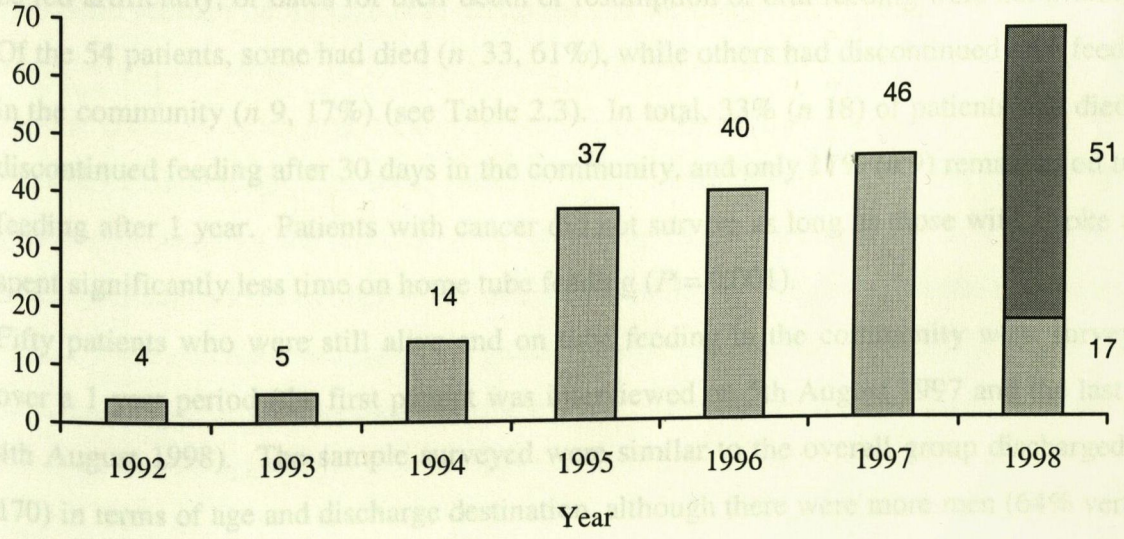


**Table 2.2** Characteristics of patients discharged on tube feeding from St. James's Hospital between the years 1990 -1997

| Characteristic | Discharged | Surveyed |
|---|---|---|
| Number | 170 | 50 |
| Age | 70.6 (SD 14.3) | 68 (18) |
| ***Sex*** | | |
| Males | 53% (90) | 64% (32) |
| Females | 47% (80) | 36% (18) |
| ***Diagnostic indications for tube feeding*** | | |
| Stroke | 35% (60) | 46% (23) |
| Cancer | 37% (63) | 24% (12) |
| Other indications | 28% (47) | 30% (15) |
| ***Geographical discharge destination*** | | |
| Dublin | 72% (122) | 100% (50) |
| Outside Dublin | 28% (48) | 0% |
| ***Discharge destination*** | | |
| Home | 41% (70) | 42% (21) |
| Nursing home facilities | 59% (100) | 58% (29) |
| ***Feeding regimen*** | | |
| Full nutrition support | 65% (110) | 72% (36) |
| Supplementary nutrition support | 45% (60) | 28% (14) |
| ***Route of feeding*** | | |
| Nasogastric/nasoduodenal tube | 7% (12) | 2% (1) |
| Gastrostomy tube | 83% (141) | 92% (46) |
| Jejunostomy tube | 10% (17) | 6% (3) |
| Average volume of feed used | 1500mls | 1500mls |

*N in parenthesis*

Initial follow up of patients in the EHB area (*n* 116) determined that many patients (*n* 50, 43%) had died since their discharge on HETF and that some (*n* 15, 13%) survivors had discontinued feeding. Information on completed tube feeding episodes (i.e. the length of time spent in the community on tube feeding before death or resuming full oral nutrition) was obtained for 54 of the 116 patients (47%). The remaining patients either continued to be fed artificially, or dates for their death or resumption of oral feeding were not available. Of the 54 patients, some had died (*n* 33, 61%), while others had discontinued tube feeding in the community (*n* 9, 17%) (see Table 2.3). In total, 33% (*n* 18) of patients had died or discontinued feeding after 30 days in the community, and only 17% (*n* 9) remained on tube feeding after 1 year. Patients with cancer did not survive as long as those with stroke and spent significantly less time on home tube feeding ($P = 0.001$).

Fifty patients who were still alive and on tube feeding in the community were surveyed over a 1 year period (the first patient was interviewed on 5th August 1997 and the last on 4th August 1998). The sample surveyed were similar to the overall group discharged (*n* 170) in terms of age and discharge destination, although there were more men (64% versus 53% in the overall sample) and more patients with stroke (46% versus 37%) in the survey group.

**Table 2.3** Length of time spent by adult patients on tube feeding in the community until death or discontinuation of feeding

| | Diagnosis | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | ***Cancer*** | | | ***Stroke*** | | | ***Other*** | | |
| Time on tube feeding (d) | median | IQR | n | median | IQR | n | median | IQR | n |
| When on tube feeding until death | 30 | 174 | 15 | 193 | 502 | 18 | 199 | 245 | 8 |
| Before resuming oral intake | 13 | 58 | 6 | 477 | 59 to 605* | 3 | 18 | 1 to 34 | 4 |

*IQR, inter-quartile range*
**Range is given where n was insufficient to yield a meaningful IQR*

### 2.4.1 Demographic details

There were more males (*n* 23, 64%) than females (*n* 18, 36%) in the group, with an average age of 68 years. The reason for the predominance of males to females in the survey group is due to the retrospective nature of the survey. Eleven percent of all female patients (*n* 9) discharged on tube feeding from St. James's to the Dublin area required tube feeding due to cancer, but at the start of the study when patients in the community were followed up, all females patients with cancer had died and none were subsequently discharged during the length of the study. Conversely, only 30% (*n* 27) of all males discharged from St. James's to the Dublin area required tube feeding following stroke, but when the male patients were followed up, a greater proportion were still alive, and so 44% of the male population in the survey group (*n* 14) were patients with stroke. This lead to the disproportionate number of males versus females in the study, and the greater proportion of patients with stroke. Figure 2.2 outlines the age distribution of the males and females in the survey group.

Men were younger on average than the women in the sample (65 y years *versus* 74 y). Just under half of the sample (*n* 21, 42%) lived in their own home, while 29 (58%) resided in nursing home or other long term care facilities (Table 2.4). Patients in nursing homes were older on average than those patients in their own homes (58 y versus 75 y), and a greater percentage of the females in the group resided in nursing (83% of females (*n* 15) lived in nursing homes as opposed to 44% (*n* 14) of males). Figure 2.3 outlines the number of days spent on home feeding by the group. One patient had been on tube feeding at home for over 7 years. The collective experience of tube feeding in the community of the sample surveyed was 49 man-years. The average length of time on tube feeding was 0.98 y.

**Figure 2.2** Age distribution of adult males and females in the survey group (n = 50)

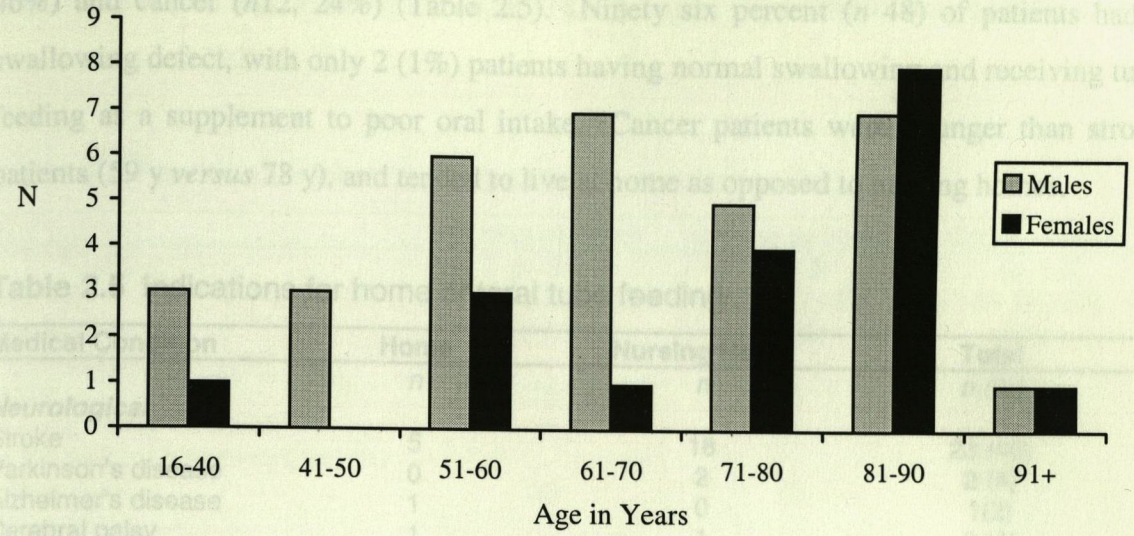



**Figure 2.3** Length of time spent by adults on tube feeding in the community (n = 50)

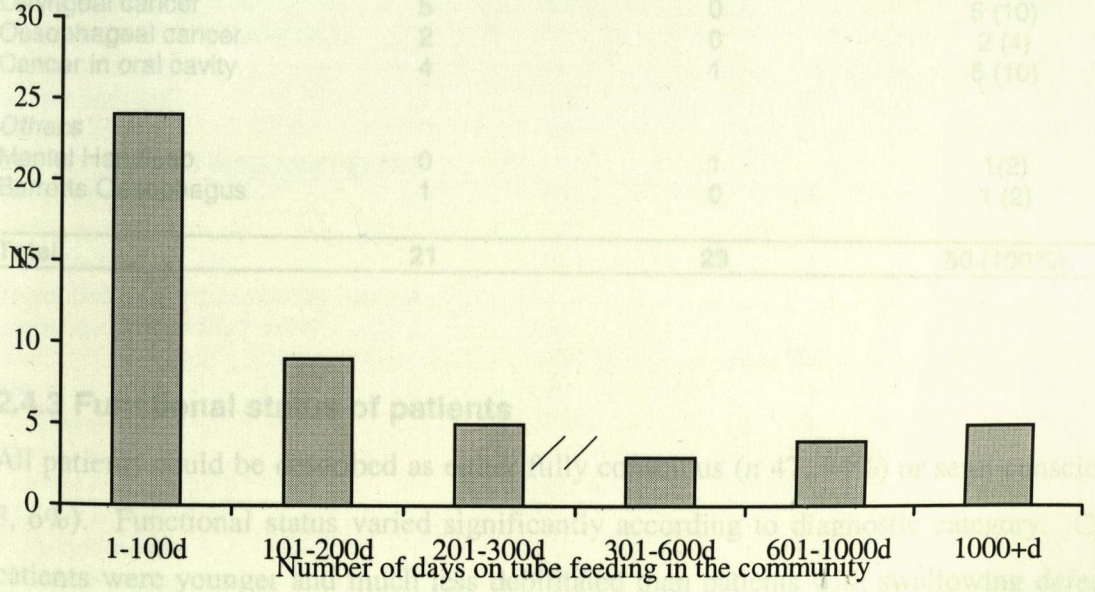



**Table 2.4** Type of residences (other than own home) of patients surveyed

| Residence | n | (%) |
|---|---|---|
| Private nursing home | 8 | 28 |
| EHB funded nursing home | 13 | 44 |
| Retired priests home | 1 | 4 |
| Retired Garda home | 1 | 4 |
| Psychiatric institution | 3 | 10 |
| Hospice (long term care unit) | 2 | 6 |
| Long term care for chronic young sick | 1 | 4 |
| **Total** | **29** | **100** |

### 2.4.2 Indications for tube feeding

The principal indications for tube feeding in this sample of adult patients were stroke (*n* 23, 46%) and cancer (*n*12, 24%) (Table 2.5). Ninety six percent (*n* 48) of patients had a swallowing defect, with only 2 (1%) patients having normal swallowing and receiving tube feeding as a supplement to poor oral intake. Cancer patients were younger than stroke patients (59 y *versus* 78 y), and tended to live at home as opposed to nursing homes.

**Table 2.5** Indications for home enteral tube feeding

| Medical Condition | Home | Nursing Home | Total |
|---|---|---|---|
| | *n* | *n* | *n (%)* |
| ***Neurological*** | | | |
| Stroke | 5 | 18 | 23 (46) |
| Parkinson's disease | 0 | 2 | 2 (4) |
| Alzheimer's disease | 1 | 0 | 1(2) |
| Cerebral palsy | 1 | 1 | 2 (4) |
| Multiple sclerosis | 1 | 1 | 2 (4) |
| Other | 1 | 5 | 6 (12) |
| ***Oncology*** | | | |
| Laryngeal cancer | 5 | 0 | 5 (10) |
| Oesophageal cancer | 2 | 0 | 2 (4) |
| Cancer in oral cavity | 4 | 1 | 5 (10) |
| ***Others*** | | | |
| Mental Handicap | 0 | 1 | 1(2) |
| Barretts Oesophagus | 1 | 0 | 1 (2) |
| **Total** | **21** | **29** | **50 (100%)** |

### 2.4.3 Functional status of patients

All patients could be described as either fully conscious (*n* 47, 94%) or semi-conscious (*n* 3, 6%). Functional status varied significantly according to diagnostic category. Cancer patients were younger and much less debilitated than patients with swallowing defects of neurological origin. Over half of the sample (*n* 29, 58%) had dysphasia (ranging from major to minor) and 16% (*n* 8) were aphasic. Fifty eight percent of those surveyed (*n* 29) were either bedridden or chair-bound, and only 30% (*n*15) could walk unaided. Fifty two percent of the survey group (*n* 26) were doubly incontinent, and 58% (*n* 29) never left their place of residence. Only 6 (3%) patients could leave their home unaided and just one patient (2%) on tube feeding continued to work (he was self-employed). The average score on the Barthel Index was 6.5 (a maximum score of 18 indicates unlimited mobility/ability to carry out the activities of daily living). The average Norton Scale score was similarly low at 17 (a maximum score of 28 indicates unlimited mobility/ability to carry out the

activities of daily living). Table 2.6 describes the functional status of cancer, stroke, and other patients in the survey group. Not surprisingly, patients living in nursing homes (the majority of whom had neurological disease) had less functional ability than patients in their own homes (see Table 2.7).

**Table 2.6** Functional status of adult patients on tube feeding

| | Stroke patients | Cancer patients | Other patients |
|---|---|---|---|
| | (*n* 23) | (*n* 13) | (*n* 14) |
| Age* (y) | 78 (SD 10) | 59 (SD 10) | 61 (SD 27) |
| Sex (M/F) | 61/39 | 100/0 | 29/71 |
| ***Place of residence (%)*** | | | |
| Home | 22 | 92 | 29 |
| Nursing home/ institution | 78 | 8 | 71 |
| ***Is the patient house-bound?(%)*** | | | |
| Yes | 83 | 23 | 50 |
| No | 17 | 77 | 50 |
| ***Patients' speech communication (%)*** | | | |
| Normal | 13 | 46 | 29 |
| Slight impairment | 22 | 15 | 21 |
| Major/minor difficulty | 48 | 39 | 21 |
| Nil (aphasic) | 17 | 0 | 29 |
| ***Patients' mobility level (%)*** | | | |
| Walks unaided | 4 | 92 | 14 |
| Walks with aid | 18 | 8 | 7 |
| Unable to walk | 78 | 0 | 79 |
| ***Assistance with tube feeding (%)*** | | | |
| No assistance | 100 | 39 | 7 |
| Some assistance | 100 | 39 | 7 |
| Full assistance | 100 | 23 | 86 |
| ***Does the patient currently have a good quality of life? †(%)*** | | | |
| Yes | 39 | 85 | 50 |
| No | 61 | 15 | 50 |
| Incontinence # (%) | 70 | 0 | 71 |
| Norton Scale Index ‡ | 15.5 (SD 3.0) | 22.6 (SD 4.18) | 14.8 (SD 3.8) |
| Barthel ADL Index § | 2.8 (SD 4.9) | 16.3 (SD 1.6) | 3.6 (SD 5.6) |
| ***Mental condition*** | | | |
| Fully orientated | 22 | 100 | 33 |
| Occasionally confused | 48 | 0 | 20 |
| Cannot answer adequately | 26 | 0 | 40 |
| No contact | 4 | 0 | 7 |

** Values given are means with (SD) standard deviation in parentheses*

*† In the opinion of the primary carer/subjective assessment of interviewer*

*‡ Norton Scale: values given are means. A maximum score of 28 indicates unlimited mobility/ability to carry out the activities of daily living*

*§ Modified Barthel ADL Index: values given are means. A method to assess functional status and/or quality of life (maximum score of 18)*

*#Incontinent : bowel & bladder*

**Table 2.7** Functional status: comparison between diagnostic categories and place of residence

| | Patients at home | Patients in care |
|---|---|---|
| **Stroke** | | |
| Barthel Index | 9.2 *(n = 5)* | 1.33 *(n = 18)* |
| Norton Scale | 15.6 *(n = 5)* | 14.7 *(n = 18)* |
| **Cancer** | | |
| Barthel Index | 17.1 *(n = 11)* | 15.0 *(n = 1)* |
| Norton Scale | 22.2 *(n = 11)* | 26.0 *(n = 1)* |
| **Other** | | |
| Barthel Index | 7.6 *(n = 5)* | 3.1 *(n = 10)* |
| Norton Scale | 16.4 *(n = 5)* | 15.1 *(n = 10)* |

**Table 2.8** Functional status: comparison between diagnostic categories

| | Neurological patients | Cancer patients | *P* |
|---|---|---|---|
| Barthel Index | 3.33 (*n* 36) | 17.0 (*n* 12) | 0.00 |
| Norton Scale | 15.0 (*n* 36) | 23.7 (*n* 12) | 0.00 |

** the patient not included suffered from Barrettes oesophagus, and was not suitable for inclusion in either group*

### 2.4.4 Feeding Practices

Eighty-six percent of patients (*n* 43) required some degree of assistance with their enteral feeding (*n* 6, 12% minor assistance and *n* 37, 74% full assistance). Only 1 (2%) patient was fed through a nasogastric tube, 92% (*n* 46) of the patients were fed by a gastrostomy tube, and 6% (*n* 3) via a jejunostomy tube. Fifty eight percent of the sample (*n* 29) were fed for more than 16 hours per day, and 16% (*n* 8) of patients were fed overnight only. Only one patient used the bolus method of feeding exclusively, while some patients (*n* 8, 16%) used both bolus and pump-assisted methods of feeding (generally 2, 3 or 4 bolus feeds during the day, and overnight pump-assisted feeding), as outlined in Table 2.9.

The majority of the sample (*n* 39, 78%) were on full nutritional support with no significant oral intake (i.e. a number of patients (*n* 3, 6%) were allowed a few spoonfuls of food per day for quality of life, which contributed little to their overall calorific intake). Well over half (*n* 35, 70%) of the patients were fed using a standard (4.2kJ per ml) feed (although one woman decanted 1 pint of Guinness daily into her husband's enteral feeding container!). The types of enteral feeds used by the group are listed in Table 2.10.

The average daily prescribed volume of feed was 1.5L (SD 0.4L), constituting an average of 6.93MJ (SD 1.85 MJ). In those who consumed significant amounts of food orally (*n* 11, 22%), this provided an average of 31% (SD19.7%) of their estimated daily energy requirements. Intake was measured using a 24 hour recall and diet history. Almost three quarters (*n* 36, 71%) of those who had some oral intake required modification of diet

consistency (e.g. semi-solid). The difference between cancer, stroke and other patients in terms of their feeding regimens are summarised in Table 2.11.

**Table 2.9** Feeding methods employed by patients on community enteral feeding.

| Methods of feeding | n patients (%) |
|---|---|
| Continuous (>16 hours per day) | 24 (48) |
| Cyclic (<16 hours per day) | 20 (40) |
| Bolus only | 1(2) |
| Bolus and Cyclic | 5 (10) |

**Table 2.10** Types of feed used by patients on community tube feeding

| Type of feed | Example | N (%) |
|---|---|---|
| Standard feed only (non-fibre containing) | Ensure† | 13 (26%) |
| Standard fibre containing feed only | Nutrison Fibre‡ | 1 (2%) |
| High protein high calorie feed (HPHC) only | Nutrison High Energy‡ | 9 (18%) |
| Standard low osmolar feed | Osmolite† | 5 (10%) |
| Special (disease specific) feed only | Pulmocare† | 2 (4%) |
| Standard non-fibre feed & Standard fibre feed | Ensure & Enrich† | 9 (18%) |
| Standard HPHC feed & Standard non-fibre feed | Ensure Plus & Ensure† | 2 (4%) |
| Standard HPHC feed & Standard fibre feed | Ensure Plus & Enrich† | 4 (8%) |
| Standard fibre feed & Guinness | Nutrison‡ & Guinness | 1 (2%) |
| Standard non-fibre feed & semi-elemental feed | Nutrison & Pre-Nutrison‡ | 3 (6%) |
| Special feed & Standard fibre feed | Pulmocare & Enrich† | 1 (2%) |
| **Total** | | **50** |

*† Manufactured by Abbott Laboratories*
*‡ Manufactured by Nutricia.*

**Table 2.11** Feeding regimens: comparison between diagnostic categories

| Variable | Stroke | Cancer | Other |
|---|---|---|---|
| | *n = 23* | *n = 12* | *n = 15* |
| Oral intake | 13 % | 39 % | 21 % |
| No oral intake | 87 % | 61 % | 79 % |
| Feed delivered daily (Mls) | 1489 (409) | 1661 (472) | 1410 (319) |
| Fibre feed included in regimen | 39% | 39% | 8% |
| Energy per day from enteral feed (MJ) | 6.7 (1.6) | 7.9 (2.3) | 6.4 (1.4) |
| Energy per day from oral intake (MJ) | 2.6 (1.8) (n = 3) | 2.0 (1.4) (n = 4) | 3.2 (1.9) (n = 4) |
| *Total energy intake (MJ)* | *7.0 (1.3)* | *8.9 (1.4)* | *6.9 (1.8)* |
| Estimated energy intake | 7.2 (n 19) | 8.9 (n 13) | 7.3 (n 10) |
| Estimated energy expenditure | 6.3 (n 19) | 7.8 (n 13) | 5.8 (n 10) |
| **Estimated energy balance** | **+0.9** | **+1.1** | **+1.5** |

### 2.4.5 Complications experienced by the group

The 50 individuals surveyed experienced 67 tube insertions. One patient spent seven years in the community on tube feeding before his PEG was eventually changed for the first time. Excluding this patient, the average length of time in the community before the first change of PEG tube was 19 d (SD 14) for cancer patients (*n* 4, 8%) and 421 d (SD 298) for patients with neurological disease (*n* 8, 16%). The survival of subsequent feeding tubes was similar (24 (SD 3.53) days for cancer patients (*n* 2, 4%) and 341 (SD 567) days for patients with neurological disease, (*n* 3, 6%). Only one patients needed a fourth tube insertion. The reason for the shorter survival of PEG tubes in cancer patients is not known, but may be due to their greater mobility and thus increased predisposition to accidental removal, or differences in tube design. As the patients were not followed up after the survey took place in the community, survival of replacement tubes is not known. Tubes were replaced because of accidental removal (*n* 7, 14%), blockage, (*n* 2, 4%), leakage of feed (*n* 1, 2%) or other malfunction (*n* 7, 14%).

Enteral feeding related complications experienced by this group whilst in the community are outlined in Table 2.12. Carers or patients were asked if a complication had occurred during their time on HETF, and an answer of "yes", "no" or "don't know" was given. No attempt was made to estimate the number of times the complication was experienced, as this would have been very difficult to estimate retrospectively. Twenty seven percent of patients (*n* 14) reported experiencing pain around the stoma site, 23 (46%) redness/erythema, 8 (16%) experienced infections around the stoma site, and 17 (34%) had suffered at least one episode of pneumonia since discharge into the community. Patients in institutional care required more visits to hospital to un-block tubes than patients in the home setting. Aside from this, for patients with disease of neurological origin, there were no significant differences in complication rates between patients in institutions and patients in their own home. As only 1 cancer patient surveyed lived in a nursing home, it was not possible to establish if the complication rates of cancer patients differed between the home and institutional setting.

### 2.4.6 Medication administration

Over three quarters (*n* 39, 78%) of the survey group could not consume medications orally, and received drugs through the feeding tube. In total, over 100 different types of drug were administered via the enteral tubes, including Warfarin, Phenobarbitone, and Theophylline. Only 5 (10%) received all their medications in liquid form, a third of patients took a

mixture of both crushed tablets and liquid medication via the tube, and the remainder crushed their tablets. Laxatives were routinely used by 26 (52%) of the patients surveyed. Seventy-eight percent of patients (*n* 39) flushed their tubes routinely after administration of medications. There did not appear to be any associations between complication rates and method of medication administration.

**Table 2.12** Enteral feeding related complications experienced by 50 adults on tube feeding

| Complication | % (n) | Comments |
|---|---|---|
| *Gastrostomy site complications:** | | |
| Pain at stoma site | 28 (14) | None experienced severe pain at stoma site |
| Erythema at stoma site | 48 (24) | More common in those on tube feeding for <3 m[1] |
| Leakage of feed at the stoma site | 8 (4) | Resolved for all after a short period |
| Discharge around stoma site | 28 (14) | More likely to have had a site infection |
| Local infection at stoma site | 16 (8) | 37% needed hospital visit to with problem |
| *Mechanical complications‡:* | | |
| Tube blockage | 30 (15) | 4 patients made hospital visits to un-block tube[†], 2 had tube replaced |
| Tube replacement | 26 (13) | 8 patients had tube replaced once, 5 had tube replaced twice |
| *GI complications‡:* | | |
| Nausea | 32 (16) | CA patients likely to suffer than stroke patients |
| Vomiting | 40 (20) | Incidence *not* significantly greater in CA patients |
| Diarrhoea | 34 (17) | Patients on fibre feeds had sign. less diarrhoea[3] |
| Constipation | 48 (24) | Significantly lower in ambulant patients [4] |
| Abdominal distension | 16 (8) | More common in patients who ate food orally[5] |
| Regurgitation of feed | 28 (14) | More likely in those suffering from cough[6] |
| *Other complications‡:* | | |
| Pneumonia | 34 (17) | More common in patients on tube feeding for more than 100d[7] 41% of these patients required hospitalisation |

*[1]p=0.04 [2]p= 0.007 [3]p=0.02 [4]p=0.05 [5]p=0.02 [6,7]p< 0.001*
**Values are percentages of 49 patients who had a gastrostomy [†]All 4 patients came from nursing home facilities ‡ Values are percentages of total group*

### 2.4.7 Nutritional Status

Due to the poor functional status of the survey group, (over 50% could not walk at all) nutritional assessment was difficult to complete in many patients, but especially in those patients with stroke and other neurological impairments. Four patients (8%) were not included in the anthropometric analysis as interpretation of anthropometric data would be confounded by their neurological impairment (e.g. patients with hydrocephalus or cerebral palsy). BMI was measurable in 34 (68%) patients (91% of cancer patients (*n* 11) and 60% (*n* 23) of all other patients). Actual weight was measured in 16 patients (32%), and estimated using the methods described in Chapter 1.2 in 18 (36%) patients; height was available for 16 patients and estimated using the methods described in Chapter 1.2 for 18

patients. Where carers were asked to make a subjective judgement as to the weight status of the patient since their discharge on enteral feeding, none believed that their patient had lost weight since their discharge from hospital. Mid-upper-arm circumference and triceps skinfold thickness were measured, and mid-arm muscle circumference calculated in a number of patients (these data are presented by diagnostic category in Table 2.13).

**Table 2.13** Nutritional assessment of adult patients on home tube feeding

| | Stroke and other* patients (*n* 38) | | | | | | Cancer patients (*n* 12), all males | | |
|---|---|---|---|---|---|---|---|---|---|
| | *n* | | *Mean* | | *SEM* | | *n* | *Mean* | *SEM* |
| | *M* | *F* | *M* | *F* | *M* | *F* | *M* | *M* | *M* |
| ‡BMI (kg/m$^2$) | 15 | 8 | 22.8 | 21.5 | 0.68 | 1.6 | 11 | 22.7 | 0.99 |
| §MUAC (cm) | 14 | 9 | 24.7 | 26.5 | 0.72 | 0.98 | 10 | 26.9 | 1.2 |
| ¶TSSF (mm) | 16 | 6 | 8.6 | 15.0 | 0.63 | 3.9 | 10 | 8.9 | 1.2 |
| ✣MAMC (cm) | 14 | 6 | 22.0 | 22.2 | 0.61 | 0.8 | 13 | 24.2 | 0.9 |

**all other diagnostic categories other than cancer*

*†SEM, standard error of the mean, ‡BMI, body mass index, §MUAC, mid-upper-arm circumference, ¶TSSF, triceps skinfold thickness, ✣MAMC, mid-arm muscle circumference*

Three patients (under 65 years of age) had a BMI = 20.0kg/m$^2$, but no patient had a BMI < 16.0 kg/m$^2$. The average BMI for males over 65 years was 23.1 kg/m$^2$ and for females over the age of 65 was 21.0 kg/m$^2$. It was possible to compare weights before discharge from hospital and on the day of the survey in 13 (26%) patients (9 cancer patients and 4 patients with other diagnostic indications for enteral tube feeding). Of the 9 cancer patients, 7 gained an average of 4.4kg (SD 4.4kg) over a period of 78 days (SD 80 days) and 2 lost weight (6.8 kg over 168 days and 0.2 over 16 days). Three of the 4 other patients gained an average of 5.0kg (SD 3.9kg) over a period of 119 days (SD 46 days) and 1 lost weight (3.1 kg over 71 days).

Where total daily calorie intake (from enteral feed ± oral intake) was comparable to estimated average requirements (EAR) (*n* 34, 68%), 7 patients (14%) were found to be receiving less than their EAR (average deficit 0.79MJ (SD 0.55MJ), however the average BMI for these patients was 27.23 kg/m$^2$ (SD 3.92 kg/m$^2$).

Of those patients who received enteral feed only (no oral intake) 7 (14%) were on <=1500mls of feed and 5 (10%) were on >=1500mls for over 1 year. Only 13 patients (26%) of patients had been weighed since their initial discharge from hospital. Fifty-five percent of patients on long-term (i.e.> 1 y) nutrition support in the community had not been reviewed by a dietitian for periods exceeding 1 year in duration.

### 2.4.8 Problems encountered by patients on community tube feeding

Patients at home (*n* 21, 42%), and their caregivers reported experiencing a number of practical problems with respect to home tube feeding. Patients obtained their nutrition products in the community by various means, some very inconvenient. Fifty-seven percent of patients in their own home (*n* 12) collected the feeds and giving sets themselves. This posed a number of problems for many of these patients and their carers; e.g. it was necessary for someone to take time off work, the journey to collect goods was long, the family did not own a car, the volume of supplies was very large, or a minder was needed to take care of the patient. The remaining 9 (43%) patients had their supplies delivered to them by a local pharmacist, a community nurse, or by commercial distributors of the products. The arrangements for delivery of supplies was often flexible. Consequently, some of these patients collected the feed or equipment themselves from time to time. Twenty percent of patients reported experiencing problems with the feeding pump. Most patients or carers said that the companies providing the pumps were prompt and efficient in their servicing of the equipment when necessary. However, a minority (*n* 3, 14%) of patients or carers said that they would contact the dietitian in the discharging hospital or their local pharmacist for help if the pump was to break down.

A number of patients (*n* 9, 43%) found that on arrival to collect supplies, the wrong variety of feed or equipment had been ordered by the community care personnel or pharmacy staff and thus had to be re-ordered, necessitating another trip to collect the correct order. Surprisingly, 3 (14%) of patients on tube feeding in their own home had no telephone, (one man lived on his own without a telephone), although all had telephone numbers at which messages could be left. One patient was refused entry into a local nursing home for day care because he had a feeding tube in place.

A noteworthy finding was the lack of confidence displayed by patients and carers at home in the community in their family practitioner's knowledge of enteral tube feeding. Eighty-one percent of patients at home (*n* 17) said that they had little or no confidence in their family practitioner's knowledge of enteral feeding.

## 2.5 Discussion

Retrospective surveys such as this are subject to a number of methodological limitations. Firstly, patients with a short survival time will be underrepresented in this sample as only those alive at the time of the survey were included in the analysis. Secondly one has to rely on accurate patient/caregiver memory. Finally, there are also problems in retrospectively reviewing patients' hospital records. The method of recruitment in this survey relied on the fact that dietitians in the hospital kept the record of all patients discharged on home tube feeding in a central location in the Department of Clinical Nutrition. In reality, patients may have been missed using this method as their notes may have been filed elsewhere in the years prior to the study thus the numbers should be interpreted with a degree of caution. The survey group was similar to the overall group of patients who were discharged from St. James's hospital over the last number of years. However, as there is no register of patients receiving tube feeding in the community in Ireland, it is difficult to know if this study group is representative of these patients in the country as a whole. Moreover, because practices with regard to discharging patients on enteral nutrition may vary between different centres, this study reflects the practices of one hospital only. Although it was beyond the scope and aims of this study to examine the experiences of patients on tube feeding outside the Dublin area, the outcome of patients in rural areas on home tube feeding warrants attention, and should be examined in a larger study. The original aim to examine the experiences of patients in the community who had been discharged on enteral feeding from a number of institutions was not feasible. All patients in the survey had been through a process of preparation before their discharge into the community. Therefore the anecdotal accounts of feeding tube problems in the community were not borne out in this survey (e.g. one company representative has told me that she had encountered patients on PEG feeding in the community whose feeding tube has been sutured to the skin, the physician who placed the tube had mistaken the air holes for suture holes). Unfortunately, these problems could not be highlighted in a survey of this type, although it is encouraging that such problems were not encountered in the patients reviewed in this study, suggesting that for the vast majority of patients who are prepared for HETF in acute hospitals with dietetic staff, the use of tube feeding in the home can be safe and well tolerated.

In spite of the limitations of this study as outlined above, the survey did serve to provide some useful, interesting and previously unknown data about patients on home tube feeding in Ireland. Dates of death or discontinuation of feeding were obtainable for 54 patients.

The median time spent by cancer patients on home tube feeding, (30 days before death) is very low and does not appear to compare well with results from other surveys, which perhaps raises the question of the purpose for which the PEG was inserted. It has been recognised that there are huge difficulties in predicting life expectancy in a cancer patient, and in predicting their likely response to aggressive nutritional support (Bozzetti *et al.* 1996). The European Association for Palliative Care have developed guidelines to help clinicians make a reasonable decision on what type of nutritional support should be provided to such patients (Bozzetti *et al.* 1996). In view of the findings from this study, it would appear that such guidelines are not adhered to in this country, and the value of inserting feeding tubes for long term tube feeding in patients who will die soon after discharge requires further examination. The use of feeding tubes in such patient raises ethical concerns.

Howard (1993) for example found that at 1 year after discharge on tube feeding, only 32% of cancer patients and 60% of patients with stroke and other neurological diseases of swallowing, were still alive. Although the numbers were quite small, it was found that only 7% of the cancer patients were still on feeding after 1 year, and 69% of the stroke/neurological diseases of swallowing group had died within one year of discharge. The lack of consistency between these results with other work is probably due to the small numbers of patients whose date of death or discontinuation of feeding were available. This information would be available if a national register of home tube fed patients were in place in this country. At the time of writing, no arrangements had been put in place for the development of a national register.

This survey showed the cancer patients surveyed to be mobile, independent or semi-independent. Conversely, neurological patients surveyed were found to have very poor functional status. Similarly poor levels were found by Parker *et al.* (1996) in a British study. Howard and Malone (1997) have also highlighted the poor outcome of geriatric dysphagic patients receiving home tube feeds in the US. In a survey by Mitchell *et al.* (1997) it was concluded that the mortality of tube-fed cognitively impaired elderly patients in nursing home did not differ significantly from those without feeding tubes. Kaw & Sekas (1994) found no improvement in either functional or nutritional status in patients with PEGs in nursing homes (93% of the survey group required PEG due to neurological cause). Therefore when discussing community tube feeding, one should distinguish between two groups of patients. Firstly, those patients with good functional status who may be mobile (e.g. certain cancer patients) and secondly, those patients with poor

functional status, who may be bedridden (e.g. those patients with severe stroke). Whilst in both groups, the goals of enteral tube feeding include the extension and improvement in quality of life, in general, the first group tend to see more improvement in quality of life than the second, and the second more extension in life than the first. These groups are very different in terms of our expectations of treatment, necessitating different consideration of the ethical and quality of life issues that surrounding the use of home tube feeding.

Anthropometric assessment in elderly, immobile patients proved difficult and meaningful analysis of the anthropometric data was difficult due to the small numbers and heterogeneity of the sample. The difficulties involved in nutritionally assessing this group of patients as a result of poor mobility and/or severe physical disability have also been recently described by Bannerman *et al.* (1999b) and Edington *et al.* (2000). The use of upper arm anthropometry (mid-arm circumference; triceps skinfold thickness; mid-arm muscle circumference and mid arm muscle circumference) may be of more benefit in these bed-bound immobile patients. Whilst these measurements are usually compared to standardised tables, serial measurements may be of more clinical value than attempts to compare to tables (Grant *et al.* 1981). None of the patients in the study had such measurements documented in their medical or dietetic noted prior to their discharge. It is also worrying that 55% of the patients in the community on long term nutrition support (i.e. for > 1 y) had spent periods of over 1 year and more without review by a dietitian, and only 26% of patients had been weighed in the community. The effects of long term enteral feeding on vitamin and mineral status have already been discussed (McWhirter *et al.* 1994). The Scientific Committee for Food (European Committee) (1997), has suggested upper limits for the vitamin and mineral and trace elements in nutritionally complete foods. Many commercial feeds currently exceed this suggested upper limit of micronutrient content. This survey found 5 patients on at least 1500mls for over 1 year in the community. The nutritional status of these patients in the community and the effects of long term feeding on vitamin and mineral status requires more attention than has been given in the past and suggest a controlled study of the micronutrient status of patients on long term full nutritional support in Ireland.

Arrowsmith (1994) has looked at the general requirements for successful home tube feeding, which included the suitability of the home environment. One of the basic requirements is a telephone, but 3 of the patients at home in the community did not have a telephone. There were also many inconsistencies with respect to delivery of feed and equipment to the home. Some patients had sympathetic community pharmacists or

community nurses who delivered the feeds to the home, but some of the more needy patients and carers received no such service, and collection of feeds and equipment was often problematic. If a supportive home environment is not available, successful management of the home tube fed patient becomes difficult (Bloch, 1989). A standard protocol for delivery of supplies to patients at home would alleviate some of the unnecessary burden placed on tube-fed patients and their carers. Since this survey was carried out certain nutrition companies have put "hospital to home" delivery schemes in place.

The complication rates experienced by the patients in this survey compare favourably with data from a recent survey of community tube feeding in a region of Northern Ireland (L'Estrange, 1997) but they appear high when compared to those found in a region of England (Parker *et al.* 1996). In particular, the levels of pneumonia and tube blockages requiring hospital admission experienced by patients in the community are a matter for concern. Pneumonia was a particular problem for older, stroke patients on feeding in the community for a long time. Although problems such as tube blockages can be expected, it is interesting that the majority came from nursing home patients, suggesting that more education regarding management of feeding tubes is necessary for nursing staff in these institutions. No attempt was made to estimate the number of times the complication was experienced, as this would have been very difficult to estimate retrospectively, and would be better investigated in a prospective study. The most serious complication was that experienced by the patient whose tube was not changed until 7 years after insertion. The patient experienced considerable difficulties when finally admitted to have it changed (the PEG had been placed through the transverse colon into the stomach. When the tube started leaking, routine replacement proved impossible and a new PEG was inserted at laparotomy when the colonic perforation was discovered and repaired), spending a total of 23 days in hospital as a result. This supports the suggestion by BAPEN that continual monitoring of patients on home tube feeding is essential if it is to be successful. The BAPEN standards of care for patients on home tube feeding recommend that there should be a post discharge monitoring protocol (which will be established by the nutrition team in each centre) (Elia *et al.* 1994). It is recommend that similar standards of care should be implemented in Ireland.

This survey has highlighted a number of interesting and previously un-investigated aspects of home tube feeding in the Republic of Ireland. An unacceptable level of disillusionment among patients with their family practitioner's knowledge of enteral feeding was found. It

is unsatisfactory that patients are discharged from hospital facilities where expert nutritional services are available, into the community where there are no community nutritional services available to them. While many patients have home visits by community nurses, there are no community nurses formally trained in this area of nutritional care. A recent final year human nutrition and dietetics student (Lisa Maher, 1999) compared the level of nutrition interest amongst GP's in Dublin in 1999 to 1993. The response rate to the latter survey was lower than the first (47% *versus* 56%), and found that access to dietetic services have decreased while referral rates have increased. A more worrying fact is while a similar percentage of doctors considered that their nutrition knowledge was inadequate (48% in 1999 and 49% in 1993), less doctors were interested in interested in further nutrition education (78% in 1999 and 85% in 1993). These and the findings in this study suggest the need for the provision of nutritional services for these patients in the community in Ireland.

In conclusion, while the majority of patients coped well with home tube feeding, their management lacks co-ordination. There are difficulties with the delivery of supplies, the access to adequate help with feeding problems, and with review of nutritional needs. There is evidently a need for improved education about tube feeding for GPs and community nurses. However, for adequate provision of service to these patients, access to clinical nutritional services should be provided in the community setting to allow appropriate multidisciplinary care for these patients.

# Chapter 3

# A survey of children on home enteral tube feeding in the Dublin area

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## 3.1 Introduction

Children constitutes approximately 26% of all registered patients on HETF in the UK and Northern Ireland. The most common indications for tube feeding in children are cerebral palsy (19%) and congenital handicap/malformation (18%) (Elia, *et al.* 1999). While the number of paediatric patients discharged yearly on HETF is not known in Ireland, a survey of dietitians (Chapter 4) found that dietitians working in paediatric practice estimated their discharges to be approximately over 450 children per year (approximately 42% of all discharges). Extrapolation from UK data would yield a figure of just under 200 children on this therapy in the community in Ireland. The actual figure is probably somewhere between the two.

In the Dublin region, there are 3 paediatric hospital where feeding tubes are inserted. No work has been carried out to look at the experiences of parents and their children on HETF in Ireland; consequently, nothing is known about children on HETF in Ireland.

## 3.2 Aims & Objectives

The aim of this part of the thesis was to examine the experiences and outcome of children on home enteral tube feeding, and to look at the effect of tube feeding on the parent. The objectives of this study were to investigate the indications for feeding, the feeding practices, complications experienced, and any problems that children had experienced whilst on home tube feeding. Other objectives were to compare practice in the paediatric hospital to the BAPEN standards, and to examine the preparation of parents for home tube feeding and their effect that tube feeding had on them and their child.

## 3.3 Methods

### 3.3.1 Patient recruitment

Recruitment of patients for the study began by contacting principal dietitians in 3 paediatric hospitals in the Dublin area, namely the National Children's Hospital, Harcourt Street, Our Lady's Hospital for Sick Children Crumlin, and finally The Children's Hospital, Temple Street.

The National Children's Hospital, Harcourt Street is a small hospital which is academically affiliated with Trinity College. Few children had been discharged on tube feeding in the Dublin area (i.e. approximately 4), and the hospital was thus unsuitable for the survey. The largest dietetic department in the city, Our Lady's Hospital for Sick Children, Crumlin were initially unable to assist us in carrying out the survey, due to a lack of personnel and time.

The Children's Hospital, Temple Street, Dublin is a small paediatric hospital with 128 in-patient and 14 day beds. At the time of the study, two dietitians were employed in the hospital (1 dietitian was employed exclusively with the Metabolic Disorders Unit, so effectively there was only 1 dietitian in the general part of the hospital). This dietitian was approached regarding the survey and was willing to participate. Approval from the hospitals ethics committee was sought and granted after 2 ethics committee meetings were attended. Permission was granted under the condition that, as non-staff members of the hospital, we would not be allowed to approach patients without prior permission from the patients parents/guardians. Access to patients records was not allowed. The ethics committee also deemed that the initial contact with parents regarding the survey should come from the patients consultant, and that Garda clearance for the primary researcher was necessary. Patients on HETF from the Metabolic Unit in the hospital were excluded from the survey, as the ethics committee felt that they were an inappropriate group for this survey.

The hospital dietitian identified all suitable patients from dietetic records. Seven relevant hospital consultants were approached and their permission was sought to involve their patients in the survey. The consultants were asked to sign cover letters for the parents, briefly outlining the aims of the survey. Patients outside the Dublin were excluded from the survey, due to logistical and financial constraints. Parents were contacted by post. The package sent included the covering letter signed by their consultant, a detailed patient information leaflet, a consent form (which, if signed, would give permission for the researchers to contact them), and a stamped-addressed envelope to return the consent form to the dietitian in Temple Street Hospital. Parents/guardians who returned the preliminary

consent form were contacted by telephone, and arrangements were made to visit them in the community to carry out the survey. Reminder letters were sent 8 weeks after the initial posting. Some reminder telephone calls were then made by the hospital dietitian; although time constraints meant that a full recruitment by telephone was not possible.

Following a poor response from Temple Street Hospital (see 3.4.1), the dietetic staff in Our Lady's Hospital for Sick Children Crumlin were approached again about the study. The staff agreed to assist this time (since first approaching them about the survey, the dietetic department had started to keep a record of patients discharged on HETF, this made it easier for them to assist in recruitment of patients). A hospital consultant agreed to be a named participant in the study. The project was passed by the hospitals Medical Advisory Council, but numerous attempts at passing the project through the hospitals ethics committee failed. This was not due to the project proposal (it never actually reached the discussion stage of the process) but rather to the ethics committee itself. Meetings were held infrequently, and an organ retention issue in the hospital resulted in a change in the priorities of the ethics committee. The proposal for the project was repeatedly taken off the agenda of the ethics committee meetings so that more pressing issues could be dealt with. The length of time between initially applying for permission and actually being discussed at the ethics committee meeting was 12 months. Permission was finally granted on the 16th August 2000. The permission was granted under the terms that the method of recruitment would be the same as that in the Temple Street study, i.e. access to patients names and address could not be supplied to an outside party without prior permission from the parent or guardian.

### 3.3.2 Questionnaire design

A questionnaire (comparable in structure and content to the adult survey questionnaire) was designed (see Appendix 2). Information collected included details of demographics, medical condition, functional status, enteral feeding habits (type of feed used, the length of time the child is fed for and the method of tube feeding), problems experienced with the tube feed, and other miscellaneous data. Mothers were also asked about their attitudes towards the feeding tube initially, and if their opinions had changed since their discharge home. Additional questions regarding psychological effects of tube insertion on parents and patients were added to the questionnaire. This part of the questionnaire was developed with the aid of an Irish educational video made for parents whose children have or are due to have, PEG tubes inserted. In the video (made in the Central Remedial Clinic (CRC) in

Dublin), parents discuss the impact of the feeding tube on their lives and on their child's lives.

Fifteen questions in the questionnaire related to the BAPEN standards of practice for HETF (Elia *et al.* 1994), which were included in order to assess how the practice in Ireland currently compare to these standards. The questionnaire was semi-standardised, i.e. while maintaining a standardised structure, additional sub-questions and prompts were included at the discretion of the interviewer to ensure that the respondent has correctly understood what information is required (Abrahamson, 1974). This also meant that it was easier for participants to talk freely about their experiences. Parental consent was sought again before the survey was carried out in the home environment, and the questionnaire took approximately 1h 20m to administer.

### 3.3.3 Anthropometric assessment

An anthropometric assessment was carried in children where feasible (ie some children were absent during the time of the interview, others were too ill at the time of the visit). Mothers were asked the child's weight before tube insertion. Weight was measured with an accuracy of ± 0.1 kg using an electronic scales (model "Soehnle"). If weight measurement was not possible, mothers were asked the child's weight when last measured in home/hospital. Mid-arm circumference and triceps skinfold thickness were measured (with a pinch calipers (model "Holtain") to ± 0.01mm) where possible. Anthropometric measurements were compared to the Irish Clinical Growth Standards (Hoey *et al.*, 19xx)

### 3.3.4 Data analysis

Questionnaires were coded and entered into the computer for analysis. As well as the usual descriptive analysis (mean, median, standard deviation, range, sum, inter-quartile range, minimum, maximum), Chi squared tests (Crosstabs), and 2 sample and independent t tests were carried out to investigate relationships between a wide range of variables. The Statistical Package for Social Sciences (SPSS for Windows, V.9.0) was used to analyse data. A small sub-sample of data was hand analysed to check for errors in the computer analysis.

## 3.4 Results

### 3.4.1 Response rate

Forty-eight parents of children on HETF in Dublin and surrounding areas were contacted by letter by the hospital dietitian. Thirteen parents responded to the letter and 12 were suitable to take part (one child was not included in the survey because he had resided in a long term care facility for a considerable length of time, and his family had moved to live in the West of Ireland). Reminder letters were sent in an attempt to increase the response rate, but no parent replied to the second letter. The overall initial response rate was therefore 27% (*n* 13), with a utilizable response rate of 25% (*n* 12). Although fathers had not been specifically excluded from the survey, only mothers replied and were subsequently interviewed.

### 3.4.2 Demographics

There were 3 boys and 9 girls in the group, with an average age of 7y 3m (SD 4y 2m). The youngest child in the survey was 2y 2m and the eldest was 13y 7m. Three children lived in institutions, one child resided in a care facility during the week, but returned home every weekend and during holidays, the other 2 resided in long term care facilities but had lived at home for a few years after their discharge on tube feeding. All of the children over 4y (*n* 9) attended school or other learning institution on a daily basis. Seven children attended schools for pupils with special needs, and 2 attended standard primary schools. The principal indication for tube feeding was cerebral palsy (*n* 5) the remaining 7 children had a variety of indications for tube feeding as outlined in Table 3.1. Nine children had a swallowing defect, with only 3 children receiving tube feeding as a supplement to oral intake. Only four of the children could walk normally, the remainder were unable to walk as a result of physical handicap. Four patients could speak normally or almost normally, the remainder were unable to communicate verbally.

### 3.4.3 Feeding Practices

The length of time spent on home tube feeding ranged from just under 1 year, to over 5 years. The collective experience on home tube feeding of the children surveyed was almost 28 years. The period of time spent in hospital on enteral feeding before discharge into the community varied considerably (from 4d to >6m). Five children spent less than 10 days in hospital after the tube was inserted. Two children were receiving tube feeding since birth.

The remaining children were on tube feeding for an average of 31% (SD 18%) of their lives at the time of the study (range 12% to 70%).

Eight children were on full nutritional support with no oral intake. Mothers were the primary carers and administrators of feed for those children who lived at home full-time, although fathers, sisters and aunts were also involved in some families. Eleven varieties of enteral feed were utilized by the 12 children, reflecting the diversity of requirements in the groups and the individualization of therapy. Half of the sample children were fed with paediatric formula feed (such as Pepti 2000®, Pediasure®, Nutrini®), the other half used "adult" feeds, such as Nepro®, Ensure® and Jevity® (Table 3.2). Those children who ate food orally (*n* 4) tended to be very poor or "fussy" eaters, and oral calorie intake varied quite considerably depending on how well the child was on a particular day. Most mothers (*n* 9) fed their children bolus feeds during the day (an average of 4 feeds per day). Eight mothers used a pump to administer the bolus feed, but one mother preferred to use gravity feeding to administer the bolus. The remaining 3 children were fed for longer periods with the aid of a pump, for an average of 7.5 hours per day. Four children were fed while they slept. No child was fed for more than 12 hours per day. Feeding practices are summerised in Table 3.3.

**Table 3.1** Indications for tube feeding

| Indication | n |
|---|---|
| ***Neurological*** | |
| Cerebral palsy | 5 |
| Absent gag reflex (unknown cause) | 1 |
| 2° to anencephaly | 1 |
| Mild spina bifida | 1 |
| Mental and physical handicap | 1 |
| ***Renal*** | |
| Polycystic kidney disease | 1 |
| ***Other*** | |
| Cystenosis | 1 |
| Retts syndrome | 1 |
| **Total** | **12** |

**Table 3.2** Commercial enteral feeds used by children on HETF

| Feed type | n |
|---|---|
| Nutrini | 1 |
| Nutrini Extra | 1 |
| Pediasure | 1 |
| Nutrison | 1 |
| Pepti 2000 | 1 |
| Neocate advance | 1 |
| Nepro | 2 |
| Peptamen | 1 |
| Ensure | 1 |
| Jevity | 2 |
| **Total** | **12** |

**Table 3.3** Summary of feeding practices

| Feeding practices | n |
|---|---|
| ***Feeding tube*** | |
| Mic-Key® gastrostomy buttons | 8 |
| Foley catheters | 2 |
| Percutaneous endoscopic gastrostomy tube | 1 |
| Surgical gastrostomy tube | 1 |
| Mother replaced feeding tubes at home | 7 |
| ***Method of feed delivery*** | |
| Bolus feeds* | 9 |
| Continuous feeding using pump | 3 |
| Full nutritional support (i.e. no oral intake) | 8 |
| Supplementary feeding (i.e. some oral intake) | 4 |
| ***Feeds and Equipment*** | |
| Varieties of enteral feed utilised | 11 |
| Mothers who experienced problems with the feeding pump | 5 |
| Mothers who collected enteral feeds from local chemist shop† | 12 |
| Mothers for whom collecting feeds posed a problem | 4 |

**8 mothers used a pump to administer the bolus feed, but 1 mother preferred to use gravity feeding to administer the bolus*

*†2 mothers had the feed delivered occasionally*

### 3.4.4 Feeding tubes

None of the children were fed by nasogastric tube, 2 were fed via Foley catheters, 8 via low-profile gastrostomy feeding device (Mic-Key® gastrostomy buttons), 1 was fed using a PEG tube, and 1 was fed through a surgical gastrostomy. The number of tube changes since initial discharge into the community varied, for example, one child had the same tube *in situ* for 12 months, another had utilized 15 tubes within the same time period. In total, there were approximately 91 tube changes in the 28 years on tube feeding. Seven mothers replaced the feeding tubes themselves in the home. A further 2 mothers had never changed the tube themselves at home, but intended on doing it the next time it was necessary. There was no particular standard protocol for the replacement of feeding tubes. Each parent had a method that was unique to them and which suited their own lifestyle. One mother had continual problems endeavouring to keep her child's tube *in situ* (the reason for the problems was unknown).

Feeding tubes were flushed regularly and fluids used to flush the tube included: cooled boiled water (*n* 4) ordinary tap water (*n* 3) bottled water (*n* 1) and sterile water (*n* 2). Syringes used varied from 10ml to 50ml variety. All parents recycled the syringes (washing between uses) until they became unusable. No parent experienced a tube blockage that was not dealt with easily in the home environment. Only one child was very bothered by the tube according to their mothers, 7 mothers said that their child was sometimes bothered by the tube, and the remaining 4 mothers said their child was never bothered by it.

### 3.4.5 Medication administration

All the children in the survey received their medications through the feeding tube. In total, over 30 different types of drug were administered via the enteral tubes. Five children received all their medications in liquid form, the remainder took a mixture of both crushed tablets and liquid medication via the tube. One child with a rare syndrome (*Cystenosis*) had a feeding tube inserted initially for the purposes of administering unpleasant tasting medications only, but when the tube was eventually placed feeding via the tube was commenced as well as the child was not meeting her nutritional requirements orally.

### 3.4.6 Education regarding tube feeding prior to discharge

Education regarding tube feeding was carried out in the discharge hospital. None of the mothers surveyed had a home visit prior to their child's discharge on tube feeding. The

nurses on the discharging ward, and the hospital dietitian as well as the company representative supplying the feeding pump were generally involved in the education of the parent. Four mothers said that they were not satisfied with the level of education they received. It took mothers an average of 3.5 weeks to get fully familiar with the feeding system at home. The importance of adequate preparation was highlighted by the fact that one mother who was herself ill at the time of her child's discharge could not attend the education found it very difficult to adjust to the home enteral feeding.

### 3.4.7 Nutritional status

Weights were available for 10 patients. Accurate heights were available for only 4 patients. All patients had put on weight since their discharge on HETF, however the variation in length of time since discharge makes meaningful analysis of this data difficult. Four children were below the 3$^{rd}$ percentile for weight, 2 were on the 10$^{th}$ percentile, and one each on the 50$^{th}$, 75$^{th}$, <20$^{th}$ and <10$^{th}$. Thus, in comparing the patients to the reference standards for the general population, half of the group could be described as being below the 50$^{th}$ percentile for weight for age. Eleven mothers reported that their child had increased in stature since tube insertion, but height was difficult to measure in many of the handicapped children. All mothers had been in touch with the hospital dietitian since their discharge (some over the phone and others in clinics).

### 3.4.8 Practical problems experienced

Two mothers had daughters on tube feeding for the long periods (4.5y and 5y). Neither of these mothers had a pump on their discharge from hospital and both described how they were initially unable to cope. One described how she "nearly went off the rails!". The other recalls staff telling her how she would be able to feed her child "in 10 minutes" after the tube was inserted. Her initial experience was of days where she says she did literally nothing *except* endeavor to feed the child via the PEG tube. Both of these children were amongst the first to have feeding tubes inserted and perhaps outline how the services to children and their parents have improved over the years. More recently, one family managed to spend 2 weeks in Spain and had no mishaps at all with the feed and equipment. Five mothers reported experiencing problems with the feeding pump, but all reported that the companies who provided the pumps were prompt in replacing the pump when necessary. No parent found the feeding pump to be too noisy, although one mother complained that at the flashing lights on the pump display was too bright in her child's

bedroom at night, another mother noticed that her pump continually under delivered feed, even after servicing. All mothers collected their feeds from their local chemist shop, although 2 mothers had the feed delivered to the home occasionally. Four mothers mentioned problems that the collection of feeds posed problems, for example, one mother had to make 3 visits to her chemist shop and carry the crates of feed over a reasonably long distance, before carrying them up a flight of stairs to her apartment. Feeding bags and giving sets were collected by some families (*n* 6), delivered to others (*n* 6). One of the children who were fed while they slept experienced some sleep disturbance. There were inconsistencies in the methods by which the mothers received supplies such as Mic-Key® extension sets, syringes and spare tubes. Some were delivered, others were collected at various locations, some convenient and others not so convenient. All mothers had been in touch with the hospital dietitian since their discharge (some over the phone and others in clinics). Although there was often no formal arrangement for follow-up made on discharge, all parents had a good relationship with the hospital dietitian and knew that they could telephone her anytime. Mothers had been in hospital with their child at some stage after the tube inserted and generally saw the dietitian at this time. While not a "drop in" service, the hospital dietitian encouraged parents to contact her when they were in the hospital for other reasons if they have problems with the feed.

### 3.4.9 Physiological problems experienced

Parents were asked if a complication had occurred during their child's time on HETF, and an answer of "yes", "no" or "don't know" was given. No attempt was made to estimate the number of times the complication was experienced, as this would have been very difficult to estimate retrospectively. Only 1 patient had dressing on the stoma site. The stoma site was washed every day by all parents, usually with water and soap. Parents were asked if the child had experienced any pain, erythema, leakage of feed, discharge or infection around the stoma site. The responses to these questions are outlined in Table 3.4. Parents were also asked if the child had experienced any gastrointestinal side-effects (e.g. constipation, diarrhoea) as a result of the feed. Responses to these questions are outlines in Table 3.5.

**Table 3.4** Stoma site complications experienced by children on HETF

| Complication | n |
|---|---|
| Pain around the stoma site | 8 |
| Erythema around the stoma site | 12 |
| Leakage of feed around the stoma site | 4 |
| Discharge around the stoma site | 9 |
| Infection around the stoma site | 7 |

**Table 3.5** Gastrointestinal complications experienced by children on HETF

| Complication | n |
|---|---|
| Nausea | 6 |
| Vomiting | 6 |
| Abdominal distention | 6 |
| Constipation | 9 |
| Diarrhoea | 10 |
| Regurgitation of feed | 7 |

### 3.4.10 Mothers attitudes to home tube feeding

Three of the twelve mothers reported that they were initially opposed to the feeding tube insertion when it was first suggested. Three mothers said that they suggested having a feeding tube inserted in their child, because they were aware feeding tube placement was possible and they believed that it was necessary for their child so they had approached their child's consultant about the procedure. Mothers were asked what *word* best describes how they felt when they first heard that their child required a feeding tube. The responses given to this question were contrasting and ranged from "devastated" to "relieved" as shown in Table 3.6. The enormity of the moral dilemma that faces parents who are given the option of having a feeding tube inserted in their child was mentioned by one mother of a handicapped child. She said that they had discussed how, in addition to prolonging their child's life, the tube would prolong the period of time which they, as parents would need to care for the child. She also pointed that although they would not readily admit it, many parents of handicapped children would go through the same thought process's when given the decision as to whether or not to have a feeding tube placed. Another mother felt that the decision to insert the tube was made too quickly, before she had really thought about it sufficiently. A number of mothers agreed that the child smelled differently than before the tube was inserted, a "side-effect" that they were unprepared for.

A number of mothers (*n* 6) commented that when home tube feeding was being discussed initially, health professionals tended to over emphasise the advantages of tube feeding and neglected to mention that there may also be disadvantages to tube feeding. Mothers felt that they were being offered a trouble-free easy therapy that was going to solve all their child's feeding problems. On initiation of therapy in the home environment, many mothers realised that the treatment was more difficult than had been described. Nonetheless, the majority of mothers (*n* 10) felt that the health professionals were sensitive to their feelings as mothers when discussing the feeding tube, although only 7 said that that found it easy to talk to health professional about tube feeding. Only one mother said that she was confident in her GPs knowledge of enteral tube feeding, and 5 said they thought they could have benefited from a longer period of training. All mothers said that the advantages of tube feeding outweighed the disadvantages, and all felt that opting for tube feeding was the right decision to make for their child. One mother was afraid that her child would be teased at school, while another described how her child ran around the school yard showing off the tube! A widespread comment made was the continual necessity to be with the child. Although some parents had relatives with whom they were confident that they could leave

their child, understandably many parents could not spend long periods away because of the difficulties of finding people whom they could trust, and who were willing to mind the child with the tube feed.

Two children were on tube feeding since birth, but all of the remaining 10 mothers were worried that their child was not getting enough food before the tube was inserted and reported that feeding the child was exceptionally time consuming. Some said it was difficult to estimate the time required for one meal, as feeding the child was more or less a constant all day task, others reported that it could take up to 2 hours to feed a main meal to their child. Only 2 mothers said that they missed spoon-feeding the child, because feeding had been an important part of the family social occasions and something the child took great pleasure from. One family avoided eating in the same room as the child on tube feeds to avoid upsetting or confusing her. Nonetheless, all mothers said that they felt more in control of their child's nutrition since feeding tube insertion. Eight mothers said that their child appeared to be happier since the feeding tube was inserted, and 7 said that their child was more active or alert. Mothers were asked to assess the effect of the tube on their child's overall "well-being", 10 of them said that since the tube insertion their child's well-being had improved. Mothers were asked to describe, in just a few words, what they feel is the *best* thing and the *worst* thing about their child having a feeding tube. They were also asked to describe, again in a few words, what advice they would give to another parent who has been told that their child will require a feeding tube. The responses given are outlined in Tables 3.7, 3.8 and 3.9.

The range in attitudes with respect to feeding in such a small group was surprising. Some mothers were philosophical about the treatment, while others were much less so. Mothers ranged in their practices from those who were very regimented about the treatment and appeared to spend a lot of time "feeding", to those who refused to be "ruled by the tube", and adapted the regimen on a daily basis to suit their needs. They also differed in attitude from those who refused to have their child tube fed during the day to those who refused to have their child fed at night and said it was irresponsible to do so! Parents were asked if, since the start of HETF, they had experienced any more employment disruption, anxiety, depression or fatigue than before. In general parents commented that employment disruption was as much or as little as before, 8 mothers said they suffered from depression, and fatigue was a problem for 6 mothers.

Parents in the CRC educational video mentioned feeling a certain kind of "loss" after the feeding tube had been inserted in their child. It appeared that this loss was mainly due to

the decrease in physical contact with the child as oral feeding (which had taken up an considerable amount of their time) was no longer permitted. Parents in the survey were asked about feelings of loss after the feeding tube was inserted. Of those parents whose children were on full nutritional support, most (6 out of 8) said they had feelings of loss after enteral feeding was commenced and oral feeding was stopped. However, all parents said that the advantages of tube feeding outweighed the disadvantages. Mother's opinions regarding tube feeding are summarised in Table 3.10.

### 3.4.11 Contact with other parents

Half of the mothers surveyed had spoken to parents of other children with feeding tubes before their own child was discharged. All of them had found it helpful to talk to other parents, and of the mothers who had not spoken to others (*n* 6), 4 said they would have liked to have discussed home tube feeding with an experienced parent. In spite of this, there was no difference between mothers who had spoken to others and those who hadn't in terms of their perceived practical preparedness for discharge (8 mothers felt that they were sufficiently prepared *practically* for home tube feeding). Half felt that they were adequately prepared *psychologically* for feeding their child at home. However, for those mothers who spoke to others before discharge (*n* 6), four felt psychologically prepared for their discharge, compared to 2 out of the 6 who didn't speak to other parents before their discharge. Three quarters of mothers interviewed felt that a support group (in the form of an available and experienced parent to contact if they wished to discuss some aspect of tube feeding) would be beneficial for parents of children on tube feeding in the home, especially in the early stages of the treatment.

### 3.4.12 Meeting the BAPEN standards

Table 3.11 outlines the responses to the questions which were based on the current BAPEN standards of practice for home enteral tube feeding. All questions were answered either with "yes", "no" or "unsure".

**Table 3.6** Word to describe how parent felt when told about feeding tube

| Word | n |
|---|---|
| Devastated | 2 |
| Afraid | 1 |
| Scared | 1 |
| Shocked | 1 |
| No way! | 2 |
| Relief | 2 |
| I don't know how I felt at the time | 1 |
| Child was always tube fed | 2 |
| **Total** | **12** |

**Table 3.7** The best thing about HETF in the opinion of parents

1. My child's quality of life has improved
2. I know my child is getting enough food now
3. My child is now healthy and *over* active!
4. The tube feed gives me, as a parent a sense of freedom
5. My daughter has put on weight and she's happier than before
6. My child is developing and putting on weight
7. I'm now in control of my child's nutrition
8. The tube is a means of eating for my child
9. She's put on weight, she's no so "chesty" and she's generally happier than before
10. Her health has improved
11. I can't really say, I don't know
12. It's convenient, it's made my child 100% better, it's wonderful and has great advantages

**Table 3.8** The worst thing about HETF in the opinion of parents

1. Our house is like an ICU* the whole time
2. The worst thing is not knowing what could happen to the tube
3. The cosmetic appearance of the tube is the worst thing
4. Knowing that complications (such as infections) might be a problem
5. Nothing!
6. The tube won't stay in!
7. The constant care and management of the tube is the worst thing
8. It's just not natural, I hate that my child must be fed with a tube
9. The tube is too long and it looks odd
10. She's excluded form the social occasions that involve eating, she used to enjoy those
11. She's excluded from family eating occasions
12. I can't really say, I don't know

* *intensive care unit*

**Table 3.9** Advice for another parent whose child is to have a feeding tube inserted

1. Talk to as many people as possible, and ask lots of questions
2. Be aware that the tube will fall out at some stage!
3. This tube is going to build up your child
4. Go for it!
5. I'd highly recommend a feeding tube
6. Go for it!
7. Find out as much as possible, speak to another parent
8. Get control of your own life as fast as possible after the discharge
9. Don't leave the hospital until your 100% confident, insist on staying in hospital until the child is stable on the feed. It'll take some time to see the advantages, but you will see them.
10. Expect a few months of difficulty, but it's well worth it
11. Get it done, I couldn't recommend it enough
12. Think about the decision you're about to make

**Table 3.10** Mother's opinions regarding tube feeding

| **Mother's opinions regarding tube feeding** | *n* |
|---|---|
| Initially opposed to the feeding tube insertion | 3 |
| Feels that health professionals were sensitive when discussing tube feeding | 10 |
| Feels more in control of their child's nutrition since tube insertion | 12 |
| Worried that child was not getting enough food before tube insertion | 12 |
| Avoids eating in the same room as the child on tube feeding | 1 |
| Thinks child appears happier since tube insertion | 8 |
| Thinks child is more active/alert since start of HETF | 7 |
| Feels child is very bothered by the tube | 1 |
| Feels child is never bothered by the tube | 4 |
| Feels that child's overall "well-being" has improved since start of HETF | 10 |

**Table 3.11** Current practice versus BAPEN standards of practice

| **Questions to establish conformity with BAPEN standards** | **Yes** *n* | **No** *n* | **Unsure** *n* |
|---|---|---|---|
| Were you confident in the hospital team that planned your child's discharge? | 9 | 3 | 0 |
| Was there a relaxed, quiet area suitable for private discussion of the treatment? | 4 | 8 | 0 |
| Were you able to express your fears and expectations of the treatment? | 9 | 3 | 1 |
| Did you receive an instruction manual for HETF? | 5 | 7 | 2 |
| Were you confident that safe care would be provided for the patient at home? | 5 | 5 | 0 |
| Do you think you could have benefited from a longer period of training? | 5 | 7 | 0 |
| Were you aware of the responsibilities of each health care professional involved in your child's care? | 10 | 2 | 2 |
| Did you have confidence in your GPs knowledge of HETF? | 1 | 8 | 1 |
| Did you have confidence in your public health nurse (PHNs) knowledge of HETF?* | 3 | 4 | 1 |
| Did you have a prescription for the enteral feed (and other necessary items) on discharge form hospital? | 12 | 0 | 0 |
| Did you have the enteral feed available at home on the day of discharge? | 12 | 0 | 0 |
| Did you know the names and telephone numbers of health care professionals to contact in case of emergency day or night? | 12 | 0 | 0 |
| Did you know how to obtain supplies and store and dispose unwanted materials? | 12 | 0 | 0 |
| Did you have an appointment for follow up on your discharge? | 12 | 0 | 0 |
| Were arrangements made for the nutritional follow up of the child? | 12 | 0 | 0 |

*N = 12, except for question 9, where n = 8 (*4 mothers did not have a PHN)*

## 3.5 Discussion

Recruitment of parents of children on HETF to take part in the study posed a major problem from the outset of this study. The ethics committee in Temple Street Children's Hospital were willing to allow us to carry out the survey using their patients, but access was not allowed to the patients names and records of any kind without prior permission from a parent or guardian. This situation lead to a reliance on the hospital dietitian to recruit patients. The hospital dietitian was the only one in the general hospital at the time, and was restricted in terms of the amount of time she could dedicate to the recruitment process. Consequently, the number of mothers interviewed in this survey was small. Parents of children on tube feeding were invited (via postal letter) to complete a consent form allowing the researchers to contact them. A letter outlining the study was provided (signed by the child's consultant) and a stamped, addressed envelope was provided. Despite a repeat mailing, the response rate remained low. Time and staff constraints prevented the hospital dietitian recruiting by telephone. However, like the present survey, many studies which have looked at the experiences of children and parents of children on long term gastrostomy feeding in the home have been carried out on small numbers of children and/or parents i.e. 20 or less (Brant *et al.* (1999); Spalding & McKeever, (1998); Rosenfeld *et al*, (1999); Cosgrove & Jenkins, (1997); Chaplen, (1997); Borrowitz *et al*, (1997); Aiges *et al*, (1989); Naureckas & Christoffel, (1994); Thorne *et al*, (1997)).

It is difficult to compare the response rate with that of other surveys of this type, as most are carried out by hospitals staff, and methods of recruitment like this survey are presumably quite rare. The sample may have been biased as those mothers who responded may have had different experiences with HETF than those who did not respond. Thus the mothers who took part in the survey may not have been representative of all mothers of children on HETF. In addition, use of postal recruitment may also have excluded illiterate or poorly literate parents. An audit of all discharges of children on tube feeding from the hospital was not possible (parental consent would have been necessary), therefore, it was not possible to ascertain if the sample was representative of all discharges in terms of sex, age and disease states. The poor response initially may have been partly due to the "official" nature of the initial contact letter and patient information leaflet which may have intimidated some parents. Temple Street Hospital is a relatively small hospital and as such, it does not have units for every medical specialty. Therefore, while the sample surveyed may have been representative of children discharged into the community on tube feeding from Temple Street, they may not have been representative of all children on HETF in

Ireland. The hospital dietitian believed that the 12 responders were from a higher socio-economic background than the general population of patients on HETF discharged from the hospital.

In 1997, 36% of home tube fed children registered in the UK had congenital handicap/malformation or cerebral palsy (Elia *et al.* 1997). In this survey, 50% (*n* 6) of patients suffered from cerebral palsy or congenital handicap. The functional capabilities of the sample (only one third of the children had either full or limited activity levels) were similar to a sample of children registered in BANS 1997, 40% of whom were capable of full activity. The sample of children surveyed was not old enough to assess the effect of the tube on child's psychosocial well-being (e.g. self-consciousness or embarrassment about the feeding tube). Further study of adolescents on long-term tube feeding is warranted to determine its effect on this group.

The study found that mothers were principally responsible for looking after the tube feed. In the majority of families of disabled children, mothers are solely responsible for feeding (Reilly, 1993). Nearly all mothers were worried that their child was not receiving enough food prior to tube insertion, and many described spending long periods feeding their child orally before tube insertion. For many parents of handicapped children, feeding represents the major difficulty in the management of the child (Couriel *et al.* 1993). Other authors have suggested that feeding a child with cerebral palsy may take to 18 times longer than feeding a "normal" child. However, direct observations of mothers feeding their handicapped children found that meal-times were often brief and no longer than those of age-matched comparisons, despite the fact that the mothers reported spending inordinate periods of time feeding their children (Reilly & Skuse, 1992). One family avoided eating in the same room as the child on tube feeding to avoid upsetting or confusing her, but it has been suggested that the child on HETF should be encouraged to sit at the meal table with the rest of the family whilst being tube fed, in order to normalise and encourage socialisation associate with mealtimes (Sidney & Torbet, 1995).

Two-thirds of mothers felt that their child appeared happier since tube insertion, and all mothers felt that opting for tube feeding had been the right decision for their child. Similar findings were found by other investigators. One study of parents of children with neurological disabilities on tube feeding showed that 65% felt their child's mood had improved since tube feeding was commenced (Naureckas & Christoffel, 1994). Smith *et al.* (1999) studied children on HETF with cerebral palsy and found that 86% of caregivers felt that tube feeding had a positive effect on their lives; similarly, McGrath *et al.* (1992)

found that 94% of parents of children with cerebral palsy on gastrostomy feeding believed gastrostomy was beneficial in management of their child.

Relatively few mothers were initially opposed to the feeding tube insertion, and later their attitude changed and all of those who were previously reluctant to have the tube inserted said they would recommend the tube to another parent. However, there are conflictual processes associated with gastrostomy decision making, and these processes create strong moral dilemmas (Thorne *et al.* 1997a). Our findings do not compare to those found by Spalding & McKeever (1998), who reported that 11 out of 12 mothers were initially very opposed to the tube insertion. Immediately after the tube insertion, however, most mothers studied by Spalding & McKeever felt considerable relief because the tube led to positive changes in the children and in their own lives. Following their return home from hospital, those mothers later still made efforts to feed the child normally (Spalding & McKeever, 1998). Although it was not specifically asked in this survey, many mothers commented anecdotally that they believed that their child would eventually eat normally again.

A number of mothers mentioned difficulties in obtaining supplies in the community. Similar findings were found in the survey of adults on tube feeding, who also reported many inconsistencies with respect to delivery of feed and equipment to the home setting (Chapter 2). It is regrettable that parents experienced such logistical difficulties, although provision of a delivery service is likely in the future. The poor confidence in GP knowledge about enteral feeding was similar to that found in the adult patients (Chapter 2). However GPs did not appear to be the primary resource for advice on tube feeding for these mothers, who kept in regular contact with the hospital staff and generally returned to the hospital if problems arose with the feed. Ideally, GPs and community nurses should be involved at an early stage when treatment plans are made (Puntis *et al.* 1991). Some mothers felt they could have benefited from more training before their discharge, similarly, Chaplen (1997) found that 56% of a group of parents felt that they weren't adequately prepared and hadn't received the appropriate information about tube feeding devices before being discharged from hospital. In terms of preparing children for HETF, Holden *et al.* (1997) found that older children and adolescents who received detailed psychological preparation for home tube feeding (nasogastric), were significantly less distressed when the tube was *in situ* than those who did not receive detailed psychological support.

Three quarters of the of the sample commented that a support group for parents of children on home tube feeding would be helpful, and those who hadn't would have liked to have spoken to other parents before their child's discharge. Talking to other parents before

discharge appeared to help parents in a psychological way, but in this small group, it did not appear to help in a practical way. Mothers realise that after spending time caring for a tube-fed child, their experience makes them suitable to advise other mothers on the kinds of problems they may expect to encounter in the home environment. In addition, mothers have experienced emotions and feelings that hospital staff, regardless of their expertise, will not have encountered and therefore this puts mothers in a better position to prepare other parents psychologically and put their minds at ease. Long term gastrostomy feeding has technical, social and psychological implications for both parents and children (Thorne *et al.* 1997b). The establishment of an organisation such as half PINNT (organisation for Patients on Intravenous and Nasogastric Nutrition Therapy) in Ireland would be useful, although the relatively small numbers of patients would possibly make this difficult. PINNT offers support and to patients and carers on artificial nutrition in the community. They provide a telephone support network across the UK and produce information booklets, holiday guidelines, teachers books and leaflets on benefits. A regular newsletter keeps members in touch about regional meetings around the UK. Membership is open to patients, family, friends, carers, health care professionals and industry. When first formed, PINNT was predominantly a group for patients on IV therapy, where patients on home parenteral nutrition made up the majority of its full members. However, the number of patients on home enteral nutrition who are members of the group is steadily increasing (Carter, 1993). In practical terms in Ireland, a support group might simply consist of an organised group of parents who are willing to speak to parents (even over the telephone) before the feeding tube is inserted, before their discharge and perhaps soon after discharge if necessary.

BAPEN produced standards of practice for patients on HETF standards in 1994 (Elia *et al.* 1994). Practices in the hospital did not show 100% concordance with all BAPEN standards. However, some standards such as the provision of a "relaxed, quiet area suitable for private discussion of the treatment" may be unrealistic in a busy hospital environment. While a proportion of the sample also felt that they were not confident that safe care would be provided for the patient at home, this group took the same amount of time to become familiar with HETF as those who were confident with tube feeding before discharge.

Michaelis *et al.* (1992) surveyed caregivers to look at perceptions associated with long-term home tube feeding. Problems related to social functioning, recreational activities, and family functioning were rated by care-givers as the most frequent and difficult. The

survey also found that problems identified by care-givers as most common and difficult are often in the social rather than the medical realm. Many of the mothers interviewed in the present study had their own particular difficulties with the feeding tube; missing hand feed, disliking the cosmetic appearance of the tube, worrying about bullying, feeling continually "tied" to the child, to name just a few. Mothers of children requiring tube feeding experienced significantly greater stress than mothers of disabilities who do not require tube feedings, they have also been found to receive less support from family and friends (Adams *et al.* 1999).

Unfortunately, due to the small numbers in the survey, the variety of time on HETF and disease states of the children, nutritional assessment proved difficult and data obtainable was poor in terms of its usefulness. Weight prior to tube insertion was not always accurately available and some children had their feeding tubes in place for so long that this information would have been ineffectual for many children. While half of the group could be described as being below the 50$^{th}$ percentile for weight for age, it should be noted that the reference data for "normal" healthy children are inappropriate for use with the majority of the children in the survey, as reference standards collated on the general healthy population will not be appropriate for children with altered morphology due to diseases such as cerebral palsy. Some work has been carried out recently on the formulation of reference standard for children with cerebral palsy in the US (Krick *et al.* 1996) but equivalent European tables are not available as yet. A prospective trial with frequent recording of anthropometric measurements in an Irish population is essential to verify the positive effects of HETF on anthropometric parameters in children as found by many other authors (Aiges *et al.* (1989); Sanders *et al.* (1990); Popadopoulou *et al.* (1995); Kang *et al.* (1998), Williams *et al.* (1999).

No serious complications were experienced by any of the children surveyed although a prospective study would be needed to elucidate this fully. In addition, all mothers interviewed in the survey maintained regular contact with medical staff in the hospital, so this sample may be a poor representation of reality in terms of complications experienced by children on HETF in Ireland. Non-responders may have experienced more serious or different types of complications. However, other authors have found home tube feeding to be safe in children with relatively few minor complications, and no serious complications (Holden *et al.* 1991).

Both the small sample size and potential for an interested bias in respondents need to be considered in interpreting these results. Children are fed by variety of methods that

generally suits their lifestyles, families experience few major problems, but when a problem is consistently experienced this can be stressful for the patient and parent. For these minority of families a clearly defined support pathway should be established. In conclusion, all mothers said that the advantages of tube feeding outweighed the disadvantages, and all felt that opting for tube feeding was the right decision to make for their child. Larger studies are necessary to investigate the impact of disease state, socio-economic status, and other factors on mother's attitudes to tube feeding. It is recommend that further investigation of the experiences of parents and their children on HETF in Ireland be carried out.

# Chapter 4

# Surveys of health care professionals involved in community-based enteral nutrition

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## 4.1 Introduction

The successful management of patients on community based enteral nutrition requires a coordinated effort and contribution from a variety of health professionals in both the community and hospital setting, which in Ireland includes hospital dietitians, GPs, public health nurses and nutritional company employees. Careful coordination of a number of factors, including extensive patient education, successful delivery of supplies and equipment in the community as well as the provision of follow up monitoring is also essential.

A BAPEN report recommended that health professionals ensure that their patients receive adequate training and quality care before starting HETF and that the quality of care be maintained throughout their treatment (Elia *et al.* 1994). Standards of practice are outlined in the report, which include a recommendation that there should be a post-discharge monitoring protocol, established by the hospital nutrition support team (NST). BAPEN also recommended that there be a policy for sharing care with the patients GP. However, the most recent BANS report stated that only 37% of all hospitals participating in the survey had a NST, and 44% of those said the NST was not primarily responsible for monitoring home nutrition support (Elia *et al.* 1997).

There are few reports in the literature which describe the practices of community based personnel with respect to patients on tube feeding outside the hospital setting, despite the fact that 73% of respondents to the BANS survey in 1997 reported that the location of follow-up for nutritional therapy is in the home (Elia *et al.* 1997). Most presentations and papers regarding services to these patients are from the hospital perspective. As the work of the nutrition company employees is entirely business related, reports regarding their experiences in the course of their work with patients on community tube feeding are thus unavailable in the scientific literature. Similarly, publications from the perspective of community dietitians, PHNs or GPs regarding community tube feeding are rare.

There are over 110 dietitians working in the health services in Ireland, the majority of whom work in the hospital environment. Teaching the patient/carer to tube feed at home is a complex process that involves many activities not traditionally performed by dietitians (such as teaching patients to operate pumps, care for tubes, organising funding etc.) however their role has evolved to accommodate these changes. The number of dietitians working in community dietetics has increased over the last decade and approximately 15-20 are currently employed. These community based dietitians are primarily involved in health promotion activities, but their role has expanded to provide dietetic services to GP

practices. Relative to population size, there are approximately 1.7 times more dietitians in the UK, where an increase of 23% in dietetic staffing levels has been recommended. To achieve a service in Ireland equivalent to the projected service in the UK in 1997, the number of posts in Ireland would have had to increase to 150 whole time equivalents (Daly, 1996). At present in Ireland, dietitians are not available in a clinical capacity in the community to allow a smoother transfer of care from hospital to community and to monitor and review patients on tube feeding outside the acute hospital setting. There are no health professionals with the required nutritional knowledge working at community level to whom the nutritional care of home tube fed patients can be transferred. This may lead to unsatisfactory patient care and to frustration and wasted time for GPs, PHNs and for patients, who may have to return to hospital for care that could be provided in the community.

GPs, are a vital component of the primary health care sector. There are approximately 900-1000 GPs in the EHB region of Ireland (ICGP *personal communication*). A survey of the nutrition interest among GPs in the Dublin region found some interesting results. Eighty-eight percent of the respondents reported that they had no formal education in nutrition as a student, although 30% did report that they had some form of postgraduate training in nutrition. Ninety-eight percent felt that GPs need to know more about nutrition, and only 25% felt that their nutritional knowledge was adequate for their needs (Mallon & Kennedy, 1993). More recently, a recent final year Human Nutrition & Dietetics student (Lisa Maher) compared the level of nutrition interest amongst GPs in Dublin in 1999 to Mallon's study in 1993. The response rate to the latter survey was lower than the first (47% *versus* 56%), and found that access to dietetic services have decreased while referral rates have increased. A more worrying fact is while a similar percentage of doctors considered that their nutrition knowledge was inadequate (48% in 1999 and 49% in 1993), less doctors were interested in further nutrition education (78% in 1999 compared to 85% in 1993). The BAPEN standards of practice recommend that written information describing home tube feeding should be available for the GP, that the hospital team should provide the GP with the information before the patient is discharged, together with the discharge date and on-call telephone numbers, and that the patient should have confidence in his/her GPs knowledge of home tube feeding (Elia *et al.* 1994). A recent survey of GP's knowledge and satisfaction with the service provided by a NST to patients on home artificial nutrition in the UK concluded that GPs are mainly satisfied with the service, but that communication between the acute and primary care services needs improvement. The survey achieved a

high response rate, however, suggesting that this is an subject of interest to GPs in the UK (McAtear, 1998). The majority of GPs in the EHB region (71.3%), are aged between 40 and 70+ years (ICGP, *personal communication*), suggesting that the practice of enteral feeding may not have been common in the hospital environment when the GPs undertook clinical training.

A number of healthcare companies in Ireland manufacture and sell products for patients on tube feeding. These companies produce a wide range of products, i.e., enteral feeding formula, enteral feeding pumps, and administration sets, as well as PEG, nasogastric, and nasojejunal tube kits (see Appendix III). In Ireland the service these companies provide to patients is based on the use of the company feeding pump(s). Usually, the company will provide the client (i.e., the patient or nursing home) with the enteral feeding pump on a free loan basis. It is then usual for that company's formula feed and administration sets to be used by the patient. When enteral feeding is no longer required, the pump is then returned to the company. Sales representatives of these nutritional companies encounter patients on enteral feeding in the hospital and/or community through their work. They may therefore, have an insight into the problems experienced by these patient's in the home environment. In Ireland, both nurses and dietitians are employed as representatives. In the US, the home care industry for tube feeding has expanded over the last number of years as the number of patients on community tube feeding increased steadily. The aim of most home care companies in the US is to carry out the treatment prescribed by the patient's physician in the comfort of the patients home (Nelson & Fleming, 1990). The services provided to patients on home tube feeding has expanded, and now many home care companies offer the patient the services of nurses, dietitians, and consultant physicians to ensure high standards of care for their clients. Selecting the most suitable home care company is important to ensure the conflicting advice is not provided (Elia, 1994). In the UK, the involvement of the home care company involves the delivery of enteral feeding products to the patients home (Elia, 1994). However, the last couple of years have seen the advent of home care companies in the UK that provide similar services to those US companies mentioned above (e.g., Caremark®). Unfortunately, the services provided by nutritional companies to patients on home tube feeding is rarely documented in books, articles or scientific papers. Anecdotal evidence suggests that they play a role in the discharge and aftercare of patients on community tube feeding in Ireland.

Before carrying out our main survey to examine the experiences of patients and their carers on tube feeding in the community (Chapters 2 and 3) it was decided to survey some of

those individuals involved in the care and management of patients on community tube feeding. It was expected that this would provide a suitable background for a more focused approach in gathering information from patients and carers.

## 4.2 Aims

The aims of the following surveys were as follows;

1. To establish the extent of the role of the Irish clinical dietitian in the preparation and post discharge monitoring of patients on community tube feeding.
2. To examine in what way, and to what extent, GPs are involved with patients on tube feeding in the community.
3. To investigate the aspects of tube feeding in the community which nutritional company representatives are involved, to establish the role played by them, and their experiences in the course of their work with these patients.
4. To establish (by extrapolation) the extent or prevalence of home enteral tube feeding in Ireland.

## 4.3 Methods

### 4.3.1 Questionnaire design

#### Questionnaire design: Dietitians

The dietitian's questionnaire consisted of 19 (primarily closed-ended) questions. It firstly addressed demographic details such as name, experience level, job title, and the hospital in which the respondent was employed. Secondly, the questionnaire examined the number of patients discharged on tube feeding annually by dietitians, and the individual(s) in their hospital who is/are responsible for the various tasks necessary before a patient is discharged. Thirdly, the questionnaire addressed the length of time spent by dietitians training patients for community nutrition, and telephone calls received regarding patients after their discharge into the community. Lastly, various ways of improving the process of discharging and managing patients on tube feeding were suggested, and the respondents were asked to rank, in their opinion these methods of improvement in order of their merit. The dietitians were then invited to make additional comments on the subject of community tube feeding if they wished (See Appendix IV).

#### Questionnaire design: GPs

The GPs questionnaire consisted of 21 questions, and covered topics such as level of experience, numbers of patients in the GPs care on tube feeding, how the GP is informed of a patients discharge on tube feeding into the community, whether or not information about the feed is supplied on discharge, problems experienced by these patients, and ways in which services to patients on home tube feeding can be improved. Only 6 questions needed to be completed by those GPs who did not have a patient on tube feeding in their care either presently or in the past. Reasons for a poor GP response to postal surveys have been investigated and include insufficient involvement with the subject being researched, qualms about encroachment of confidentiality and resentment to the interference to his or her work (McAvoy, 1996). To counteract these pitfalls, the questionnaire used for this survey was short, simple to complete, and included a comprehensive explanatory letter of the survey, as well as the inclusion of a stamped addressed envelope. The GP was also given the option of remaining anonymous. Insufficient involvement in the subject being researched should not have had a bearing on the response rate in the second survey as the very nature of the survey was to investigate involvement with patients on home tube feeds, rather than surveying attitudes and knowledge of the topic.

### Questionnaire design: Company representatives

A questionnaire was devised which addressed general information about the representative, the role of the representatives in the education of patients/carers, equipment provided by the company, and finally, problems experienced in the community with respect to patients on HETF (Appendix V). Participants were also asked if and how they considered that community tube feeding could be improved. All questions in the questionnaire were of an open nature, to allow for maximum discussion of the subject.

## 4.3.2 Selection of candidates

### Selection of candidates: Hospital dietitians

The hospitals in the 8 Health Board regions of Ireland in which dietitians are employed and the number of full and part-time clinical dietetic posts in each were determined from the INDI. Due to the relatively small number of dietitians employed in Ireland, it was decided not to focus exclusively on those dietitians with definite knowledge and experience of discharging patients on tube feeding (e.g. those working in the areas of medicine for the elderly, or gastroenterology). Instead it was decided to target all dietitians employed in clinical practice, either in full or part time posts. Using this approach, it was possible to examine the level of involvement of many dietitians across the country, rather than focusing only on the practices of dietitians experienced in the routine of discharging patients on tube feeding. The Principal (or most senior) dietitian in each dietetic department was sent an appropriate number of questionnaires for the dietitians in her department and asked to distribute them amongst her colleagues. A covering letter, explaining the aims of the survey was attached to each questionnaire.

### Selection of candidates: GPs

GPs were chosen at random from a list of the GPs participating in the General Medical Scheme (GMS) in the EHB region for both the pilot and main survey.

### Selection of candidates: Company representatives

The companies in Ireland in which nutritional product sales representatives are employed (who are involved with patients on community tube feeding) were identified. Letters were written to the company representatives explaining the aim of the survey, and inviting them to take part. Each letter was followed up with a telephone call, and arrangements were made to meet each of the representatives individually.

### 4.3.3 Pilot surveys

#### Pilot surveys : hospital dietitians

The dietitian's questionnaire was piloted by 5 dietitians and reviewed and revised appropriately. Members of the pilot group were also potential participants in the survey to avoid diminishing the already small target population.

#### Pilot surveys: GPs

Thirty GPs were chosen at random from a list of the GPs participating in the GMS in the EHB region. A covering letter was drafted, explaining the aims of the survey of patients in the community on tube feeding and the aims this pilot survey. The covering letter was signed by a medical practitioner, which has been shown to increase the response rate of postal questionnaire surveys to GPs (Heywood *et al.* 1995). The questionnaire was posted to the 30 GPs. A stamped addressed envelope was included in each, again in an attempt to increase the response rate as suggested by Smith *et al.* (1985). No special attention was given to the day of the week that the questionnaires were posted as it has been shown that response rates to postal surveys sent to doctors cannot be improved by their receiving the questionnaire at a particular day in the week (Olivarius & Andreasen, 1995). After 2 weeks 12 questionnaires had been returned which constituted an initial response rate of 40%. Attempts were made to contact the 18 non-responders by telephone. Thirteen were successfully contacted (1 GP was deceased). Numerous unsuccessful attempts were made to contact the remaining 4 GPs. When contacted, the GP (or the GPs secretary) was asked to return the questionnaire, although some admitted that they had already discarded the questionnaire. Others said they would fill out the questionnaire if they found the time to do so (only 1 GP subsequently returned the questionnaire, which gave an overall response rate of 43%). In all cases, when the GP or secretary were contacted by telephone an attempt was made to identify whether or not the GP currently had a patient in their care on home tube feeding or whether they had a patient of this type in the past.

The level of association with patients on HETF was similar for the responders and for the non-responders. Of those GPs who responded (*n* 13), 30.7% had a patient on home tube feeding in their care at present or in the past, but *none* of these had successfully filled out all parts of the questionnaire. Of those non-responding GPs who were successfully contacted by telephone to discuss their involvement with patients on home tube feeding (*n* 11), 4 (36.0%) had patients in their care at that time or at some time in the past.

Following analysis of the pilot survey results, it was decided that the number of questions in the questionnaire was excessive and some of the questions were irrelevant, as all GPs

who had a patient of this type in their care had only *one or two* such patient, and many of the questions assumed a greater experience with tube feeding. The questionnaire was subsequently modified (Appendix VI). The aim of the GP postal survey was also changed. It was decided to now investigate a larger sample of GPs in the Dublin area, to determine how many of these GPs had patients on tube feeding in their care at present or in the past, and *how many* patients were *currently* in the GPs care on tube feeding, in other words, to determine more fully the extent of exposure to enteral feeding in GP practice.

### 4.3.4 Main surveys

#### Main survey: hospital dietitians

A total of 105 questionnaires were posted to dietitians in the Republic of Ireland. Seventy (66%) of those were mailed to dietitians in the EHB region of the country, while the remainder, 35 (34%) were sent to dietitians working in other Health Board regions. Three weeks after the initial posting, follow-up reminder phone calls were made in an effort to increase the response rate. The questionnaire took approximately 5 minutes to complete.

#### Main survey: GPs

The modified questionnaire was sent to 150 GPs in the Dublin area. A stamped addressed envelope was enclosed, along with a covering letter explaining the aims of the project, in view of the previously carried out pilot survey. The same criteria as the pilot survey were applied in an effort to achieve the highest response rate possible. The questionnaire used for this survey was short and less time consuming to complete (about one minute). The GP was also given the option of remaining anonymous.

#### Main survey: Company representatives

Company representatives were interviewed at a convenient location. Meetings were of an informal nature, and on average lasted between 45 minutes and 1 hour. Representatives were interviewed using an open questionnaire. Open questions can elicit information and areas of interest not predicted by the investigator and can produce more detailed responses. The drawbacks to open ended questionnaires include lengthened administration time as a greater volume of responses must be recorded. Long and varied responses are also difficult to handle statistically. However, the open question format is an important method of assessing individual experience in detail (Bennett & Ritchie 1975). The open question format was useful for this survey, as the number of company representatives interviewed was small and the aim of the survey was to explore their experiences and ascertain opinions.

### 4.3.5 Data analysis

Completed questionnaires were coded and responses were entered into a computer for analysis. Results were recorded as percentages of valid (*i.e. answered*) responses for each question. Where appropriate, results are expressed as mean ± standard deviation. Two sample t-tests and Chi-squared tests were used to investigate differences between groups. Statistical analysis was performed using the Statistical Package for Social Sciences (SPSS) for Windows (Version 6.0, SPSS Inc.).

## 4.4 Results

### 4.4.1 Results: Hospital dietitians

Seventy-seven questionnaires out of 105 were returned, yielding an overall response rate of 73%. Fifty were returned from the EHB (71% response rate) region and 27 from the rest of the country (77% response rate). Table 4.1 shows the distribution of responses from each of the Health Board regions. Five of the returned questionnaires were only partially completed, but the answered questions were included in the analysis. The primary reason for unanswered questions was inexperience with discharging patients on home enteral feeds.

The average level of experience in clinical dietetics was 7.9 years (SD 6.3 years). Approximately 8% (*n* 6) of the responders were principal dietitians, 42% (*n* 32) of responders held senior positions, and the remainder, 50% (*n* 38) were basic grade dietitians. One respondent worked in both the community and hospital setting. The majority (80%, *n* 61) of responders worked in hospitals with more than 200 beds and the majority (78%, *n* 60) of the respondents were employed in teaching hospitals. Only 11% (*n* 8) of the responders worked in exclusively paediatric hospitals as outlined in Table 4.2.

**Table 4.1.** Response rate according to Health Board region (dietitians)

| Health Board region | Number of questionnaires posted | Number of questionnaires returned (% response rate) | Percentage of total response |
|---|---|---|---|
| Eastern Health Board | 70 | 49 (70%) | 63.5% |
| North Eastern Health Board | 5 | 5 (100%) | 6.5% |
| Midland Health Board | 2 | 1 (50%) | 1.4% |
| Western Health Board | 7 | 5 (71%) | 6.5% |
| Mid-Western Health Board | 3 | 3 (100%) | 3.9% |
| North Western Health Board | 3 | 3 (100%) | 3.9% |
| Southern Health Board | 10 | 7 (70%) | 9.1% |
| South Eastern Health Board | 5 | 4 (80%) | 5.2% |
| **Total** | **105** | **77 (73%)** | **100%** |

**Table 4.2.** Demographic characteristics of dietitians who responded to survey

| Characteristic | *n* | % |
|---|---|---|
| **1. Hospital Size** | | |
| Small (200 beds or less) | 16 | 20% |
| Medium (201 - 499 beds ) | 28 | 37% |
| Large (500 beds or more) | 33 | 43% |
| **2. Hospital Type** | | |
| Teaching | 60 | 78% |
| Non Teaching | 17 | 22% |
| General Non Regional | 38 | 49% |
| Fully Paediatric | 8 | 11% |
| Regional | 27 | 35% |
| Other | 4 | 5% |
| **3. Job Description** | | |
| Principal Dietitian | 6 | 8% |
| Senior Dietitian | 32 | 42% |
| Basic Grade Dietitian | 38 | 50% |

## Time spent preparing for discharge

The average number of patients discharged from hospital on nutrition support was 11.5 patients annually per dietitian (SD 19.75, *n* 74). The total estimated number of patients discharged per year among the responding dietitians was 854. The number of patients discharged per dietitian varied, especially according to the type of hospital in which they were employed (see Table 4.3). Since the response rate was 73%, and all hospital dietitians in the country were surveyed it could be estimated that 854 patient represents 73% of the total number of discharges on tube feeding per annum. In total therefore, we would expect an annual *incidence* of approximately 1170 patients (679 adults and 491 children) on tube feeding in Ireland (see Fig 4.1). This relates to 32.5, 18.9 and 13.6 *per 100,000* of the population respectively.

Dietitians were found to spend an average of 2 hours and 35 minutes (SD 1 hours and 24 minutes) on the education and preparation of patients before their discharge into the community. Preparation is carried out over an average of 3.7 days (SD 1.87 days).

**Table 4.3.** Number of patients discharged on home tube feeding according to hospital type.

| Hospital category | Dietitians | Patients discharged on tube feeding annually per dietitian | | Total number of patients discharged annually per hospital type |
|---|---|---|---|---|
| | *n* | *Mean* | *SD* | *n* |
| Teaching | 58 | 12.9 | 22.04 | 751 |
| Non Teaching | 16 | 6.4 | 4.2 | 102 |
| General Non Regional | 37 | 8.2 | 7.7 | 301 |
| Fully Paediatric | 8 | 44.8 | 46.0 | 358 |
| Regional | 4 | 4.7 | 5.5 | 18 |
| Other | 25 | 7.0 | 8.0 | 176 |

Seventy-eight percent of the respondents considered that the length of time they spend on the education of these patients is limited due to other work commitments. The time spent on preparing patients for discharge was not dependant on the number of patients the dietitian discharged.

### Premature discharge

Dietitians were asked if patients on tube feeding in their care had been prematurely discharged from hospital into the community (i.e. before their education regarding feeding was complete). Respondents were asked to estimate how often this would occur for every 10 patients that were discharged on enteral feeding. Fifty-one percent (*n* 36) reported that patients in their care had been discharged on enteral feeding prior to completion of their education. This was found to occur in an average of 1 in 5 discharges, which relates to 77 patients annually or 9% of all patients discharged into the community on enteral nutrition.

### Telephone calls

Almost all respondents (92%, *n* 71) said they received telephone calls regarding patients they had discharged on tube feeding. Respondents were asked to estimate how many telephone calls were received for every 10 patients discharged. For those that receive telephone calls (*n* 71), the average number of calls received is 7 (SD 14) for every 10 patients discharged into the community. Dietitians in regional hospitals received significantly less calls than those in other hospitals ($P = 0.05$). The nature of the calls received was also investigated. Respondents were given list of inquiries and asked to tick those they had received. An "others" option was also given, and respondents were asked to specify the nature of those calls. Tables 4.4 & 4.5 show the nature of inquiries received over the telephone and from whom the telephone calls are received.

Dietitians in paediatric hospitals received significantly more calls than other dietitians in relation to inquiries about the feeding pump ($P = 0.004$), and dietitians in regional hospitals received significantly fewer inquiries about funding issues ($P = 0.04$).

**Table 4.4.** Inquiries received by dietitians over the telephone regarding patients

| Inquiry received over the phone | n | % of dietitians who received the enquiry |
|---|---|---|
| Enquiry regarding feeding pump | 37 | 51% |
| Enquiry regarding feeding schedule | 52 | 72% |
| Enquiry regarding physiological problems | 58 | 81% |
| Enquiry regarding funding for feed & equipment | 28 | 39% |
| Enquiry regarding blocked tubes | 41 | 57% |
| Other enquiries * | 32 | 45% |

** Other enquiries received included: enquiries regarding patients weight loss or gain, PEG site complications, emotional and moral support, removal of tube due to increased oral intake, decreasing and increasing the feed volume.*

**Table 4.5.** Source of telephone calls to dietitians regarding patients on home tube feeds

| Source of telephone call | n | % of dietitians who received an inquiry |
|---|---|---|
| General practitioners | 6 | 8.5% |
| Public health nurses | 56 | 77.8% |
| Patients/Carers | 66 | 91.7% |
| Others* | 22 | 30.6% |

** Other callers included nutritional company employees, nursing homes, community pharmacists.*

### Responsibility for preparation of patients

Respondents were asked to tick which individual(s) in their hospital carried out the particular tasks necessary before patients are discharged into the community on tube feeding. A list of individuals and tasks were given. The tasks necessary could be divided into three sections, firstly, organising the access route for feeding, feed type, and feeding schedule, secondly, teaching the psychomotor tasks associated with enteral feeding, and lastly, organising the transfer to home from hospital. Respondents were also given a space to name other individuals who may have been responsible for particular tasks in their place of employment. The results of this question are given in Table 4.6. Analysis of the results did not show any differences in terms of number of telephone calls received about patients after their discharge between dietitians who worked in an area where 1 individual was responsible for the education of the patients and dietitians who worked in an area where multiple professionals were responsible.

### Improving tube feeding in the community

The respondents were asked to rate a number of suggestions for the improvement of nutrition support in the community. A rating scale was used, where 1 was to be assigned to the suggestion that was least useful and 7 the most useful suggestion. Not surprisingly, practically all (98%) of the respondents felt that the process of discharging patients on tube feeding could be improved (see Table 4.7).

### Additional comments made

A number of respondents referred to the involvement of nutrition company employees in the care of the community-tube-fed patient. While some respondents commented on how invaluable the service the companies provided was, others deemed their involvement "unethical" and stated that community dietitians, rather than nutrition company employees should be available to deal with patients problems with community tube feeding. Some respondents commented on the lack of clarification with respect to responsibility for monitoring patients on tube feeding outside the hospital setting, and others suggested that specific guidelines would be useful. Difficulties with respect to the funding of home tube feeding were also mentioned.

Other dietitians suggested that both GPs and PHNs need more education regarding community tube feeding. There appeared to be an element of confusion regarding the responsibility for and protocols regarding patients on home tube feeds, "the rules keep

changing", and "standardise the procedure", were some of the comments made. The need for community dietitians was often mentioned, while one respondent felt that it would be difficult for a community dietitian to be experienced in all the different medical conditions requiring tube feeding.

Comments made regarding the proposed national register of patients on community tube feeding in Ireland tended to be negative in tone. Some remarks made were, "a national register would only be useful if there were community dietitians" "it would be very difficult to keep up to date", and "a register merely highlights the problem instead of addressing it".

**Table 4.6.** Tasks performed by dietitians before discharging patients on tube feeding

| Tasks | n | % Responders who carry out task |
|---|---|---|
| Determining the patients nutrient requirements | 73 | 91.8% |
| Determining patients fluid requirements | 72 | 57.0% |
| Selecting the enteral feeding formula | 73 | 96.0% |
| Selecting access route | 73 | 6.8% |
| Selecting the feeding schedule | 73 | 80.8% |
| Contacting nutritional company employee | 68 | 89.7% |
| Contacting the primary carer | 72 | 53.0% |
| Contacting local pharmacy | 71 | 69.0% |
| Contacting director of community care | 68 | 57.4% |
| Contacting local public health nurse | 70 | 54.3% |
| Contacting hospital liaison officer | 40 | 40.0% |
| Teaching patient to avoid complications | 69 | 64.0% |
| Ensuring home environment is suitable for feeding | 60 | 11.7% |
| Ensuring supplies at home for the patient | 71 | 54.9% |
| Teaching patient to recognise formula intolerance | 65 | 58.5% |
| Teaching the patient to administer feed | 76 | 23.0% |
| Teaching the patient to operate feeding pump | 71 | 17.0% |
| Teaching the patient to flush the feeding tube | 71 | 15.5% |
| Teaching patient to care for the stoma site | 70 | 2.9% |
| Teaching patient to administer drugs via tube | 71 | 7.0% |

**Table 4.7** Dietitians opinions on how home tube feeding could be improved

| Suggestion | 1st choice % | 2nd choice % | 3rd choice % |
|---|---|---|---|
| More community dietitians needed | 52 | 19 | 4 |
| National guidelines needed | 18 | 11 | 16 |
| Hospital nurse specialists needed | 9 | 14 | 26 |
| National register should be set up | 9 | 17 | 9 |
| Self help group for patients needed | 5 | 8 | 9 |
| Funding for equipment etc. should be easier to obtain | 4 | 20 | 10 |
| Educational packages needed for GP's and PHN's | 3 | 11 | 26 |

### 4.4.2 Results: General practitioners

#### Response rate

Eighty-one questionnaires were returned, all were fully completed except for 1 questionnaire that was returned unanswered, (the GP had retired) this gave a 53.3% response rate. Respondents were given the option to identify themselves and 80% of GPs chose to do so.

### Number of GPs with patients on tube feeding in their care

Twenty-four percent (*n* 19) of respondents reported having a patient on tube feeding in their care at the time of the survey. Sixty-five percent (*n* 61) of GPs reported having a patient of this type in their care in the past. GPs were not asked how many patients they had in the past, in an attempt to keep the questionnaire as simple as possible. The majority (77.5%, *n* 63) of GPs reported that they attended nursing homes. Table 4.8 shows the significant difference in the experience with tube feeding between those GPs who attend nursing homes and those who do not.

**Table 4.8**. Experience with tube feeding: nursing home GPs vs. non nursing home GPs

| Attends Nursing Home | Currently have patient on tube feeding in care | Previously had patient on tube feeding in care |
|---|---|---|
| Yes | 29% (*n* 18) | 72.6% (*n* 45) |
| No | 5.6% (*n* 1) | 38.9% (*n* 7) |

### Number of patients on tube feeding in GPs care

GPs were asked to indicate the number of patients on home tube feeding in their care at the time of the survey, both adult and children. The sum of patients reported was 35, which consisted of 14 children and 21 adults. The mean number of paediatric patients per GP was 0.17 (± 0.55) and the mean number of adult patients per GP was 0.26 (±0.58). See Table 4.9 for more details. There are approximately 2427 GPs in Ireland (Murphy, 1998). Since 80 GPs in the present survey reported having 35 patients on HETF in their care, on the basis of this figure, (assuming the respondents are typical of all GP's) we could extrapolate that the *point prevalence* patients on HETF in Ireland at *the time of the survey* was 1061 (636 adults and 425 children). This relates to 29.4, 17.6 and 11.8 per 100,000 of the population respectively. See Figure 4.1.

**Table 4.9**. Current exposure to tube feeding: number of patients in GPs care

| Number of patients | Adults | | Children | |
|---|---|---|---|---|
| | % | *N consultants* | % | *N consultants* |
| 0 | 81 | 65 | 89 | 71 |
| 1 | 14 | 11 | 6 | 5 |
| 2 | 4 | 3 | 4 | 3 |
| 3 | 0 | 0 | 1 | 1 |
| 4 | 1 | 1 | 0 | 0 |
| 4+ | 0 | 0 | 0 | 0 |
| **Total** | **100** | **80** | **100** | **80** |

### 4.4.3 Results: Company representatives

Ten company representatives were interviewed (7 dietitians and 3 nurses). At least one representative was interviewed from each of the companies in listed in Appendix III. Results are not specific to any particular company (in order to maintain company confidentiality).

#### Topics of education covered by the company representatives

Sales representatives were asked to outline the main areas of patient/carer education with respect to tube feeding in which they were involved, which are summarised in Table 4.10 below.

**Table 4.10** Company representatives: Topics of education

| | |
|---|---|
| 1. | The use and care of the feeding pump |
| 2. | Setting up of the feeding system, e.g. how to prime the line |
| 3. | Care of the PEG site |
| 4. | Financial reimbursement for home tube feeding |
| 5. | Flushing/care of the feeding tube |
| 6. | Administration of medications down the feeding tube |
| 7. | Information on follow up service |
| 8. | Modifying the feeding regimen to suit the patients lifestyle |
| 9. | Problem solving, e.g. management of blocked tubes |

#### Time spent educating patients and carers

All interviewees reported that the time spent educating patients and carers about tube feeding varies enormously. The duration of education sessions ranges between 30 minutes and three hours. The length of time required to educate nurses and staff in nursing homes logically depends on the level of experience with enteral nutrition by the staff in the home. The time required to educate families depends on the education level and/or the age of patient/carer. Some families are capable of learning the technique in one short education session, while others require up to five visits by the representative before they are confident in their ability to deal with the pump and feeding system. Some company representatives educate patients in the hospital setting before discharge into the community (*n* 1), others visit patients in their homes (*n* 2) post discharge, while others educate patients in either or both settings (*n* 7)

### Enteral nutrition in nursing homes: knowledge of nursing staff

All (100%) of the company representatives reported that they found the level of knowledge of nurses in nursing homes concerning enteral nutrition to be quite poor in general. They reported that nurses tended to be nervous about enteral feeding especially if it has not been practiced in the institution before. Three participants (25%) commented that staff in small nursing homes, especially outside the Dublin area, have particularly poor knowledge of enteral nutrition. Younger nurses were deemed to be more capable of mastering the feeding systems, and older nurses are more familiar with bolus feeding than with pump-assisted feeding. All candidates felt that nurses in the community require more education regarding enteral feeding, although there was a general acceptance that their awareness of enteral nutrition has increased over the last few years. All respondents felt that once nurses became familiar with the feeding system they had very few problems with it.

When educating staff in nursing homes, company representative endeavor to see as many nurses from the home as possible (e.g., organising the session at the time of the staff changeover) in order to avoid the situation of information being filtered through a number of personnel and inevitably becoming misinterpreted.

### Number of visits made to patients by the nutritional company staff

Patients are educated by the company representatives initially in either the discharging hospital or the home/nursing home. After this, the majority of the participants stated that they usually only meet patients again if they are contacted to do so. One individual said that she routinely telephones the patient/carer two or three weeks after their discharge to ensure that the feeding system is working properly, and to answer any questions the patient/carer might have.

All those interviewed stated that the dietitian in the discharging hospital is the most likely individual to inform them of a patients pending discharge from hospital. Less often, nursing staff contact them (e.g., usually where there is no dietitian in the particular hospital from which the patient was being discharged).

### Contacts with other health professionals

Of other health professionals, participants were found to have most frequent contact with hospital dietitians to discuss patient education on discharge. None had contact with GPs in relation to patients on home tube feeding. Nearly all the representatives dealt with pharmacists in the community, usually when advising them on ordering feeds and giving

sets for patients. All of the interviewees liased with PHNs regarding patients on home tube feeds. Some of the contact with PHNs was on a one to one basis, (in relation to specific patients discharged home on enteral feeding), but representatives were also involved in the education of PHNs regarding enteral feeding.

### Reviewing patients feeding regimens in the community setting

Eight of the representatives (66%) reported that they do not manipulate or review patients feeding regimens if they are asked to do so. Most said that they contact (or advise the patient/carer to contact) the dietitian in the discharging hospital to inform her of any problems, and arrange for changes to be made to the feeding schedule as appropriate. Two representatives (16%) acknowledged that they make very simple changes to the feeding schedule if necessary, (e.g. reorganising the feeding times to suit the patient's lifestyle). One participant commented that patients/carers are found to make inappropriate changes to the feed themselves, and another commented that while she would never, and had never changed patients feeding schedules in the community, it was evident to her that other representatives from other companies had been manipulating feeding regimens.

All of the company employees felt that it is not appropriate for them to change or review patients feeds in the community setting, but because they are present in the patient's home/nursing home, they tend to be asked about the problems being experienced by the patients anyway. They are therefore often placed in an awkward position of having to solve the problems presented to them.

### Role of the nutritional company representatives in the community

One of the questions posed in this survey was "what is your role in relation to patients on home enteral nutrition?". Table 4.11 outlines the responses to this question.

**Table 4.11** Company representatives: role in relation to patients on home tube feeding

| |
|---|
| "Educator in the use of feeding pumps and giving sets" |
| "A support person, co-ordinator, liaison between all individuals involved in home tube feeding " |
| "We try to make the discharge of patients run as smoothly as possible" |
| "Educator" |
| "Nutritional advisor, educator, and facilitator" |
| "After sales service provider " |

### Problems with tube feeding in the community

All representatives commented that in their experience, both GPs and PHNs had poor knowledge of enteral nutrition. Other problems cited were the lack of community dietitians, and the absence of regular follow up and review of patients on tube feeding in the community (see Table 4.12). Representatives mentioned that GPs "do not want to become involved", that nobody appears to know who is responsible for patients feeds, and that they (representatives) are continually being requested to make decisions about feeds in the community.

All of the company employees interviewed feel that the situation for patients on home tube feeding in Ireland needs to be improved. They were asked how they felt the situation could be improved. A list of the suggestions made for improving home tube feeding are presented in Table 4.13.

**Table 4.12** Problems encountered by company representatives regarding

| Mechanical Problems | Physiological Problems | Hygiene Problems |
|---|---|---|
| Tube blockages | Stoma infections | Reusing of giving sets |
| Tube dislodgement | Diarrhoea | Dirty tubes |
| Leaking PEG's | Constipation | Non sterile procedures |
| Pump malfunction | Dehydration | Lack of care around |
| Y-port connectors broken | Weight loss | the stoma site |
| Blocked giving sets | Inadequate nutrition support | Feed leaking into pump |
| Loose connections leading to leakage of feeds | | |

**Table 4.13** Company representatives views on methods to improve home tube feeding

| |
|---|
| "More structured procedures are necessary" |
| "Improved co-ordination of practices" |
| "Community or liaison dietitians are needed" |
| "GPs and PHNs need to be more aware of nutrition support generally" |
| "Protocols are needed for discharging patients on home tube feeds" |
| "There needs to be a named individual responsible for patient's on home tube feeds " |
| "Provision for placement and removal of PEGs in the community is necessary" |
| "We need more notice of the discharge of patients to be better organised for home tube feeds " |

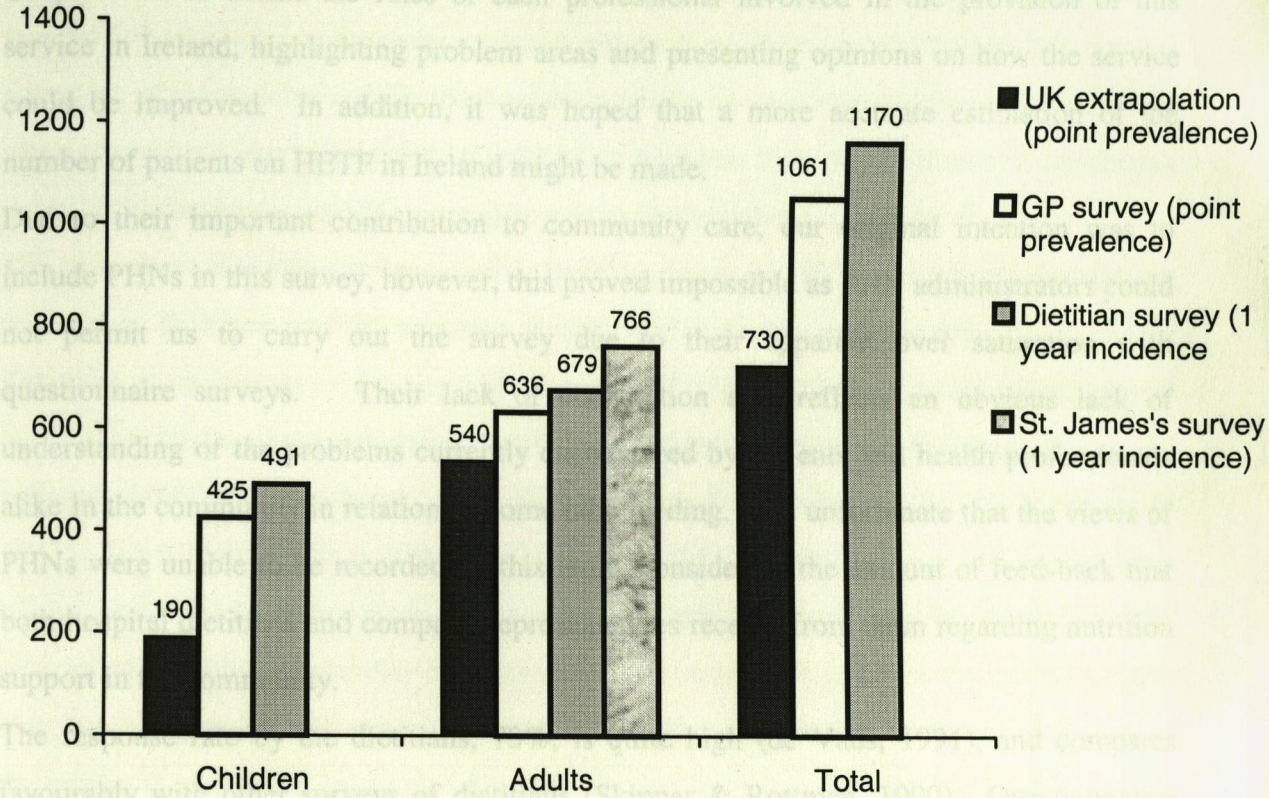
### 4.4.4 Number of patients on HETF in Ireland

In Chapter 1 it was estimated that there are approximately 730 patient on HETF in Ireland, by extrapolating from UK BANS data (see Chapter 1.3.2). However, we also asked Irish dietitians to estimate the number of patients they discharged on HETF annually (*incidence*), and Dublin GPs were asked to estimate the number of patients on HETF in their care in the community at one point in time (*point prevalence*).

Another way to estimate the number of patients on HETF in Ireland is by extrapolating from the data reported in Chapter 2. It was found that there were 46 discharges on HETF from St. James's in 1997. There is an annual discharge/death rate of 21,394 patients from St. James's Hospital (DoH&C, 1999), which constitutes 4.7% of all discharges from relevant* adult acute hospitals in Ireland. Since the proportion of discharges from St. James's is 4.7% of the Irish total, it could be assumed that the proportion of HETF discharges is also 4.7% of the Irish total. In 1997, this figure was 46, therefore the total number of adult patients discharged on HETF from hospitals in Ireland could be estimated to be 978 patients. This figure is likely to be an over-estimate of the exact number, because St. James's is a teaching, tertiary referral hospital, and has more dietetic staff than any other hospital in the country: these factors may have resulted in more discharges of patients on HETF per annum than other hospitals. If the calculation is based on the *main teaching and larger hospitals* in each region of the country, the figure becomes 6% of the total relating to 766 adult patients per annum. Figure 4.1 compares the results from the 4 methods by which the number of patients on HETF in Ireland has be estimated.

**i.e. excluding maternity, orthopaedic, paediatric and other specialist hospitals*

**Figure 4.1** Estimated number of patients on HETF in Ireland.




*Average point prevalence*

Adults: (540 + 636) / 2 = **588**

Children: (190 + 425) / 2 = **307**

*Average yearly incidence*

Adults: (679 + 766) / 2 = **722**

Children: **491**

## 4.5 Discussion

Successful enteral feeding in the community is only achieved through the team efforts of a number of health care professionals. The main objective of the surveys described in this Chapter was to define the roles of each professional involved in the provision of this service in Ireland, highlighting problem areas and presenting opinions on how the service could be improved. In addition, it was hoped that a more accurate estimation of the number of patients on HETF in Ireland might be made.

Due to their important contribution to community care, our original intention was to include PHNs in this survey, however, this proved impossible as PHN administrators could not permit us to carry out the survey due to their apparent over saturation with questionnaire surveys. Their lack of cooperation also reflects an obvious lack of understanding of the problems currently encountered by patients and health professionals alike in the community in relation to home tube feeding. It is unfortunate that the views of PHNs were unable to be recorded on this issue, considering the amount of feed-back that both hospital dietitians and company representatives receive from them regarding nutrition support in the community.

The response rate by the dietitians, 73%, is quite high (de Vaus, 1991), and compares favourably with other surveys of dietitians (Skipper & Rottman, 1990). Questionnaires were returned from 45 different institutions, which constituted a broad range of hospital sizes and types, as well as Health Boards. This range of respondents served to give a comprehensive profile of the role of the Irish dietitian in discharging and managing patients on tube feeding in the community.

There was large variation in the number of patients discharged annually on tube feeding by different groups of dietitians. Most significantly, dietitians working in paediatric hospitals, appear to discharge a much larger number of patients on tube feeding yearly. In terms of numbers of patients discharged annually by the respondents ($n$ 856), 58% of patients are discharged from adult hospitals and 42% are discharged from paediatric hospitals. This ratio is quite different from the age distribution of patients described in the BANS report of 1996, where 28% of patients were < 16 years of age, and 72% of the HETF population were > 16 years of age (Elia *et al.* 1996). However, a study of community tube feeding in East Anglia found a similar distribution to that described by Irish dietitians, as 39% of the community tube fed population studied were children (≤ 16 years of age) (Parker *et al.*1996).

Some respondents stated that more than 1 health professional was responsible for a variety of the tasks necessary before discharging patients on tube feeding. This suggests that there may be a lack of coordination and organisation in certain hospitals in terms of responsibility for patient's preparation. However, there were no differences between the number of telephone calls received by dietitians who were solely responsible for the education of the patients and dietitians who worked in an area where multiple professionals were responsible, suggesting that in spite of an apparent lack of coordination, this hasn't led to an increased demand for more information by the patient following discharge.

The time spent educating patients before their discharge on HETF varied, but the average time spent (2 hours and 35 minutes) is comparable to the average time spent by US dietitians, at an average of 2 hours and 48 minutes (Skipper, 1990). Studies of patients on home tube feeding have estimated that between 2 and 6 hours are necessary to prepare patients sufficiently (Newmark *et al.* 1981; Adams & Wirsching 1984; Gulledge *et al.* 1987). Some Irish dietitians commented that more time is spent on the actual organization of the home feeds, rather than on the education process itself (i.e. organising pumps, equipment, funding, availability of feeds in the community etc.). Other respondents stated that the time spent on discharging patients varied depending on the discharge destination of the patient (i.e., patients being discharged to nursing homes took less time to organise than patient returning to their own homes in the community).

The majority of respondents received telephone calls regarding patients on tube feeding in the community. GPs were less likely than PHNs to contact hospital dietitians with problems relating to tube feeding. A wide range of enquiries were received, which suggests that hospital dietitians are involved to a considerable extent in the post-discharge problem-solving for patients on HETF over the telephone. Thirty-nine percent of dietitians received telephone calls regarding funding for home tube feeding. This compares with 28% of BANS respondents who said that experienced difficulties with the funding of home tube feeding (Elia *et al.* 1996).

An estimated 9% of patients were being discharged annually before their preparation was complete, which could suggest a lack of understanding on the part of some hospital staff of the importance of adequate organisation and preparation of these patients before discharge.

Nearly all hospital dietitians felt that the organisation and current management of patients on home tube feeding requires improvement, a reflection of their current dissatisfaction, and not surprisingly the majority felt the best way to improve the current situation for patients would be the provision of a community nutrition service.

A good response rate was obtained in the postal questionnaire survey of GPs (54%) and compares favourably with other surveys that have reported similar responses of 49% (Murphy, 1990) and 59% (Jack *et al.* 1990). In previous postal surveys of Dublin GPs, response rates of 56% and 47% have been achieved (Mallon, 1993; Maher, 1999). Interestingly, only 31% of the responders to the pilot survey had patients on tube feeding in their care (either currently or previously). This suggests a level of interest amongst GPs in this particular topic, as GPs have been found to have the motivation to respond to surveys if they are involved in the subject matter of the survey (Mayer & Pract, 1966).

It is not known if the GPs who responded to this survey are representative of all Irish GPs in terms of their involvement with patients on HETF. If there was a selection bias, then the GPs who did respond would be those who already had an interest in the topic, and would probably produce an overestimation of the approximate number of GPs involved with patients on this form of treatment. However, follow up of the non-responders to the *pilot* survey found that the level of involvement with HETF of non-responders was similar to the responders, and therefore other factors explained the lack of response in the main survey (e.g. lack of interest, saturation with postal surveys etc.).

As expected, few responders had patients on tube feeding in their care at present, and those that did had very few. The fact that those GPs who attend nursing homes as part of their work had more experience with patients on tube feeding is not surprising, as the many adult patients on tube feeding in the community are elderly, incapacitated and cared for in nursing home facilities. In Chapter 2 we found that 59% of patients discharged from St. James Hospital on tube feeding were sent to nursing homes, and the majority of these patients suffered from stoke and other neurological disorders and tended to survive for longer periods than other types of patients on HETF (see Tables 2.3 & 2.5).

The number of participants in the company representative's survey was small, but representative of nutritional company representatives working in Ireland, as at least one individual was interviewed from each of the companies involved in HETF. This survey found that many company representatives spend a considerable amount of time educating patients in the home and hospital setting, on topics other than the use of the feeding pump, often visiting patients a number of times in the community. Companies provide this service free of charge, and thus provide a valuable service to these patients.

Nutritional company representatives found the knowledge of nursing staff in the community with respect to enteral feeding to be quite poor. Not surprisingly, if the nursing home staff had not previously cared for a patient on enteral feeding they were perceived to

be quite apprehensive about starting the feed. However, all company representatives found nurses to be eager to learn about the feeding system, and found them all to be competent after training. Company representatives organise education sessions with PHNs and for staff of nursing homes. One representative mentioned that although a previous education session for GPs in the Dublin area had been unsuccessful (no one turned up to the lecture), a more recent education session (organised since this survey was carried out) for GPs on the subject of PEG feeding was more successful, which is indicative of an increasing awareness amongst GPs about enteral nutrition in the community.

Theoretically, it is both unethical and unprofessional for a dietitian or nurse who is employed by a commercial company to manipulate the feeding schedule recommended by that patient's dietitian and hospital team, as they (representatives) are unlikely to have full knowledge of the patient's medical and other relevant details. Nonetheless, considering the lack of expertise in the community regarding enteral feeding, company representatives encounter problems with HETF and (unsurprisingly) are asked to deal with these problems. It obviously poses a dilemma for professionally qualified and capable company representatives, with a sound knowledge of nutrition and dietetics, when they encounter patients with dirty tubes, constipation, dehydration, etc., to refrain from giving advice when asked by the patient/carer. This again raises the question of inconsistent follow-up of nutritional care needs of patients on HETF. However, it was clear from this survey that company representatives recognise that it is inappropriate for them to be involved in nutritional management decisions. These issues further highlight the need for an individual in the community who is in a position to deal with these problems, before the patient requires re-hospitalisation.

Participants believed that the process of discharging and managing patients on HETF needed to be more structured and better coordinated with universal protocols and particular individuals (preferably community dietitians) responsible for the nutritional care of patients in the community. It is significant that almost all of the company representatives felt that both GPs and PHNs needed more education on enteral nutrition, and regarded this as a priority in the improvement of community tube feeding. In general, hospital dietitians consider the company rep as an integral part of the transfer a patient from hospital to community on tube feeding. However, the survey of dietitians found that some deemed their involvement "unethical". There are currently no guidelines on the role of the rep in relation to the care of patients on HETF, and practice varies from hospital to hospital as the survey of dietitians found (in some hospitals the reps were responsible for tasks that in

other hospitals, nurses or dietitians carried out). Until now, the system, as it stands has caused no problems, but it would seem sensible for dietitians in Ireland, in conjunction with the companies involves in the home care industry to devise a code of practice in terms of the reps role. This would serve to standardise procedures and would ensure that everyone involved in the care of these patients were aware of the responsibilities and limitations of input of the company representatives.

As already stated, the exact number of patients on HETF in this country is not known. Extrapolation of UK BANS figures from 1999 leads a prevalence of approximately 700 patients. The extrapolated figures from the GP and dietitians surveys (1061 and 1170 respectively) would suggest that a higher number of patients are discharged annually on tube feeding in Ireland. We would have expected the figure given by dietitians to be higher than that given by GPs, as the dietitians figure relates to the total number of patients discharged in the year, whereas the GPs figure relates to one period in time. Over the year, some patients will die, and others will resume oral feeding, in fact, it has been estimated that the incidence of HETF may be 2 or 3 times the prevalence (Elia, 1995). Our incidence figure is not much larger than our prevalence figure, perhaps reflecting a national use of tube feeding for patients with long-term requirements. Dietitians are unlikely to have over-estimated the numbers of patients discharged, because when a respondent stated the number of patients discharged annually was large (i.e. over 30), these figures were double-checked by telephoning the respondent to ensure they have not misinterpreted the question. The GPs were also likely to have been typical of most GPs, because follow up of the non-responders to the pilot survey found that the level of involvement with enteral tube feeding of those non-responders similar to the responders. Extrapolation of the discharge figures from St. James's hospital may also have lead to an overestimation of the number of patients on HETF in Ireland, however, these are the only precise data available on HETF discharges at present and are thus valuable as a point of reference.

Since there are no community nutritionists available to monitor the status of patients on nutrition support outside the hospital setting, and visits to the out patients department are often not practical (due to the immobility of such patients), the responsibility for monitoring and reviewing patients on home tube feeding currently lies with the primary health care professionals. While GPs and PHNs cannot be expected to have broad ranging expertise on the subject of enteral feeding, their knowledge of enteral nutrition should at least be sufficient to deal with the minor problems that can arise for these patients. Poor knowledge and experience of these health professional with respect to enteral feeding may

lead to unsatisfactory patient care. To reinforce this, a policy document published by the Department of Health in 1994 ("Shaping a Healthier Future") stated "in order to support the provision of care for patients in the most appropriate setting, linkages between services need to be strengthened. Hospitals, GPs, and other community services need to be able to operate as elements of an integrated system, within which patients can move freely as their needs dictate. At present the system is too compartmentalised to permit flexibility" (Department of Health, 1994).

# Chapter 5

# Irish hospital consultants views' on tube feeding

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## 5.1 Introduction

The number of patients receiving tube feeding in the community is increasing at a rate of around 20% per annum (Elia *et al.* 1999). Recently, the originator of the percutaneous PEG tube has expressed concern about excessive utilisation. He attributes this in part to the simplicity of the method, its minimal invasiveness and low complication rate (Gauderer, 2000). The clinical benefits of enteral nutrition for many patient types, such as those with short bowel, liver disease and inflammatory bowel disease are well established (Klein, *et al.* 1997). However, the use of tube feeding in certain patients remains controversial. The clinical evidence supporting the use of tube feeding in dementia patients has been challenged recently (Gillick, 2000; Finucane *et al.* 1999). Tube feeding patients in a PVS is also contentious (Payne *et al.* 1996). The appropriateness and benefits of tube feeding cancer patients near death is also questionable (McCann *et al.* 1994).

Conflicting results have been found in studies examining physician's attitudes to tube feeding, although comparisons between studies are difficult due to methodological differences. Nearly half (47%) of Welsh geriatricians think that PEG has a role in dementia with rejection of food (Hasan *et al.* 1995), but only 16% of US interns are in favour of tube feeding a patient with advanced dementia. Eighty percent of the same group of US interns favoured withdrawing a tube feed from a PVS patient (Hodges *et al.* 1994). Israeli physicians were found to use life-sustaining treatments more frequent than an elderly Israeli population had reported that they would want. Fifty-four percent said they would provide tube feeding to a patient with metastatic cancer, and three quarters said they would tube feed an 80-year-old patient with severe mental impairment (Carmel, 1999). Clearly, the decision to insert a feeding tube in some patients poses moral and ethical dilemmas. While the decision to insert a feeding tube is sometimes multidisciplinary (Hasan *et al.* 1995), and should include input from patient and family where appropriate (Mitchell & Lawson, 1999), doctors tend to lead in medical decision-making (Van Rosendaal *et al.* 1999). The timing of the decision to insert a feeding tube can be difficult for patients and families, particularly when the potential benefit from feeding are unclear. Physicians have reported a substantial amount of conflict between health professionals and family members regarding decision making to proceed or defer gastrostomy (Callahan *et al.* 1999).

## 5.2 Aims

Nothing is known about the opinions and practices of Irish doctors regarding the use of enteral nutrition. In this context, this study had 3 aims. Firstly, to examine what influences the Irish consultant when deciding to insert a feeding tube in elderly demented patients. Secondly, to examine consultant's opinions vis-à-vis the use of tube feeding in patients for whom the benefits of enteral nutrition are contentious. Finally, to look at physician's preferences for tube feeding for themselves under circumstances.

## 5.3 Methods

### 5.3.1 Selection of candidates

Consultants working in specialty areas likely to have exposure to enteral feeding were identified from the Irish Medical Directory (a extensive guidebook to Medical Health Care and the Medical Profession in Ireland). A total of 329 consultants in 14 specialty areas were identified. For most specialty areas, all consultants were identified as suitable for inclusion in the survey, with the exception of *psychiatrists* (only those stating an interest in psychiatry of the elderly were included) and *radiologists* (only those with a stated interest in GI radiology or interventional radiology were included). The package posted to each selected consultant included the questionnaire, a stamped addressed envelope, and a cover letter outlining the aims of the study (signed by a doctor and a research dietitian). Reminder letters were posted 14 days after the initial posting in an effort to increase the response rate. The survey was anonymous, so reminder letters were sent to all candidates, thanking those who had already returned the questionnaire, and encouraging those who hadn't to complete and return it.

### 5.3.2 Questionnaire design

The questionnaire contained 4 sections, with a total of 23 questions (Appendix VII). The questionnaire was first piloted among 8 senior registrars working in the Department of Clinical Medicine, Trinity College Dublin, and discussed at length with a consultant geriatrician in St. James's Hospital. While ideally, consultants should have been used to pilot the questionnaire, the senior registrars were used in the pilot because they were accessible and were able to devote time to discuss the questionnaire content at length. It was felt that consultants would not have been able to commit so much time to discussing the questionnaire. The first section included questions relating to general demographic information, including questions that examined the extent of the consultant's involvement with enteral feeding. The second section enquired about how decisions are made regarding feeding-tube insertion and what factors influence the decision to insert a feeding-tube in an end stage severely demented patient. In the third section, 4 fictitious patient scenarios were outlined, and consultants were given a 10-point tick scale to express the extent of their favour or opposition to inserting a feeding-tube in 3 cases and withdrawing a feeding-tube in 1 case. The 10 point scale meant that there was no "middle" point, so all respondents have to make a definite choice about how they felt in each case. Consultants were asked to tick their primary reason for choosing to tube-feed or not to tube-feed the patient in each scenario. An "other reason" option was also included. In the final section,

consultants were asked about their preferences for tube-feeding for themselves if they couldn't swallow under 5 certain circumstances, namely: in advanced deteriorating cancer, in a condition of severe dementia, in a persistent vegetative state, in a state of mental awareness but physical incapacity, and finally following a stroke with severe functional impairment. The cases were chosen because they represented the areas in which tube feeding was most contentious; namely, end stage cancer, PVS, and dementia. As these are patient types where the issue of tube feeding is a matter for debate, there were no model answers to the questions posed.

The final case represented a less controversial area but one in which tube feeding is extremely common, that is the use of tube feeding in stroke patients. To avoid the addition of too many compounding variables, the cases were made as neutral as possible. For example, in the first case to avoid doctors responding with "I'd discuss the patients wishes regarding tube feeding", the scenario outlined that the patient had already expressed that she wanted to do "whatever the doctor thinks is best". In the third case it was stated that the patient had never previously expressed wishes regarding life-sustaining therapy. In the last case when asked about the possibility of having a feeding tube inserted, the patient said he "didn't mind". These pieces of information were included to exclude patient preference as a possible influence on the doctors opinion.

### 5.3.3 Data analysis

Returned questionnaires were coded, and data was entered and analysed using SPSS V9.0 for Windows. Statistical tests used included $\chi^2$, and Student's t-tests for independent samples to compare responses. Additional comments made by consultants were also noted and analysed by hand. Consultants opinions on tube feeding each of the 4 cases outlined were compared using Kruskal-Wallis and Mann-Whitney *U* tests.

## 5.4 Results

### 5.4.1 Response rate

In total, 134 responses were received (41% response rate), of which 128 (39%) were suitable for analysis. The response rate from each speciality area and a summary of the total group is outlined in Table 5.1. Two unanswered questionnaires were returned from doctors who had retired from practice. One further questionnaire was returned only partially completed, and was unsuitable for inclusion in the database, and one more doctor returned the questionnaire and stated he was insufficiently involved with enteral feeding to answer the questionnaire appropriately. A further 2 consultants declined to fill out the questionnaire, because they felt that the questionnaire inadequately addressed the issues relating to tube feeding. Gastroenterologists were the best responders, with 69% replying to the survey. This may be because they had significantly most exposure to tube feeding than the other groups ($P < 0.00$). Neurologists and oncologists were poor responders, with a response rate of 23% each. The remaining speciality groups had similar response rates. Respondents were practising for an average of 24 years (SD 7.7 years). Sixty one percent worked in University Teaching Hospitals, and 56% practiced outside the Dublin area.

### 5.4.2 Exposure to tube feeding

Respondents were asked to indicate at which stage(s) they were involved in tube feeding, if at all. The responses are outlined in Table 5.2. Many (88%) of the responders were involved at the decision making stage, but just over half (54%) reported that they were involved in monitoring patients after discharge from hospital. Most respondents who were involved in the care of patients on tube feeding were involved at a quite a low level, with 38% stating involvement with less than 5 patients in the last year (Table 5.3).

### 5.4.3 Decision making

Twenty percent of responders said that they occasionally cared for patients for whom they felt tube feeding was unwarranted due to the patient's limited life expectancy, but felt compelled to proceed due to perceived pressure from the patient's family. Approximately 11% said that they occasionally felt compelled to *defer* your recommendation to initiate tube feeding for the same reason.

The questionnaire listed 9 factors that might affect the doctor's decision to insert a feeding tube in an end stage severely demented patient. Respondents were asked to rank factors in terms of their importance to them when deciding to insert tubes (1 for the strongest factor and 9 for the weakest factor). Table 5.4 lists the factors, and the percentage of the

respondents giving each factor as the primary, secondary, and tertiary influence when deciding to insert a feeding tube in such a patient. Eighty-two percent (*n* 105) of the responders answered this question, although some respondents only ranked a few of the factors as relevant. Some (*n* 7) stated that the issue wasn't relevant to them in their specialty area; others (*n* 6) wrote that they felt a feeding tube was not indicated *at all* in this type of patient.

**Table 5.1**. Response rate* from different groups

| | Sent *n* | Returned *n* | Response % |
|---|---|---|---|
| ***Geography*** | | | |
| Dublin | 136 | 55 | 40 |
| Outside Dublin | 193 | 71 | 38 |
| *Total* | *329* | *126*† | *39* |
| Gastroenterology | 32 | 22 | 69 |
| ENT Surgery | 6 | 3 | 50 |
| Radiology | 20 | 9 | 45 |
| Psychiatry | 9 | 4 | 44 |
| Respiratory medicine | 9 | 4 | 44 |
| Anaesthetics / intensive care medicine | 28 | 13 | 46 |
| Geriatrics | 29 | 11 | 38 |
| General surgery | 97 | 35 | 36 |
| Neurosurgery | 9 | 3 | 33 |
| General medicine | 49 | 15 | 31 |
| Neurology | 17 | 4 | 23 |
| Oncologist | 17 | 4 | 23 |
| Palliative medicine | 5 | 1 | 20 |
| Maxillofacial surgery | 2 | 0 | 0 |
| *Total* | *329* | *128* | *37* |
| ***Gender*** | | | |
| Male | 302 | 117 | 38 |
| Female | 27 | 11 | 40 |
| *Total* | *329* | *128* | 39 |

** Analysable questionnaires*

*†2 responders did not answer this question*

**Table 5.2** Respondent's level of involvement with tube feeding

| **Period of involvement** | **%** | ***(n)*** |
|---|---|---|
| Contributes to the decision to recommend tube feeding | 88 | *(113)* |
| Contributes to the decision to remove feeding tubes | 70 | *(89)* |
| Contributes to the insertion of feeding tubes | 77 | *(99)* |
| Contributes to the removal of feeding tubes | 63 | *(81)* |
| Contributes in the monitoring of patients on tube feeding (pre-discharge) | 74 | *(95)* |
| Contributes in the monitoring of patients on tube feeding (post-discharge) | 54 | *(69)* |

**Table 5.3** Exposure to tube feeding

| **Number of new patients in past year** | **%** | ***(n)*** |
|---|---|---|
| None | 6 | *(8)* |
| Less than 5 | 38 | *(49)* |
| 6 - 10 | 26 | *(31)* |
| 11 - 15 | 12 | *(17)* |
| 16 - 20 | 5 | *(6)* |
| 21 - 25 | 5 | *(6)* |
| 26 – 30 | 4 | *(5)* |
| 31 or more | 4 | *(5)* |
| **Total** | **100** | **(127*)** |

** 1 responder did not answer this question*

### 5.4.4 Case Studies

Consultants were given 4 fictitious case studies to read and make a decision on how likely they would be to tube-feed the patients, based on the details given. Just 4% of the total group favoured initiating tube feeding (or continuing to tube feed) all 4 cases, and 9% were opposed to tube feeding (or favoured withdrawing tube feeding) in all 4 cases. Physicians opinions are summarised in Table 5.5 and Figure 5.1.

#### Case 1

The first case study was a 78-year-old unmarried lady with metastasising oesophageal cancer. Her ability to swallow was deteriorating, and she could only manage to consume about 30% of her protein and energy requirements orally in the form of semi-solid food. She had also lost about 5% of her usual weight. Medical treatment was palliative and the patient was getting progressively weaker, and was quite depressed. When asked about the possibility of tube feeding, she said to do "whatever the doctor thinks is best". On a scale of 1 to 10, consultants were asked to rate their likelihood of tube feeding or not tube feeding the patient. Twenty three percent of respondents tended (*i.e. ticked 1-5)* to favour tube feeding, and 77% tended to be opposed to feeding (*i.e. ticked 6-10*). Thirty eight percent were strongly opposed to tube feeding (*ticking 10 on the scale given*), and 4% were strongly in favour of tube feeding (*ticking 1 on the scale*). The principal reason for tube feeding was that it might help the patient to recover some function (50%). The main reason for choosing not to tube-feed was that the patient's death was imminent and she was unlikely to recover any significant function as a result of tube feeding (81%).

#### Case 2

The second case study described a 45-year-old unmarried woman on PEG feeding in a PVS for 5 years (following a car crash). Her parents, who were initially supportive of tube feeding, now wished for her tube feeding to be withdrawn. The woman never previously expressed wishes regarding life-sustaining therapy. Consultants were asked to rate on a scale how much in *favour* of or *opposed* to withdrawing the tube feeding they were. Sixty-four percent of the respondents were generally in favour of withdrawing the tube feed, while the remaining 36% were generally opposed to withdrawing the feeding tube. Nineteen percent were strongly in favour of withdrawing the tube; only 9% were strongly opposed to its withdrawal. The principal reason for favouring withdrawal of the tube feed because the patient wasn't likely to ever recover from the persistent vegetative state (58%). The principal reason opposing tube withdrawal was that there was a small chance that the patient may recover from the PVS in the future (43%). Only 1 respondent stated that their opposition to withdrawing tube feeding was based on personal experience. They reported

seeing a PVS patient die slowly by starvation following tube removal. The patient's family were no happier when the patient died and suffered guilt about possible additional suffering caused by the bedsores etc., as starvation progressed.

### Case 3

The third case scenario given to the consultants described a 70-year-old widowed gentleman living in a nursing home. He was totally dependent in all his activities, and didn't recognise the nursing staff, or family (who rarely visited). The patient had gone off his food, and was refusing to eat for the nursing staff. This was thought to be due to his advancing dementia. Spoon-feeding was commenced, but the patient was also refusing that. The patient had never previously expressed wishes regarding life-sustaining therapy. On a scale of 1 to 10, consultants were asked to rate their likelihood to feed or not to feed the patient. Twenty nine percent of respondents tended to favour feeding, and 71% tended to be opposed to feeding (31% strongly opposed). The principal reason for choosing to tube feed was that it is the physician's role to sustain life and prevent malnutrition and dehydration (50%). The main reason for choosing not to feed the patient was that the patient appeared to have irreversible disease and was not likely to recover significant function (76%). Those respondents with experience in monitoring patients on tube feeding after discharge from hospital were less likely to recommend tube feeding this patient ($P < 0.05$). Those who favoured feeding this patient were also more likely to favour feeding Case 1 ($P < 0.05$). Interestingly, consultants who reported *dietitians* in the top 5 factors influencing their decision to insert a tube in a severely demented patient were slightly more likely to feed such a patient, those who listed *nurses* in the top 5 were significantly *less* likely to tube feed this patient ($P < 0.05$). Geriatricians were more inclined to feed this patient than other consultants ($P < 0.05$).

### Case 4

The final case described an 86-year-old widowed gentleman who had suffered a stroke 14 days previously. His swallow reflex was impaired and following videofluoroscopy, the speech and language therapist recommended a soft consistency diet with thickened fluids. Since the stroke, the patient had made poor progress with the physiotherapist, was physically very dependent, and in addition, was quite depressed and had been prescribed a course of antidepressants. He had a poor appetite, and had lost 7% of his weight since admission. The dietitian suggested inserting a nasogastric tube, as the patient was not meeting his nutritional and fluid requirements orally, even with the use of high protein high calorie supplements. When asked about the possibility of having a feeding tube inserted, the patient said he "didn't mind". The majority of consultants (85%) were in

favour of inserting a tube in this case. Nearly one quarter (24%) were strongly in favour. Fifty-eight percent felt that tube feeding would help to patient recover some physical function and 45% felt that tube feeding would help to make the patient more comfortable and improve his quality of life. While both surgeons and physicians were inclined to tube feed this patient, physicians were slightly more inclined to do so ($P < 0.05$). Those opposed to withdrawing the tube from the PVS patient were more likely to favour feeding the patient in this scenario ($P < 0.05$).

Table 5.5 and Figure 5.1 summarises the physicians attitudes to tube feeding the patients in the scenarios. Save for the instances noted above, there were no statistically significant differences in willingness to tube feed patients noted between the different consultant specialties.

### 5.4.5 Consultants opinions regarding tube feeding for themselves

Five ill health scenarios were described in the questionnaire and consultants were asked to decide whether or not they would wish to be tube-fed if the condition applied to them. A five-point response scale (definitely not, probably not, unsure, probably yes and definitely yes) was given. The 5 scenarios and the responses given are outlined in Table 5.6. Respondents most often chose *not* to be tube-fed in the PVS and Alzheimer's disease scenario. Few were positive that they would want to be tube fed in any of the circumstances, but approximately one third said they would probably want to be tube-fed in the cancer and stroke scenario. While the majority of consultants were in favour of inserting a tube in the patient with stroke, consultants wishing to be tube fed themselves in event of a stroke tended to be more strongly in favour of feeding the stroke patient in the scenario outlined ($P < 0.001$). Similarly, those who wanted to be tube fed themselves if they had cancer were more likely to tube feed the cancer patient in the scenario given ($P < 0.001$). Those consultants who said they "definitely" did not want to be tube fed if in a PVS or in end stage dementia were more likely to favour tube withdrawal from the PVS patient in the case scenario ($P < 0.001$), and less likely to feed the dementia patient ($P < 0.00$). The number of tube fed patients that consultants cared for appeared to have an effect on their wishes for tube feeding for themselves. Consultants encountering more patients per year were *less* likely to want to be tube fed themselves in the cancer scenario ($P < 0.02$).

**Table 5.4** Factors affecting consultant's decision to insert a feeding tube in an end-stage severely demented patient

| Factor affecting decision to insert feeding tube | Strongest influence % | 2nd strongest influence % | 3rd strongest influence % |
|---|---|---|---|
| Personal opinion based on medical knowledge & experience | 58 | 21 | 10 |
| Stated patient preference | 29 | 23 | 6 |
| Opinion of patient's family | 9 | 24 | 26 |
| Opinion of colleagues | 2 | 17 | 27 |
| Dietitians opinion | 1 | 5 | 9 |
| Hospital policy | 1 | 0 | 2 |
| Nursing staff opinion | 0 | 8 | 14 |
| Concern about litigation | 0 | 1 | 4 |
| Religious or philosophical beliefs | 0 | 1 | 2 |
| **Total** | **100%** | **100%** | **100%** |

**Table 5.5** Case scenarios

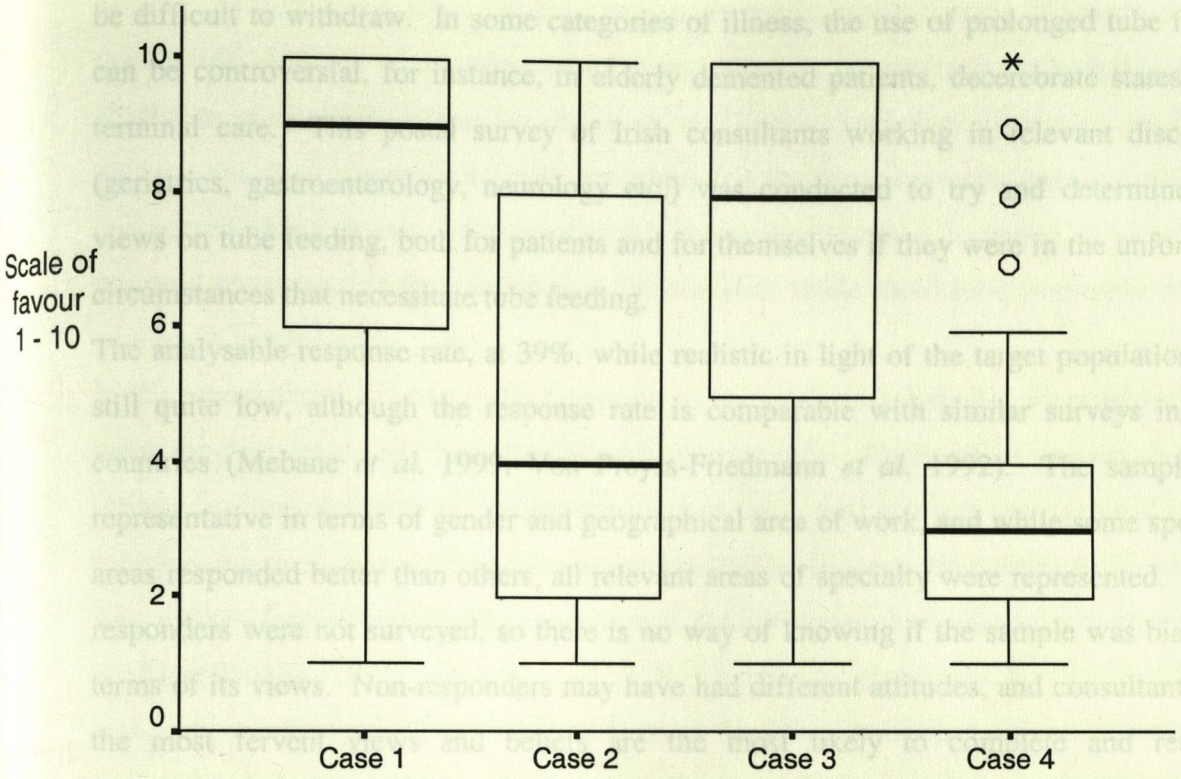
| Scenario | In favour of tube feed | | Opposed to tube feed | |
|---|---|---|---|---|
| | *generally in favour* % | *very in favour** % | *% generally opposed* % | *% very opposed*† % |
| Cancer patient | 23 | 4 | 77 | 38 |
| PVS patient | 36 | 9 | 64 | 19 |
| Dementia patient | 29 | 6 | 71 | 31 |
| Stroke patient | 85 | 24 | 15 | 8 |

**ticked 1 on scale of 1-10 (or 10 in PVS case)*
†*ticked 10 on scale of 1-10 (or 1 in PVS case)*

**Table 5.6** Consultant's preferences for tube feeding for themselves

| Condition | Definitely no % | Probably not % | Unsure % | Probably yes % | Definitely yes % |
|---|---|---|---|---|---|
| Persistent vegetative state | 74 | 14 | 6 | 6 | 0 |
| Severe dementia | 68 | 22 | 7 | 3 | 0 |
| Totally physically incapacitated | 30 | 28 | 19 | 21 | 2 |
| Advanced & deteriorating cancer | 19 | 28 | 13 | 34 | 6 |
| Stroke | 18 | 22 | 22 | 32 | 6 |

**Figure 5.1** Boxplots: Consultants opinions on case scenarios




*Note: Case 2, the higher the mark out of 10, the more in favour of leaving the tube in situ in the PVS patient*

## 5.5 Discussion

The use of long-term tube feeding appears to be increasingly popular in the management of a variety of disorders. However, when this mode of nutritional support is initiated, it can be difficult to withdraw. In some categories of illness, the use of prolonged tube feeding can be controversial, for instance, in elderly demented patients, decerebrate states, or in terminal care. This postal survey of Irish consultants working in relevant disciplines (geriatrics, gastroenterology, neurology etc.) was conducted to try and determine their views on tube feeding, both for patients and for themselves if they were in the unfortunate circumstances that necessitate tube feeding.

The analysable response rate, at 39%, while realistic in light of the target population, was still quite low, although the response rate is comparable with similar surveys in other countries (Mebane *et al.* 1999, Von Preyss-Friedmann *et al.* 1992). The sample was representative in terms of gender and geographical area of work, and while some specialty areas responded better than others, all relevant areas of specialty were represented. Non-responders were not surveyed, so there is no way of knowing if the sample was biased in terms of its views. Non-responders may have had different attitudes, and consultants with the most fervent views and beliefs are the most likely to complete and return a questionnaire. A reasonably short self-administered questionnaire was used to elicit information from candidates. The aim was to endeavour to attain as much information in as short a questionnaire as possible, in order to achieve the highest response rate. A longer, more detailed questionnaire may have elicited more in-depth information, but would almost certainly have yielded a much lower response rate. In addition, the results would not have been generalisable, as the responses would have been received from a very interested minority. It is appreciated that in keeping the questionnaire as short as possible, the scenarios given may have been insufficiently detailed, and may have been interpreted differently between physicians. However, the level of information given in the case scenarios compares well with other postal questionnaire surveys of this type (Watts *et al.* 1986; Von-Preys Friedman *et al.* 1992; Carmel, 1999).

It was noteworthy that 20% of responders had occasionally cared for patients for whom they felt tube feeding was unwarranted due to the patient's limited life expectancy, but felt compelled to proceed due to perceived pressure from the patients family and from other physicians. The obvious weakness in this result is in responder's personal interpretation of the word "occasionally". However, a scale was used because it was judged that it would have been difficult for responders to quantify this type of experience, and more in-depth questioning would have rendered the questionnaire too complicated and would have

compromised the response rate. What *is* important is that some physicians *do* feel pressurised to insert feeding tubes when, in their own opinions, the tube feed isn't necessary. There is often a climate of inevitability in the decision to proceed with artificial feeding, and decisions about feeding are usually made in the context of severe and life-threatening sickness, where often information regarding the patient's prognosis is unclear (Callahan *et al.* 1999). Van Rosendaal *et al.* (1999) found that significant numbers of patients and their responsible family members felt that their opinions were not sought or considered and in several instances they felt pressurised to make decisions. In view of this it would be interesting to examine how decisions are made about tube feeding in the Irish context in greater detail.

In the management of cancer, there appears to be consistency between what Irish doctors want for themselves and how they would treat patients. Eighty-three percent (*n* 20) of those who favoured feeding the cancer patient in the scenario given were inclined to have tube feeding themselves if they were in that condition. Sixty-seven percent (*n* 54) of those who did not favour feeding the cancer patient did not want tube feeding for themselves. In contrast, Carmel (1999) and Asai *et al.* (1995) found that physicians wanted significantly less treatment for themselves if they had cancer than they would have given to patients. It is possible that the opinions of physicians "on paper" may not be comparable to actual attitudes and practice in real situations. Consultants encountering more tube-fed patients per year were *less* likely to want to be tube fed themselves in the cancer scenario. A large US study of 687 physicians and 759 nurses found that nearly half felt that "the burdens of continuing nutrition and hydration to a terminally ill patient can outweigh the benefits of prolonging life", and slightly more than half felt that for critically ill and terminally ill patients they managed, artificial nutrition and hydration were used inappropriately (Solomon *et al.* 1993).

Payne *et al.* (1996), surveyed neurologists and nursing home medical directors and found that the majority felt that patients in a PVS would be better off dead, and that all medical therapy, including nutrition and hydration could be withheld in specific circumstances. Only 10% of nursing home medical directors and 13% of neurologists said they would want to be fed if they were in a PVS. Similarly, 80% of outpatients and members of the general public in the Boston area reported not wanting artificial nutrition if in a PVS (Emanuel *et al.* 1991). More recently 96% of white physicians and 82% of black physicians in the US reported that they did not want aggressive treatment if in a PVS (Mebane *et al.* 1999). In contrast, 60% of Japanese physicians reported that they *would* want nutrition and hydration if they were in a PVS, and only 3% would favour

withdrawing nutrition and hydration from a PVS patient who had no previous expressed wishes (Asai *et al.* 1999). This present study demonstrated that the majority of Irish consultants did not want to be tube fed themselves if in a PVS and did not favour PEG feeding the patient described in the PVS scenario. There are few patients in a PVS in Ireland. It is unlikely, therefore that this issue will affect many Irish doctors. Experience in the care of the PVS patient decreases the willingness to terminate life-sustaining treatment (Asai *et al.* 1999). Interestingly, the only responder in the present study who expressed experience with a PVS case was unwilling to withdraw treatment.

Unsurprisingly, "personal opinion based on medical knowledge and experience" was the factor that most clearly affected the doctor's decision to insert a feeding tube in an end-stage severely demented patient. Forty percent gave both "stated patient preference" and "personal opinion based on medical knowledge and experience" as either the primary or secondary factors affecting their decision. Unfortunately the treatment preferences of demented patients are rarely known in practice. Regrettably, it is almost inevitable that non-autonomous patients may be given life-sustaining treatments that they would have refused had they been capable. Therefore, informing the patient of their diagnosis as early as possible is recommended so that communication about future health care issues can be addressed when the patient is competent (Swanwick & Lawlor, 1998). Only 5% of respondents were very strongly in favour of tube feeding the gentleman with dementia who was refusing to eat, and only 3% of doctors wanted tube feeding for themselves in the case of end-stage Alzheimer's disease. Approximately 30% of feeding tubes inserted in the US are inserted in patients with dementia (Rabeneck *et al.* 1996). The high percentage may be because many nursing homes in the US can refuse to admit patients if they cannot maintain adequate nutrition orally, and do not have a feeding tube inserted (Ackerman, 1996). Approximately 10% of patients discharged on tube feeding from St. James's Hospital had a tube inserted because they had feeding difficulties caused by dementia (see Chapter 2). In view of our aging population, the issue regarding the use of life sustaining treatments in elderly dementia patients is likely to become increasingly important in the future.

Consultants favoured tube feeding the stroke patient, but many did not want to be tube fed themselves if they had a stroke, despite the fact that the 2 scenarios given were quite similar. The male patient in the stroke scenario was in his late 80's, had swallow impairment, and poor functional status. Physicians were asked if they would want to be tube fed if they had were in their late 80's and had suffered a stroke, resulting in poor functional status and swallow impairment. It appears that Irish consultants are willing to

treat stroke patients more aggressively than they are prepared to be treated themselves. This contrasts with their views on management in the cancer scenario.

Physicians held reasonably diverse views on tube feeding. Other studies have found attitudes of physicians toward tube feeding to be highly variable, with possible influences on attitudes being religious or moral beliefs (Von Preyss Friedman, *et al.* 1992). Some individuals believe tube feeding is a basic medical care, other view it as a invasive medical intervention (Goldstein & Fuller, 1994). Social and cultural factors shape the way people view medical care, sickness, death and dying (Mebane *et al.* 1999), and some physicians may have personal ethical beliefs that require them to provide artificial nutrition in all cases (Goldstein & Fuller, 1994).

In conclusion, this study has provided a novel insight into the practices, opinions and attitudes of a sample of Irish consultants in relation to tube feeding, although the relatively low response rate and the possibility of an interested bias must be taken into account when considering the results. In keeping with the findings of other studies, only a few Irish consultants would want tube feeding themselves in terminal or irreversible circumstances where tube feeding might be considered an option. In view of the doctor's unwillingness to be tube fed themselves, it may be of interest to determine the views of different age groups of the general population on this issue. It would also be interesting to compare the Irish consultants views on the use of tube feeding with the views of other Irish health-care professionals. Such information would be helpful in formulating guidelines for the use life sustaining treatments in the future.

# Chapter 6

# The cost of community tube feeding in Ireland

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## 6.1 Introduction

The number of patients receiving tube feeding in the hospital setting is increasing, leading to a subsequent increase in the number of patients being discharged on HETF into the community. This trend has implications for funding such treatments in the community. In 1992, between 2,000 and 2,500 patients were receiving home enteral tube feeding in the UK. Towards the end of 1998, the annual BANS report stated that there were approximately 12,000 patients on HETF in the UK and Northern Ireland (Elia *et al.* 1999). This constituted a 5-fold increase in HETF in only 6 years. The relatively large number of these patients has resulted in an increased emphasis on the cost of enteral feeding in the community, and consequently studies on the cost effectiveness and cost benefit of home tube feeding have been recommended. In 1995 Pironi and Tognoni (1995) recommended the implementation of cost-effectiveness and cost-benefit studies with respect to home tube feeding, and in 1997 Baldwin *et al.* stated that the benefits, detriments and cost-effectiveness of home tube feeding in patients with cerebral palsy and stroke required "formal and urgent investigation" (Baldwin *et al.* 1997).

In 1995, a reappraisal of available data on the cost-benefit analysis of home enteral nutrition (using a Medline® search) found that few papers were published between 1970 and April 1994 (Pironi & Tognioni, 1995). A Medline® search using the same keywords for the period April 1994 to 1999 found that few papers have been published since then either. As the number of patients receiving HETF continues to rise (Elia *et al.* 1999), the financial implications of this treatment is going to become a more important issue for the payer of this treatment, i.e. the Department of Health and Children in Ireland.

The number of patients currently receiving home tube feeding in the Dublin area is not known. Estimates from Chapter 4 put the national point prevalence at around 588 adult patients (and 307 children) on HETF in Ireland. Since the population of Dublin is roughly one third that of the total in Ireland, we would expect to find approximately 200 adults and 100 children on HETF in the Dublin area at any one time. Given that approximately half of patients discharged from hospitals on tube feeding return to their own home, we would expect approximately 100 adults on HETF in the Dublin region at any one time. The number of patients being discharged on tube feeding is increasing; between 1995 and 1997 the number of these patients discharged from St. James's hospital increased by 24% (see Figure 2.1).

In Ireland the management of patients on community tube feeding lacks coordination, current management protocols are sporadic and patients lack continuity of care in the

community. The role of community dietitians does not include domiciliary visits to patients in the community on tube feeding, although funding for such personnel has been sought on a number of occasions (*personal communication, Sheena Rafferty, community dietitian, ERHA*).

There is no organization (similar to BAPEN) in Ireland with a special interest in enteral feeding. The only non-commercial organisation that has attempted to tackle the problems associated with community tube feeding is the National Register Committee, a subcommittee of the Enteral Interest Group (EIG) of the INDI. This subcommittee was established in 1995 when the EIG were approached by INDI council members, requesting that a national register of all patients on home enteral tube feeding be completed. The purpose of the original request for the register was to highlight the rising numbers of patients on such treatment and the subsequent necessity for community nutritionists. At the time of writing this thesis, the special interest group had been disbanded, and the register has not been established due to continuing difficulties in attracting funding of the project.

In the hospital setting, nutrition support teams (NSTs) have been in existence since the 1970s and are an enduring concept of how nutrition support should be provided. While not all hospitals have, or need nutrition support teams, the team approach has been demonstrated to be an excellent mechanism for identifying patients in need of nutrition support, reducing the complications associated with enteral and parenteral nutrition, and providing cost-effective nutrition support in a variety of hospital environments (Roberts & Levine 1992; Hassell, 1994; Wesley, 1995). In some case, the NST can increase the cost of nutrition support within an institution, in view of the potential to increase the usage of both enteral and parenteral nutrition. The NST normally consists of a doctor or surgeon, nurse specialist, pharmacist and dietitian. To date in Ireland, nutrition support teams have not been developed to the same extent as they have been established in many hospitals in the UK, although a few hospitals have Working Groups to establish protocols for artificial feeding in certain departments, such as ICUs. Since the presence of NSTs in the hospital setting have been shown to reduce the costs of inpatient treatment, nutrition support personnel in the community may also reduce the total cost of treating patients on home enteral feeding, by working with PHNs and GP's in a multidisciplinary capacity to reduce complication and hospital admission rates. The nutrition support personnel would have the function of coordinating and monitoring nutrition support practices, enabling them to

improve the services available to patients on tube feeding outside the hospital setting. There appear to be no published studies which have looked at this issue in particular.

Examining the costs of community enteral nutrition and the relative contribution of various components to the overall cost of the treatment is important in order to understand how the overall cost of the therapy might be reduced. In addition, in order to establish the cost effectiveness of a community-based, publicly-funded nutrition service the current costs of community tube feeding in Ireland need to be ascertained. The theoretical effect of the service on the current cost (and thus the economic viability of the service) can then be estimated. To be viable, a publicly-funded community-based community nutrition service would need to provide its services to all adult patients discharged on tube feeding from a number of hospitals in the Dublin area.

In this chapter, the cost of tube feeding will be reviewed, in addition to a projection of the cost to the payer of providing a community-based nutrition service (i.e., cost feasibility study).

## 6.2 Aims

1. To investigate the cost of tube feeding patients discharged from St. James's hospital to their own homes in the community.
2. To project the cost of providing a publicly funded community-based nutrition service to coordinate and monitor nutrition support practices in the community.

## 6.3 Methods

For the purposes of this cost feasibility analysis, information gathered on patients who were discharged on tube feeding to their *own homes* in the community from St. James's Hospital was utilised as outlined in Chapter 2 (*n* 21). Patient's medical records were examined for additional information. Information gathered on patients in nursing homes (*n* 29) in the same Chapter was not included in the cost analysis. The costs (besides the costs of enteral feeding) involved in maintaining these patients in nursing homes vary considerably and would have complicated the cost analysis, thus the 2 sets of patients were not comparable for the purposes of this analysis.

The costs and benefits of home tube feeding may be classified as direct, indirect and intangible. **Direct costs** are the obvious costs involved, including the costs of the formula feeds and giving sets; **direct benefits** include the reduction in hospital costs as a result of the patient being discharged into community care. **Indirect costs** include the costs to relatives, who may need to take time away from work to take care of the patient; an **indirect benefit** would be the patient returning to the work environment, although this rarely happens in practice. **Intangible costs** are distress and anxiety that may be experienced by the patient on tube feeding; conversely, **intangible benefits** include feelings of being more independent and being in familiar environment (Goff, 1998). Indirect costs such as travel time and loss of income were difficult to identify in this retrospective analysis. A list of direct, indirect and intangible costs involved in home enteral tube feeding are outlined in Table 6.1. The costs examined in this Chapter are also listed.

In this exercise, the cost of HETF was analysed from the time of the patients discharge into the community until the survey visit. The cost analysis was carried out from the payer perspective. Costs are expressed *per patient per year on home tube feeding* and were collected before the 1st June 1999. In the time it took to collect the data, some of the prices may have changed. In addition, it wasn't always possible to get comprehensive cost data, (e.g. from commercial companies) and while this should not invalidate cost projections, it should be borne in mind when interpreting the results.

### 6.3.1 Cost of feeding tube insertion

Information regarding the cost of PEG tube insertion was obtained by consultation with personnel in the Health Care Centre in St. James's Hospital (where PEG tubes are inserted), and in the Pharmacy Department in the same hospital.

### 6.3.2 Costs of feeds, equipment and other supplies

Information regarding the costs of enteral feeds was requested from sources in the community, including the *General Medical Services* (GMS). The retail price of feeds was ascertained from pharmacy retail outlets in the community. A nutritional company representative also advised on the cost of giving sets. The cost of other miscellaneous items, such as plastic syringes and stoma site dressings were based on current average trade prices of a variety of types and sizes of these products.

### 6.3.3 Personnel costs

Salary scales for public health nurses (PHNs), hospital doctors and staff nurses was obtained from the biennial report of the public sector trade union (IMPACT†, 1998). Personal communication with PHNs evaluated the average time spent by a PHN in the patients home in the community. Salary scales for hospital and community dietitians were also obtained from the biennial IMPACT report (1998). Twelve percent was added for employers contribution to pay related social insurance (PRSI) (Department of Social, Community and Family Affairs, 2000). The prospective travel expenses for a community dietitian were estimated from personal communication with community dietitians already working in the Dublin area.

### 6.3.4 Complication costs

The costs incurred as a result of complications experienced by patients in the community were based on the cost of necessary hospital visits to deal with such complications. Daily hospital costs were estimated based on the average Irish hospital cost per day in Ireland. According to the Department of Health the cost of keeping a patient in an acute bed is approximately £200 per day (Dillon, 1998). The bill for acute hospital beds in Ireland was £1.8 million per day and there are approximately 13,000 beds available in acute hospitals in Ireland, 9,200 of which are designated public beds (Dillon, 1998).

### 6.3.5 Potential cost savings

While studies have looked at the cost saving involved in home parenteral nutrition, which is approximately 65% more cost-effective than hospital care (Richards & Irving, 1996), there appear to be no papers in the literature which have evaluated the effect of providing community nutrition services on the overall cost of *any* medical treatment including that of

home tube feeding. Thus, the potential areas in which costs could be saved following the initiation of a community nutrition service were hypothesized and the cost savings quoted in this exercise are theoretical.

**Table 6.1 Costs involved in home enteral tube feeding**

| Category | | Cost | Examined |
|---|---|---|---|
| Direct | ***Start up*** | Tube insertion cost | Yes |
| | | Training and patient preparation costs | Yes |
| | ***Supplies*** | Nutritional product | Yes |
| | | Giving sets | Yes |
| | | Pump & drip stand | Yes |
| | | Stoma site dressings | Yes |
| | | Syringes | Yes |
| | ***Personnel*** | Nurse-visits | Yes |
| | | GP visits | Yes |
| | | Hospital dietitian costs | Yes |
| | ***Complication*** | Hospital costs for re-admissions due to tube feeding | Yes |
| | | Clinical procedure costs (after initial tube placement) | Yes |
| | ***Other*** | Telephone costs | No |
| | | Transport costs | No |
| Indirect | | Time off work for family to care for the patient | No |
| | | Time off work to collect goods | No |
| | | Travel costs for follow-up visits & collection of goods | No |
| | | Loss of income (due to above) | No |
| Intangible | | Pain from disease or feeding tube | No |
| | | Worry (re prognosis, work, enteral feeding system) | No |

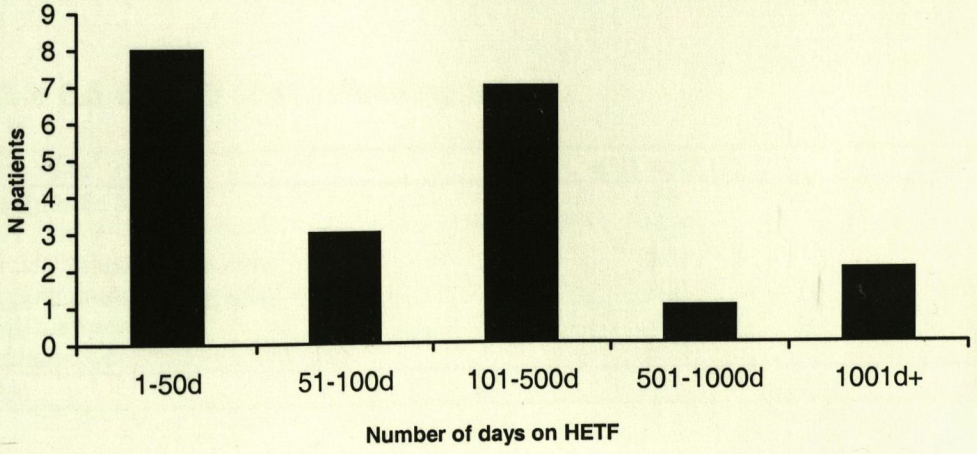
## 6.4 Results

Twenty-one patients and/or their spouses were interviewed in their own homes in the community. Fourteen percent of this group were female and 86% male, with an average of 58y (SD 15.7y). The reason for the disproportional gender mix is due to the higher percentage of males in the survey with head and neck cancer, and a lower percentage of patients with stroke. The main diagnostic indication for tube feeding in this group of patients was cancer, as outlined in Table 6.2. Patients had been on tube feeding in the community for an average of 342d (SD 654d) when surveyed, constituting a total of 7182 d on tube feeding in the community (see Figure 6.1).

**Table 6.2.** Indications for HETF: patients in cost feasibility analysis

| Indication | n | % | Average duration of HETF (d) |
|---|---|---|---|
| Cancer | 11 | 57 | 58.5 (SD 63.6) |
| Stroke | 5 | 23 | 336 (SD 359) |
| Alzheimer's disease | 1 | 4 | 215 |
| Cerebral Palsy | 1 | 4 | 1800 |
| Multiple sclerosis | 1 | 4 | 150 |
| Hydrocephalus | 1 | 4 | 2555 |
| Barrett's Oesophagus | 1 | 4 | 71 |
| **Total** | **21** | **100** | **340** |

**Figure 6.1.** Time spent on tube feeding by patients in their own homes




### 6.4.1 Cost 1: Cost of feeding tube insertion

Only one patient in the group (5%) was fed via an nasogastric tube. There were 28 feeding tubes inserted in the remaining 20 patients, which consisted of 19 percutaneous endoscopic gastrostomy tube insertions (15 initial placements and 4 replacements), 3 surgical jejunostomy insertions (2 initial placements and 1 replacement) and 2 surgical gastrostomy

insertion (both initial placements). There were also 3 replacement Foley Catheter insertions and 1 patient was fed via a tracheo-oesophago-jejunal tube (see Table 6.3).

No adult patient or their carer replaced tubes themselves in the community, therefore all tube replacements required a hospital visit. The average cost per initial PEG insertion was approximately £IR160, and the main factor affecting the cost was the PEG kit (see Table 6.4). The cost of placing a surgical jejunostomy/gastrostomy/tracheo-oesophago-jejunal tube is approximately 1.6 times the cost of a PEG insertion (Barkmeier *et al.* 1998). The average cost of a Foley catheter is approximately £33 (based on the current cost per Foley catheter @ £18 and 30mins physician time). The cost of the nasogastric tube is approximately £30 (based on the cost of the tube @ £15 and 30mins physician time). The median life-span of a feeding tube 36 days (the average was 516 days (SD 888 days). The *total* cost of placing feeding tubes for this group of patients therefore calculated at approximately £4614 (as outlined in Table 6.5), or approximately £234 per year on home tube feeding.

**Cost 1: Tube insertion**

The average cost of a tube insertion per patient per year on home tube feeding is

£4614 ÷ 7182 (days on tube feeding in total) x 365 (days in 1 year)

**= £234 per patient on home tube feeding per year**

**Table 6.3** Types of feeding tubes inserted and replaced

| Tube type | No. initial placements | No. replacements |
|---|---|---|
| Nasogastric tube | 1 | 0 |
| PEG tube | 15 | 4 |
| Surgical jejunostomy tube | 2 | 1 |
| Surgical gastrostomy tube | 2 | 0 |
| Foley Catheter | 0 | 3 |
| Tracheo-oesophago-jejunal tube | 1 | 0 |
| Subtotal | 21 | 8 |
| *Total* | *29* | |

**Table 6.4 Cost of PEG tube insertion in St. James's Hospital (1999)**

| Factor affecting cost | Cost | Total average cost per insertion |
|---|---|---|
| **PEG tube** | | |
| Kit | £85 | |
| Disposable snare | £18 | |
| *Subtotal* | | £103 |
| **Gastroscope expenses** *(average 2000 procedures per gastroscope)* | £16,000 | £8 |
| **Drugs used during procedure** | | |
| Pethidine @ dose of 50-100mg | £1.50 | |
| Lignocaine 2% subcut injection | £1.00 | |
| *Subtotal* | | £2.50 |
| **Staff** | | |
| Doctor (2 x 30 minutes) | £30 | |
| Nurse (2 x 30 minutes) | £15 | |
| *Subtotal* | | £45 |
| **Total average cost** | | £158.50 |

**Table 6.5 Overall cost of feeding tubes**

| Tube type | n | unit cost (£) | total cost (£) |
|---|---|---|---|
| Nasogastric tube | 1 | 25 | 25 |
| PEG tube | 19 | 160 | 3040 |
| Surgical jejunostomy tube | 3 | 240 | 720 |
| Surgical gastrostomy tube | 2 | 240 | 480 |
| Foley Catheter | 3 | 33 | 99 |
| Tracheo-oesophago-jejunal tube | 1 | 240 | 250 |
| **Total** | **29** | | **4614** |

### 6.4.2 Cost 2: Costs of feeds, giving sets and miscellaneous supplies

#### Feeds

The majority of the patients in the sample (71%) received full nutritional support with no oral intake. Sixty-seven percent of the patients were fed using a standard (4.2kJ per ml) feed with an average daily prescribed volume of 1.6L. The average cost of the feed per day was £10.88 (SD £3.22), but ranged between £5.44 and £15.20 per day (see Table 6.6). Therefore, the average cost of feed for 1 patient for 1 year was £3971. The cost of feeding depended on 2 things, firstly where the patients obtained the feed in the community, and secondly, whether or not they were entitled to a medical card. Sixteen patients were medical card holders, 2 had long-term illness books, and 3 availed of the drug cost subsidization scheme. Six patients received their feed in their local pharmacy shop, and the remainder received their feeds from EHB sources (either in the EHB central pharmacy or their local EHB health centre). The price paid by customers in the community (e.g., central EHB pharmacy, community care areas) varies depending on contract agreement with different companies. In addition, the price offered by companies to different customers is confidential. The price structure for enteral feeds in the community is outlined in more detail below. For the purposes of this cost analysis, the GMS price for feeding formulas will be used for all patients, as no other price could be accurately obtained. The EHB pharmacy price may be lower, but the retail pharmacy price may be higher, so the GMS price seems a reasonable indicator of the actual price.

#### Medical Card Holders

The majority of enteral feeds, when prescribed to patients with medical cards will be paid for by the GMS. The patient's GP writes a prescription for the enteral feed, and the cost of the feed is covered by the GP's GMS budget. GPs are provided with a GMS budget (by the Department of Health) annually. The patient may acquire the feed in 3 ways:

***1. Collected from or delivered by the local retail pharmacist***

When a patient obtains enteral feed from a retail pharmacist, the cost of the feed was that which is set by the GMS (re-negotiated every year), i.e., the retail pharmacist does not "mark-up" the price above the GMS price. However, the pharmacist receives 15% of the cost back from the GMS, so the actual cost to the payer is the GMS price *plus 15%.*

When the feed is delivered to the patients home this was generally as a courtesy to the family by the PHN (who was visiting anyway) or a pharmacist who delivered as a good

deed to the patient. However, when the patient/carer collected the feed themselves, the cost of delivery was borne by them. The delivery costs incurred were not accounted for in this study.

***2. Collect from or delivered by from the local health centre or central pharmacy***

Regional EHB health centres receive their feeds from a central EHB pharmacy. The central EHB pharmacy purchases large quantities of enteral feed from one nutrition company (the contract is tendered each year by the EHB). The price paid is generally lower than the GMS price (*the actual price paid is confidential company information*). Companies without a large contract with the central EHB pharmacy are likely to charge more than the tendered company for similar type feeds. The central EHB pharmacy purchases all types of enteral feed necessary to accommodate patients in their care on tube feeding *(i.e. in nursing homes etc*). Therefore, the cost to the payer depends on the type of feed the patient is using. If a patient is discharged on a feed produced by the company with the EHB central pharmacy contract, then that patient will be less costly to the payer than a patient using a feed which is not produced by the company with the contract.

***3. Delivered by the company who make the feed (in the study, this rarely occurred)***

If the feed is delivered by the company who make the feed then the cost of the feed is still borne by the GP's budget, but this method of delivery is more convenient for the patient. In addition, the retail pharmacist is not involved, the actual cost to the payer is less than Method 1. The delivery cost is borne by the company.

### Non-Medical card holders

Patients without medical cards generally do not pay for the entire cost of the feed. Until 1st July 1999, 2 schemes were available to these patients. The first was the *Scheme for Assistance towards the Cost of Prescribed Medicines* the second was the *Drug Cost Subsidization Scheme (Health Act 1970).* Since the 1st July, 1999 the Drugs Cost Subsidisation and Drugs Refund Schemes have been merged into one new **Drugs Payments Scheme** with a threshold of £42 per month per family unit.

### 1. Scheme for Assistance towards the Cost of Prescribed Medicines

This scheme applied to all persons normally resident in the State. Where the cost of medicines purchased for use over a 3 month period, commencing on the 1st January, 1st April, 1st July, 1st October was more than £90, then a refund of the balance in excess of the £90 (for an individual) was made. Receipts were kept of the purchases made, and a claim

form submitted to the Health Board at the end of each 3 month period. The cost over £90 per month is borne by the payer.

## 2. Drug Cost Subsidization Scheme (Health Act 1970)

This scheme applied to patients who did not have a medical card or long-term illness book, but those who were certified to have a long term medical condition (in normal circumstances this means 12 months) with a regular and ongoing requirement for prescribed drugs and medications in excess of a certain amount per month (£32). Having applied for the scheme, the Health Board provided the candidate with an identity card that they presented at their pharmacy when collecting drugs and medications. Applicants deemed eligible to participate under this scheme were liable for a maximum charge of £32 in a calendar month for prescription medicines. The excess cost over £32 per month was borne by the payer.

In a similar manner to patients with medical cards, these patients obtained their feeds by 3 different methods:

***1. Collected from / delivered by the local retail pharmacist***

Where the feeds were ordered through the patients local retail pharmacist, then the pharmacist could potentially put a mark-up of about 50% on the goods, thus the cost to the payer is more than it would be if the patient was covered by the GMS.

***2. Collected from / delivered by from the local health centre or central pharmacy***

Feeds were rarely delivered this way for patients without medical cards.

***3. Delivered by the company who make the feed (in the study, this rarely occurred)***

In some circumstances the company representative or hospital dietitian arranged for the enteral feed to be delivered to the patient's home. This usually occurred in special circumstances for certain patients.

**Table 6.6.** Estimated average daily cost of feeding formula

| No | Feed 1 | Feed 2 | Mls feed 2 | Mls feed 2 | Feed source | £ feed 1 | £ feed 2 | Total Cost |
|---|---|---|---|---|---|---|---|---|
| 1 | Ensure Plus | None | 1000 | 0 | Local Pharmacy | **8.62** | **0.00** | **8.62** |
| 2 | Nutrison Standard | Nutrison Fibre | 1000 | 500 | EHB pharmacy | **6.49** | **3.27** | **9.76** |
| 3 | Nutrison Energy | None | 1000 | 0 | Local Pharmacy | **7.60** | **0.00** | **7.60** |
| 4 | Nutrison Fibre | Guinness | 2000 | 500 | EHB pharmacy | **14.48** | **0.00** | **14.48** |
| 5 | Nutrison Standard | None | 2000 | 0 | EHB pharmacy | **12.98** | **0.00** | **12.98** |
| 6 | Ensure | None | 1500 | 0 | EHB pharmacy | **13.93** | **0.00** | **13.93** |
| 7 | Nutrison Standard | Nutrison Fibre | 1000 | 1000 | EHB pharmacy | **6.49** | **7.24** | **13.73** |
| 8 | Ensure Plus | Nutrison | 1000 | 600 | EHB pharmacy | **8.62** | **3.25** | **11.87** |
| 9 | Nutrison Standard | None | 1000 | 0 | EHB pharmacy | **6.49** | **0.00** | **6.49** |
| 10 | Nutrison Energy | None | 2000 | 0 | EHB pharmacy | **15.20** | **0.00** | **15.20** |
| 11 | Nutrison Standard | Nutrison Fibre | 1000 | 1000 | EHB pharmacy | **6.49** | **7.24** | **13.73** |
| 12 | Nutrison Energy | None | 1000 | 0 | EHB pharmacy | **7.60** | **0.00** | **7.60** |
| 13 | Fresubin | None | 1000 | 0 | Local Pharmacy | **6.55** | **0.00** | **6.55** |
| 14 | Nutrison Standard | Nutrison Fibre | 1000 | 1000 | EHB pharmacy | **6.49** | **7.24** | **13.73** |
| 15 | Nutrison Standard | Nutrison Fibre | 1000 | 1000 | Local Pharmacy | **6.49** | **7.24** | **13.73** |
| 16 | Nutrison Standard | Nutrison Fibre | 1000 | 1000 | EHB pharmacy | **6.49** | **7.24** | **13.73** |
| 17 | Nutrison Standard | Nutrison Fibre | 1000 | 1000 | Local Pharmacy | **6.49** | **7.24** | **13.73** |
| 18 | Nutrison Energy | Nutrison Fibre | 1000 | 1000 | EHB pharmacy | **6.49** | **2.33** | **8.82** |
| 19 | Ensure | Ensure Plus | 1000 | 1000 | EHB pharmacy | **2.72** | **2.72** | **5.44** |
| 20 | Nutrison Energy | None | 1000 | 0 | Local Pharmacy | **7.60** | **0.00** | **7.60** |
| 21 | Fresubin | None | 1000 | 0 | EHB pharmacy | **9.17** | **0.00** | **9.17** |
| | **Total** | | | | | | | **228.49** |
| | **Average (SD)** | | | | | | | **10.88 (3.22)** |

### Giving sets

The GMS do not pay for patients giving sets in Ireland. Usually, before the patient is discharged from hospital, funding for the giving sets is sought for the patients from their local *Director of Community Care* (DCC) and therefore the cost is borne by the community care budget. The decision to fund the giving sets is at the discretion of the DCC, however, funding is rarely denied - although problems have been encountered when patients are being discharged into private nursing homes. Patients are generally dependent on the companies who supply and manufacture the giving sets to supply "start-up-packs" for home until the patients funding has been sanctioned. If funding is not provided by community care, however, patients were not obliged to pay the total cost the giving sets themselves, because up until July 1st 1999, the equipment was covered by the *Scheme for Assistance towards the Cost of Prescribed Medicines* (described above). Therefore, the funding and processes involved in collecting and paying for giving sets are the same for GMS and non-GMS patients.

The patient may obtain the giving sets in the same 3 ways as the feeds

***1. Collected from or delivered by the local retail pharmacist***

The giving sets are delivered to the retail pharmacist by the distributor and collected from the pharmacist shop by the patient/carer.

***2. Collected from or delivered by from the local health centre or central pharmacy***

The giving sets are delivered to the local health centre or central pharmacy by the distributor and collected from there by the patient/carer.

***3. Delivered by the company who make the feed (in the study, this rarely occurred)***

This method of delivery cuts out the "middle-man" and makes the process more convenient for the patient/carer.

Company representatives advised that the cost of giving sets do not vary greatly regardless of company contracts with the EHB, and for the purposes of this cost analysis, the cost of all giving sets should be assumed to be £5.00 each.

### Miscellaneous supplies

Eleven patients required dressings on their feeding tube sites which were changed an average of 5 times per week. The yearly cost for dressings was estimated at £70 per year per patient. Plastic syringes contributed relatively little to the overall cost of home tube

feeding, an estimated of £20 per patient per year. Feeding pumps were provided to patients free of charge by the various nutritional companies involved.

The organisation and payment for giving sets and enteral feeds by the various categories of patients are outlined in Table 6.7.

**Table 6.7 Summary of costs and organisation of feeds and equipment for patient on HETF**

| Refund Category | | Giving Sets and Plastics | Enteral Feeds |
|---|---|---|---|
| **Medical Card (GMS)** | *Going home* | 1. Apply to local Director of Community care for funding<br>2. Arrange for patient to collect GS from Local health centre | 1. Is the feed covered by GMS?<br>2. Ring local pharmacy to arrange for feed to be ordered & collected by patient |
| | *Going to nursing home* | 1. Apply to local Director of Community care for funding<br>2. Arrange for nursing home to collect GS from Local health centre | 1. Is the feed covered by GMS?<br>2. Ring nursing home to arrange for feed to be ordered |
| **Long Term Illness (LTI)** | *Going home* | 1. Ring local pharmacy to arrange for sets and plastics to be ordered & collected by patient.<br>2. Cost covered by LTI card | 1. Ring local pharmacy to arrange for feed to be ordered & collected by patient.<br>2. Cost covered by LTI card |
| | *Going to nursing home* | 1. Ring local pharmacy to arrange for sets and plastics to be ordered & collected by nursing home.<br>2. Cost covered by LTI card | 1. Ring nursing home to arrange for feed to be ordered & collected from pharmacy by nursing home<br>2. Cost covered by LTI card |
| **Drugs Payment Scheme (DPS)** (i.e. not either of above) | *Going home* | 1. Apply to local Director of Community care for funding<br>2. Arrange for patient to collect GS from Local health centre | 1.Is the feed covered by the DPS?<br>2. Ring local pharmacy to arrange for feed to be ordered & collected by patient |
| | *Going to nursing home* | 1. Apply to local Director of Community care for funding<br>2. Arrange for nursing home to collect GS from Local health centre | 1.Is the feed covered by the DPS?<br>2. Ring local pharmacy to arrange for feed to be ordered & collected by nursing home. |

**Cost 2: Supplies**

The average cost of feed, equipment and other supplies per patient per year on home tube feeding is

Feed (£10.88 x 365) + Equipment (£5.00 x 365) + Other supplies (£90 per year)

= £3,971.20 + £1,825 + £90

**= £5,887 per patient on home tube feeding per year**

### 6.4.3 Cost 3: Personnel costs

#### Public Health Nurse

All but one patient surveyed (95%) required the services of a PHN in the community. It was difficult to evaluate the proportion of the PHN visit on enteral feeding, as no patient required a PHN to visit them for the purposes of dealing with the enteral feed only. However, it is likely that *at least* 5 to 10 percent of the time spent by the PHN with the patients will be on enteral tube related tasks. The salary for a PHN is £20,397-24,708 (+12% PRSI = £22,844 – 27,672). Based on an estimated average length of visit of 20 minutes, the average time spent with patients by PHNs is approximately 63 hours annually. The total cost of these visits is approximately £784 per patient on home tube feeding per year (based on a junior PHN salary). Five to ten percent (average of 7.5 %) of £784 pounds yields an approximate cost of £59 per year on enteral feed related work.

#### General Practitioner

Visits to GPs for enteral tube feeding related issues were estimated to be at least 12 per patient per year (for collection of enteral feed prescriptions). Eighty-six percent (*n* 18) of patients were entitled to free GP costs. The actual cost to the Department of Health for GP visits made by patients with GMS cards is difficult to determine, because GPs are not paid *per visit* by these patients, but are given an annual capitation payment. The actual capitation payment depends on a number of factors, including geographical location of the GP, number of GMS patients in their care etc.

#### Hospital dietitian

Assessment of hospital dietetic records showed that the patients surveyed made approximately 15 visits made to the dietetic out-patients department (OPD) during their time on home tube feeding (i.e. 15 visits in 7182 days, which is approximately 1 visit every 479 days). The costs of these visits per patient per year were therefore considered to be quite small. However, it is possible that more visits were made by these patients to the dietetic OPD, but have been recorded elsewhere. Telephone calls made to hospital dietitians regarding patients on home tube feeding may have contributed more significantly to dietitian time and resources. While the number and duration of these calls are difficult to quantify, but personal communication with numerous dietitians has found that telephone generate approximately 2 hours work per year. The salary for a basic grade clinical nutritionist in an Irish hospital is £17,661-23,343 (+ 12% PRSI = £19,780 – 26,144). The average cost of hospital dietitian input per year is therefore calculated at approximately £25 per patient.

**Cost 3: Personnel**

The average cost of personnel /patient /year on home tube feeding is:

PHN costs = £59.00

Hospital dietitian costs = £25.00

Giving an average total cost of

**£84 per patient on home tube feeding per year**

### 6.4.4 Cost 4: Cost of complications experienced by patients in the community

Over the course of their time on home tube feeding (7182 days) 7 patients (33%) were admitted for enteral feeding related complications (as outlined in Table 6.8) and spent approximately 70 days in hospital as a result. The number of hospital days is approximate as some patients were admitted to hospital with nutrition-related complications, but remained in hospital for other medical reasons related to their condition and vice versa. The exact number of days spent in hospital for nutrition related complications was therefore difficult to assess retrospectively from patient records or patient/carer memory. The cost of keeping a patient in an acute bed is around £200 a night, (£1400 per week) according to the Department of Health (Dillon, 1998). The average annual cost of re-hospitalisation for nutrition related complications can therefore be calculated at roughly £35 per patient per year on home tube feeding (see below). It is possible that patients may have made more visits to the hospital Accident & Emergency that they (or their carers) did not recall or hospital records of which had been misfiled.

All of the costs and their percentage contribution to the overall cost of HETF are outlined in Table 6.8.

**Table 6.8** Complications and hospital stay for patients on home tube feeding

| Patient No. | Time on tube feeding | Time in hospital since discharge | Nutrition related days in hospital | Reason(s) for admission |
|---|---|---|---|---|
| 1 | 916 | 35 | 10 | Weight loss, PEG tied in a knot |
| 2 | 251 | 0 | 0 | *No admissions* |
| 3 | 423 | 7 | 7 | Aspiration pneumonia |
| 4 | 238 | 15 | 0 | *Admitted for respite care* |
| 5 | 168 | 0 | 0 | *No admissions* |
| 6 | 1800 | 182 | 0 | *Aspiration pneumonia* |
| 7 | 105 | 0 | 0 | *No admissions* |
| 8 | 167 | 0 | 0 | *No admissions* |
| 9 | 36 | 3 | 3 | Nausea, pain & vomiting |
| 10 | 24 | 2 | 2 | Admitted when PEG tube fell out |
| 11 | 69 | 0 | 0 | *Admitted for respite care only* |
| 12 | 26 | 2 | 2 | Reinsertion of PEG tube |
| 13 | 71 | 7 | 1 | Reinsertion of Jejunostomy tube |
| 14 | 13 | 0 | 0 | *No admissions* |
| 15 | 35 | 0 | 0 | *No admissions* |
| 16 | 19 | 0 | 0 | *No admissions* |
| 17 | 11 | 0 | 0 | *No admissions* |
| 18 | 16 | 0 | 0 | *No admissions* |
| 19 | 99 | 0 | 0 | *No admissions* |
| 20 | 150 | 0 | 0 | *No admissions* |
| 21 | 2555 | 45 | 45 | X 2 times for PEG reinsertion |
| **Total** | **7192** | **298** | **70** | |

### Cost 4: Complications

The average cost of complications experienced by patients in the community per patient per year on tube feeding is:

70 days x £200 (cost per day in hospital) = £14000

£14,000 ÷ 7182 days = £1.95 per day on home tube feeding (for 21 patients)

£1.95 x 365 = £712 per year (for 21 patients)

£712 ÷ 21 = £34 per patient per year on home tube feeding

**£34 per patient per year on home tube feeding**

**Table 6.9** The cost of home tube feeding for 21 patients in the Dublin area

| | Costs (£) | % of overall cost |
|---|---|---|
| ***Start up costs*** | | |
| Tube insertion costs | 234 | 4.0 |
| ***Supplies*** | | |
| Formula feeds | 3971 | 63.5 |
| Giving sets | 1825 | 29.0 |
| Plastic syringes | 20 | 0.5 |
| Surgical dressings | 70 | 1.0 |
| ***Personnel*** | | |
| PHN visits | 59 | 1.0 |
| Hosp dietitian input | 25 | 0.5 |
| ***Complications*** | | |
| Readmission costs | 34 | 0.5 |
| **Total** | **£6238** | **100** |

### 6.4.5 Potential areas of cost saving

In Ireland there are no community-based dietitians to monitor patients on community tube feeding, thus there is a lack of coordination in their management and patients lack continuity of care in the community. In addition to an improvement in the management and coordination of nutrition monitoring practices, hypothetically, a number of *cost* savings could be made if a publicly-funded nutrition service were made available, as outlined in Table 6.10. The cost of this service would be £20,274-24,904 (+12% PRSI = £22,706 – 27,892, average **£25,299**) which is the current salary scale for a senior dietitian. Expenses of between £180-240 per month (average £2520/yr) would be expected. The indirect costs of staffing (such as office space, & equipment, heating, lighting, telephone etc) were not included in this analysis. However, it is expected that if such a service were to be established, the community dietitian would be located in the offices of an established community nutrition service (i.e. those involved with health promotion).

**Additional cost 1: community dietetic service**

Salary scale for a senior dietitian + PRSI = £22,706 – 27,892

Average £25,299 per year

Expenses £180-240 per month

Average £2520 per year

Total average yearly cost = £25,299 + £2520 = **£27,819**

**Table 6.10** Potential areas of cost saving

1. Reduction in the cost of enteral feeds
2. Reduction in the number of nutrition related admissions to hospital (assuming role would include the reinsertion of tubes in the community)
3. Reduction in the amount of PHN time spent with the patient
4. Reduction in the amount of hospital dietitian time spent dealing with home tube feeding issues
5. Education of PHNs and GPs to increase their knowledge and awareness of tube feeding, to further reduce incidence of complications associated with home tube feeding

### 6.4.6 Saving 1. Reduction in the cost of enteral feeds

Enteral feeds contribute most significantly to the overall cost of HETF (see Table 6.9). Thus, a small percentage reduction in this cost could potentially lead to massive savings overall. A centrally based community nutrition service to which patients could be referred following discharge into the community on tube feeding would help to achieve this. Such a system would allow for a single contract for enteral feeds and equipment to be negotiated with one nutrition products company, allowing a more competitive price to be agreed, thus significant reducing the overall cost of HETF. A system similar to the one suggested here has been described in Chapter1.4 (the Liverpool model). The actual reduction in cost is difficult to predict, considering the current prices are also difficult to determine. However, a conservative estimate of 5% will be taken for the purposes of this study.

**Cost saving 1: Reduction in the cost of enteral feeds**

Enteral feed costs reduced by 5%

Current enteral feed costs is £3971 per patient per annum on HETF

Cost saving is £3971 x 5% = £159 per annum

**£159 per year per patient on home tube feeding**

### 6.4.7 Saving 2. Reduction in nutrition related admissions to hospital

In theory, it is possible that the number of nutrition related hospital re-admissions could be reduced if a community-based nutrition service were made available for patients on home tube feeding. A community-based dietitian would be in a position to recognise tube or feed related problems before they require hospitalisation, A&E visit or GP consultation. No data exists in the literature concerning this issue, therefore, the actual reduction is difficult to quantify. However, in the UK, Parker *et al.* (1996) found that the number of dietitians employed in community *hospitals* was inversely related to the number of readmission's necessary to deal with tube feeding related complications. The actual reduction was not quantified, but it could be postulated that admissions could be reduced by up to 50%, giving a cost saving (based on the above figures) of £17.00 per year per patient on home tube feeding. Community dietitians can also reinsert patients feeding tubes in the community when necessary or possible, further reducing the number of necessary hospital admissions. Any necessary hospital admissions could be booked in advance, rather than emergency admissions, thus further reducing costs.

**Cost saving 2: Fewer readmissions**

Admissions to hospital reduced by up to 50%

Current hospital cost is £34 per patient on home tube feeding

Cost saving of £17 per year per patient on home tube feeding

**£17 per year per patient on home tube feeding**

### 6.4.8 Saving 3: Reduction in the amount of PHN time spent with the patient

The actual proportion of PHN time spent on enteral nutrition related matters is not known, but it is unlikely to be *less* than 5-10% of their time. It was also assumed that the workload (and therefore the cost of the PHN) could be reduced by at least 10% if a community dietitian were present to carry out the nutritional services which are currently supplied by the PHN. This would be especially true if the community dietitian's role included practical "hands on" work such as dealing with tube related problems. This would lead (based on the above figures) to a total yearly saving of ~ £6 per patient on home tube feeding.

**Cost saving 3: Reduced PHN costs**

Current PHN costs = £59.00 per patient on home tube feeding

Cost of the PHN could be reduced by at least 10%

**Total yearly saving of ~£6 per patient on home tube feeding.**

### 6.4.9 Cost saving 4: Reduction in hospital dietitian time dealing with HETF

Hospital dietitians currently carry out all dietetic input necessary for patient on home tube feeding. The approximate 2 hours of work carried out by each hospital dietitian for each patient on home tube feeding could be significantly reduced if a community dietitian were present in the community. It is likely that this would be the area of greatest reduction, a factor of 75% reduction in current input has been assumed. This would lead (based on the above figures) to an estimated cost saving of £38 per year per patient on home tube feeding.

**Cost saving 4: Reduced dietetic costs**

Current hospital dietitian costs = £25.00 per patient on home tube feeding

Reduction of workload by 75%

**Total yearly saving of £19 per patient on home tube feeding**

### 6.4.10 Cost saving 5: Education of PHNs and GPs

Aside from the estimated cost savings involved in having a community-based nutrition service, there are other advantages, including on-going education for community medical personnel, such as GPs and PHNs. This education would increase their knowledge and awareness of tube feeding, to further reduce incidence of complications associated with home tube feeding. Education regarding reinsertion of feeding tubes in the community and management of enteral feeding, may lead to a further reduction in complication rates and an overall improvement in the multidisciplinary care of these patients. A community-based dietitian could act as a liaison to ensure a smoother transfer of care from hospital to community for patients, and also be present to continuously monitor the nutritional status of these patients to ensure appropriate feeding.

Table 6.10 outlines the current estimated cost of feeding a patient in the community on home tube feeding with the projected cost if a community nutrition service was available in Dublin. Table 6.11 summarises the cost and cost savings.

**Table 6.10** Current costs of HETF per patient per year vs projected costs* per patient per year

| Cost issues | Current costs | | % of overall cost | Cost saving* | | Projected costs | | % of overall cost |
|---|---|---|---|---|---|---|---|---|
| | £ | € | | £ | € | £ | € | |
| Tube insertion costs | 234 | 297 | **4** | 0 | 0 | 234 | 297 | **3.9** |
| ***Equipment*** | | | | | | | | |
| Formula feeds | 3971 | 5024 | **63.5** | 159 | 202 | 3812 | 4840 | **63.2** |
| Giving sets | 1825 | 2317 | **29** | 0 | 0 | 1825 | 2317 | **30.2** |
| Plastic syringes | 20 | 25 | **0.5** | 0 | 0 | 20 | 25 | **0.3** |
| Surgical dressings | 70 | 89 | **1.0** | 0 | 0 | 70 | 89 | **1.2** |
| ***Personnel*** | | | | | | | | |
| PHN visits | 59 | 72 | **1.0** | 6 | 8 | 53 | 65 | **0.8** |
| Hospital dietitian input | 25 | 32 | **0.5** | 19 | 24 | 6 | 8 | **0.1** |
| ***Complications*** | | | | | | | | |
| Readmission costs | 34 | 43 | **0.5** | 17 | 22 | 17 | 22 | **0.3** |
| **Total** | **£6238** | **7918** | **100** | **£220** | **279** | **£6037** | **7663** | **100** |

** i.e. with a community nutrition service n place*

**Table 6.12a** Total costs and cost savings (Irish Pounds)

| Costs | Patients | | | |
|---|---|---|---|---|
| | *n* 1 | *n* 100 | *n* 150 | *n* 200 |
| Current | £6,238 | £623,800 | £935,700 | £1,247,600 |
| Projected | £6,037 | £603,700 | £905,550 | £1,207,400 |
| + dietitians salary + expenses | | +£27,819 | +£27,819 | +£27,819 |
| Total | | £631,519 | £933,369 | £1,235219 |
| **Possible savings (i.e. current – projected)** | **£201** | **-£7,719** | **+£2331** | **+£12,381** |

*Total approximate cost/cost saving if a community dietetic service were in place would be -£7,719 - £12,381, depending on the number of patients on home tube feeding.*

**Table 6.12b** Total costs and cost savings (Euros)

| Costs | Patients | | | |
|---|---|---|---|---|
| | *n* 1 | *n* 100 | *n* 150 | *n* 200 |
| Current | 7,918 | 791,785 | 1,187,677 | 1,583,570 |
| Projected | 7,663 | 766264 | 1,149,396 | 1,532,528 |
| + dietitians salary + expenses | | 31,880 | 31,880 | 31,880 |
| Total | | 798145 | 1,181277 | 1,564,409 |
| **Possible savings (i.e. current – projected)** | **€255** | **-€6360** | **+€6400** | **€19,161** |

*Total approximate cost/cost saving if a community dietetic service were in place would be* **-€6360 - +€19,161** *depending on the number of patients on home tube feeding.*

## 6.5 Discussion

Data from only 21 patients were used in this analysis. Although this is a small proportion of the overall population of patients on HETF in Dublin, the group was representative in view of it's heterogeneity in terms of diagnosis and length of time on HETF. Cost feasibility studies are difficult to carry out when much of the necessary information to carry out the study is hypothetical, and this flaw is recognised in the present exercise. To calculate the entire list of costs and benefits of HETF in this study would have been difficult, particularly in view of the retrospective nature of the work. However as long as deficiencies are recognised and comparisons made using the same calculations and assumptions, some conclusions can be made about an intervention (Goff, 1998) (in this case, the provision of a community nutrition service).

In order to estimate the cost of tube insertion for 1 year on HETF, it was necessary to establish the average life-span of the enteral tubes used by the group. There were 8 tube reinsertions, however there was a large variation (6 - 2,450 days) in the length of time on HETF before tubes required replacement. If the cost of tube insertion is to be considered as part of the overall cost of HETF, then the relative cost of the tube insertion to the overall yearly cost will decrease, the longer the tube remains *in-situ*. In other words, the cost of HETF is relatively more expensive if the patient uses the tube for a short period of time. Dietitians in Ireland (*as members of the Irish Nutrition and Dietetic Institute*) are currently covered by professional indemnity insurance to carry out procedures such as replacing gastrostomy tubes and nasogastric tubes. It is possible therefore, that an INDI member, as a community dietitian could carry out these tasks and further reduce hospital visits by patients. In addition, Kadaka *et al.* (1993) have shown that Foley catheters are considerably cheaper than commercial replacement gastrostomy tubes and their effectiveness and complication rates are similar to replacement gastrostomy tubes.

The price of enteral feeds and equipment varied, depending on where the patient obtained the goods in the community. The cost analysis of enteral feeds was difficult due to the understandable reluctance of companies and purchasers to release their costs. The GMS price of enteral feeds was known however, and thus was used as a guide - though the actual price may have been lower than this, and this must be taken into account when interpreting the results of this exercise.

It has been outlined that the contribution of the cost of PHNs services to patients on HETF would be reduced by 5-10% (average 7.5%) if a community nutrition service were introduced. While the actual *overall cost* of PHNs would not be reduced (i.e. there would

still be the same amount of PHNs employed), by reducing the time spent with patients on HETF, the extra time gained could be used more efficiently elsewhere.

The cost of nutrition-related hospital readmissions was difficult to determine, because by retrospectively reviewing patients medical records, it was sometimes difficult to distinguish between nutrition and non-nutrition related admissions to hospital. For example, patients admitted for nutrition-related complications sometimes remained in hospital for other treatments and tests and vice-versa. Thus, it was occasionally necessary to assume the proportion of the hospital stay that could be attributable to nutrition related complications by assessment of medical records. In contrast to the findings from this exercise, a recent American study, (Reddy & Malone 1998) noted that patients on HETF in the US typically did not require hospitalisation to deal with complications of therapy. In the UK, Parker *et al.* (1996) found that the number of dietitians in community hospitals was inversely related to the number of readmissions necessary to deal with complications related to tube feeding. In the present exercise, a total of 6 patients were admitted to hospital a total of 7 times to deal with problems specifically relating to the tube feed, in the course of 19½ years on HETF. The contribution of the cost of hospital admissions to the overall cost of HETF when all 21 patients in the group were considered was estimated at less than 1 percent. However, the intangible cost to patients in terms of distress and anxiety when faced with hospital admission should not be forgotten.

The method by which hospital costs are estimated is important. If the cost of inpatient treatment is based on *all* hospital costs (i.e. fixed and variable), then the cost of 1 patient day in hospital is much higher than if the cost is based on *variable* costs only. Fixed costs in a hospital (e.g. buildings, equipment, staff costs) generally do not change much in the short term, regardless of hospital bed occupancy. One study showed that as much as 84% of the costs in a hospital are fixed costs (Roberts *et al.* 1999). In this study, hospital costs have been based on total annual national budget for acute care, the figure quoted by Dillon (1998) is crudely based on national health care budgets.

This study aimed to identify if the provision of a community nutrition service for the purposes of monitoring patients on HETF was feasible from a purely cost perspective. The cost of feeding a patient in Dublin has been estimated at approximately IR£6236 per annum. This is higher than the cost quoted for patients in Italy at IR£4282 (Sartori *et al.* 1996) and slightly lower than the cost in the UK (Wilson, 1996) at £5,000stg (approximately IR£4850 in June 1996) per annum. However the costs for this type of treatment vary enormously between countries and with time and the value of direct

comparisons is dubious. With approximately 100 adult patients in the community at present, the annual cost to the Department of Health is approximately IEP£623,800. Having compared the current costs with our estimated costs savings if a community nutrition service were present, it would appear that such a service could be a viable option, costing *at most* £7,719 (see Table 6.12a). However, if there were more patients in the care of the dietitian (and with the increase in the number of discharges on HETF, it is very likely that there are more than 100 patients on HETF in the Dublin area at present) the community nutrition service could potentially pay for itself, and reduce the overall costs of HETF by up to £12,381 annually. While the current exercise excluded the extension of the community dietetic service to children and to patients in nursing home facilities, if these patients were also under the care of the dietitian, the cost could be potentially reduced even further. In addition, the continuing education of community personnel (GPs and PHNs) regarding enteral feeding by a designated individual in the community would eventually lead to further cost reductions as a result of improved practice. There would also be considerable quality of life increases for patients who deal with problems at home rather than having to return to the hospital environment.

The heterogeneity of patients on HETF (in terms of disease status and methods of feeding) means accurate cost effectiveness analysis of home tube feeding is only achievable in certain patient types. Once a PEG is inserted, it will almost certainly lead to long term feeding in certain types of patients (e.g. cerebral palsy, MND, MS, many stroke patients). In order to examine the cost effectiveness or cost-benefit of home tube feeding in these patients, one must compare outcome and cost to a similar group of patients who are not tube fed. This type of study would be difficult to carry out, in view of the obvious ethical difficulties. However, one study of nursing home residents with severe cognitive impairment found that after adjusting for independent risk factors, tube feeding did not prolong the survival of nursing home residents with severe cognitive impairment. The authors themselves, however, note the need for a prospective randomized controlled trial to match 2 groups of patients accurately. They also recognize that such a study would be impossible to carry out due to the ethical and emotional issues involved (Mitchell *et al.* 1997). In order to carry out an accurate cost benefit analysis, one should ideally be able to measure all the costs involved in the treatment of a patient, and similarly, one should be able to quantify and put a cost on all of the outcomes measures of a treatment or intervention. In reality, few studies will evaluate more than the direct costs involved in a treatment. In theory, patients who are able to eat orally could consume food using methods

*other* than via an enteral tube, and therefore comparison could be made of different methods of feed delivery and the cost effectiveness of each method could be determined. Studies which look at the cost effectiveness of providing services to patients on HETF are warranted, e.g. the cost-effectiveness of providing of a community dietetic service. Studies which examine the effect on the overall cost of HETF where community dietetic services are available to patients have not been published in the UK or Ireland. However, it has been shown that tube feeding related problems that require hospitalisation are less common in areas where the dietetic input in the community is strongest in the UK (Parker *et al.* 1996). An American study found the addition of a dietitian to a home health-care agency was cost beneficial for a number of reason, however, this cost analysis was taken from the agencies point of view (Sousa, 1994). Unfortunately, variations between countries with respect to the different methods of payment and reimbursement for HETF makes comparative analysis or application of results to different countries difficult (Goff, 1998). When evaluating or comparing the costs of interventions or treatments, it is essential to recognise that different groups (e.g. patients, health professionals, and hospital managers) may vary in their perspective towards cost and benefits.

In conclusion, the provision of a community nutrition service in Dublin would appear to be viable, depending on the number of patients under the care of the dietitian. However, in order to test this accurately, the service needs to be audited whilst it is in progress. Cost effectiveness studies (in the strict sense), on home enteral tube feeding are not possible due to ethical difficulties. It might be argued that an administrator with the purpose of coordinating services for these patients between hospital and home is more justifiable in terms of cost than a dietitian. However, a pilot programme of a community nutrition service for HETF patients is justifiable for a few reasons. Firstly, in addition to the potential cost saving, the advantages of the service in terms of quality of care provision should not be underestimated. Such a service could serve to reduce the number of nutrition related admissions to hospital, as well as increasing knowledge and awareness of tube feeding amongst PHNs and GPs, to further help in reducing complications, and improve the quality of care given to these patients. The survey of adults in Chapter 2 highlighted a high incidence of complications which may have been associated with tube feeding, these complications could be dealt with and resolved in the home; further improving quality of care. Secondly, a similar service has proved to be successful in Belfast and Liverpool (see Chapter 1.4). Thirdly, the analysis outlined in this Chapter has shown that the service would be relatively inexpensive. Fourthly, such a service would increase the quality of

nutrition care to patients who at present have no nutrition service at all. The nutritional follow up of many poorly mobile adult patients is almost impossible to carry out in the OPD setting, as found in Chapter 2. Lastly, the work carried out in Chapters 2 & 3 & 4 has already demonstrated that GPs are not in a position to advise on issues relating got enteral feeding. The community nutrition service could decrease the unnecessary distraction of GPs and PHNs with issues relating to these patients with which they are presently unable to deal with effectively.

# Chapter 7

## General Discussion

# 7. Discussion

Little or nothing was documented about patients on tube feeding in the community in Ireland before this research was carried out. The principal aim of this work was to describe the experiences of these patients, and to investigate the contribution of a variety of health care professionals involved in their care. This information is required to effectively plan appropriate community nutrition services, which anecdotally, many Irish dietitians believe to be necessary. In addition to outlining current trends, a cost feasibility study was carried out to explore the financial practicalities of providing such as service. During this research it became apparent from reading the literature and attending relevant conferences that ethical questions were being raised regarding the use of long term tube feeding in certain patients.

The study of adults on tube feeding outside the hospital setting revealed that many patients experienced problems, for example they suffered more complications than similar patients in comparable studies. Logistical difficulties and follow up issues were the main concerns in the survey of adult patients. Many of these patients had extremely poor functional status and therefore anthropometric assessment, particularly the direct measurement of weight, was difficult to carry out in many patients. For this reason, measurement of upper arm anthropometry may be a more practical nutritional assessment tool in these patients. In addition, review of all 160 patient discharges from the hospital found that cancer patients, in particular, had poor survival rates following discharge. The study of consultants attitudes (Chapter 5) found that most (approximately three quarters) were, in fact, opposed to tube feeding end stage cancer patients such patients. The survey of consultants also found that physicians held diverse views on tube feeding. Generally, consultants were in favour of tube feeding when the subject is a stroke patient, but their views are divided on the issue of tube feeding patients with PVS, terminal cancer or dementia, although most would prefer not to tube feed these patients. The survey indicated that most doctors would choose not to tube feed patients with dementia. However, 10% of the patients discharged from the hospital required tube feeding due to dementia, illustrating that the use of tube feeding in this group is by no means an uncommon event in this country. This issue is particularly important considering the continued increase in the use of tube feeding, as found in the review of discharges over 6 years, and reiterates the importance of careful patient selection for long term tube feeding. In view of these findings from Chapter 2 & 5, it is perhaps timely for the production of national guidelines for the appropriate use of tube feeding for health care professionals involved in the

care of enterally tube fed patients in Ireland. In addition, it would be interesting to compare the views of Irish consultants on the use of tube feeding with the views of other Irish health-care professionals. Such information would be helpful in formulating guidelines for the use of life sustaining-treatments in the future.

While the survey of children was small due to limitations of the recruitment method imposed by the ethics committee, it highlighted several psychosocial issues surrounding the use of tube feeding in these children. Mothers experience emotional distress, and agreed that a support network should be available in the community. Such a network could facilitate parents to discuss the day to day obstacles that confront children on home tube feeding and their families, in addition to assisting in the preparation of parents of children who require gastrostomy tubes. This advice will be passed on to the paediatric interest group of the Irish Nutrition and Dietetic Institute, who are in an ideal position to oversee the established of such network. The recruitment difficulties also underlined the problems involved in studying paediatric patients in Ireland. If future research of this nature is to be carried out, it would be advisable that the research be carried out by a member of staff from the institution through which the children are being recruited. For both the adults and children, it was recommended that a home delivery service of enteral feeds and equipment would be helpful. Since these studies have been carried out, and the results disseminated at local and international meetings, most companies now provide these services.

Mothers of children and carers of adult patients on tube feeding in the community experience similar difficulties in terms of logistics, but both groups were also found to be lacking in their access to appropriate nutrition support personnel in the community. Both mothers of children and carers of adult patients were unsure of their GPs knowledge about tube feeding, and dietitians received many telephone calls from patients and carers. However, Chapter 4 found that GPs have very few patients on tube feeding in their care, at any one point in time, and therefore it is unsurprising that their knowledge of enteral feeding is not depended on by patients and carers. Thus it was not unexpected to find that commercial company reps are continually asked to deal with problems in the community by patients and their carers. Surveys of dietitians and company representatives found that both groups were frustrated with the level of dietetic service provided to patients on home tube feeding, dietitians in hospitals received numerous telephone calls about patients, and company representatives were

uncomfortable about their position in terms of their advising patients on home tube feeding. GPs have little contact with these patients, which reduces the interest of GPs on this topic. Perhaps it would be beneficial to provide ethical guidelines for company employees involved with patients on HETF, in addition to providing further education to GPs and PHNs regarding enteral nutrition. Therefore, it is imperative that links between community and hospital be established as there is clearly poor coordination between services, and an obvious need for a centralised service to harmonise practices. Unfortunately, however, without the appropriate personnel in the community setting these necessary links would be difficult to establish.

The costs of home tube feeding and the costs of providing a community nutrition service have been discussed (see Chapter 6). The possible effect of a community nutrition service on the cost of home tube feeding was predicated. Although some approximation was necessary in this exercise, it could be concluded that such a service would lead to reductions in the overall cost of community tube feeding, mostly through the implementation of a centralised purchasing system. It might be argued that this service could, in theory, be an administrative service only; to facilitate integration of services; however, the experiences in other centres and the cost findings from Chapter 6 have shown that the cost of providing a service is quite low, as a percentage of the overall cost of HETF, and the advantages of a community nutritionist over a purely administrative individual are numerous in terms of the quality of patient care. In view of the findings in Chapters 2 & 3, many patients, particularly immobile adult patients, require the services of a dietitian at community level. Many of the problems experienced by these patients could be prevented if the services were in place in the community. In the future, if the health services do not provide funding for community dietitians to manage patients on home tube feeding, it is possible that commercial companies may provide some or all the funds necessary to employ community dietitians for this purpose, thereby introducing the potential for commercial bias in the provision of an essential community service. At this juncture, it might be helpful if the Irish Nutrition & Dietetic Institute produced a position paper to define the involvement of the Irish Dietitian in the care and management of patients on HETF at all stages of their treatment. Such a paper might serve to clarify many issues for both dietitians and other health care professional involved with these patients.

Finally, extrapolation of figures obtained from some of the above studies has shown that HETF in Ireland may be more prevalent than in the UK, using BANS data as a reference. Using figures from the GP survey, the dietitians survey, and the 6-year discharges from the hospital an average figure of approximately 1061 patients was estimated as the point prevalence of (GP survey) and a yearly incidence of 1213 patients was approximated (dietitians survey, and hospital data). In the absence of a national HETF register in Ireland, it is recommended that local audit of discharges and outcome be carried out on these patients. Regular reporting of patient outcome in the future may help to guide decision makers on the appropriateness of patient selection for this treatment.

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# Appendices

## Section 1. Patient details

**Subject number** _____

**Date** _____

**Patient Name** _____

**MRN** _____

**Address** _____

_____

_____

_____

**Tel No** _____

**Date of birth** _____

**Age at time of interview** _____

**Sex** 1. Male ☐ 2. Female ☐

**Place of residence**
1. Patients own home ☐
2. Other home in the community ☐
3. Nursing Home (EHB) ☐
4. Private Nursing Home ☐
5. Long Stay Institution ☐
6. Other ☐

**Patients occupation**
1. Work full time ☐
2. Work part time ☐
3. School \ College ☐
4. Housewife \ Husband ☐
5. Retired ☐
6. Sick leave ☐
7. Retired early due to illness ☐
8. Unemployed ☐
9. Never worked due to illness ☐
10. Infant ☐
11. Other (Specify) ☐

**Is the patient** 1. Fully conscious ☐ 2. Semi conscious ☐ 3. Unconscious ☐

**Patients speech communication**
1. Normal ☐
2. Slight Impairment ☐
3. Difficulty ☐
4. Major Difficulty ☐
5. Nil ☐

**Patients communication other than speech**
1. Writing ☐
2. Typing ☐
3. Signals ☐
4. None ☐
5. Other (Specify) ☐

**Does the patient *normally* leave the place of residence?**
1. Yes
2. No
3. DK

**Does the patient need accompaniment (help or aid) on leaving home?**
1. All the time ☐
2. Sometimes ☐
3. Never ☐
4. DK
5. NA

**How frequently does the patient leave their place of residence?**
1. Daily ☐
2. Weekly ☐
3. Fortnightly ☐
4. Monthly ☐
5. Every few months ☐
6. Few times per year ☐
7. Never ☐
8. Other ☐

**Patients mobility level**

1. Able to walk unaided
2. Able to walk with aid
3. Unable to walk
4. Other

**Assistance required with HETF**

1. No assistance
2. Minor assistance
3. Major assistance
4. Full assistance
5. Depends
6. Other

**Does the patient presently attend a day care centre?**

1. Yes, at the present
2. No, never has
3. No, but used to
4. Other
5. Not applicable

**Does patient *currently* have home help?**

1. Yes
2. No
3. NA

**If "yes" then how often?**

1. On a daily basis
2. More than once per week
3. On a weekly basis
4. On an ad hoc basis
5. NA

**Who administers the patients feed ?** (i.e. Setting up feed and pump)

1. Patient only
2. Primary Carer only
3. Other family member
4. Varies
5. Other
6. PHN
7. Staff nurse
8. Other nursing home staff

## Section 2: Primary carer details / Nursing home details

**Name** _____

**Address** _____

_____

_____

_____

***If the Carer is a staff member in an institution, ignore the rest of is section***

**Tel No** _____

**Date of birth** _____

**Age at time of interview** _____

**Sex of Carer**
1. Male
2. Female

**Relationship to Patient**
1. Spouse
2. Sister
3. Brother
4. Son
5. Daughter
6. Unrelated
7. Other (specify)

***If the Carer is a staff member in an institution fill in the following***

**Job title**_____

**Is the Patient:**
1. A Private Patient
2. A Public Patient

**Type of Nursing \ Residential Home**
1. Private Nursing Home
2. Health Board Funded
3. Other

## Section 3. Feeding regimen details

**Current principle objective of the nutrition support**

Palliative Care ☐

Supplementary nutrition (expected short term) ☐

Supplementary nutrition (expected long term) ☐

Full nutrition support (expected short term) ☐

Full nutrition support (expected long term) ☐

**Current aim of nutritional support**

To improve nutritional status ☐

To maintain nutritional status ☐

DK ☐

**Feeding route**

Nasogastric ☐

Nasoduodenal ☐

Gastrostomy (endoscopic) ☐

Gastrostomy (surgical) ☐

Jejunostomy (endoscopic) ☐

Jejunostomy (surgical) ☐

**Feeding schedule administration1**

1. Continuous drip* ☐
2. Bolus feeding** ☐
3. Cyclic feeding*** ☐
4. Varies ☐

**Feeding method**

1. With non portable pump ☐
2. With portable pump ☐
3. Without pump ☐
4. With portable pump and carry bag ☐

**Does feeding occur during**

1. Day only ☐
2. Night only ☐
3. Both ☐
4. Depends ☐

**The enteral feed is given as a constant infusion over 16 -24 hours via a fine bore tube*
***The administration of 300-400 mls of feed at once*
****Feed given over less than 16 hours in the day e.g. night time feeding*

**If *Continuous* feeding occurs**

1. What is the duration of the feeding session ? _____
2. What is the rate of feed administration ? _____ mls per hour
3. How much feed is given per session? _____ mls

**If *Bolus* feeding occurs**

1. How often is bolus feed administered ? _____ ( times per day)
2. How long does feed take to administer ? _____ mins
3. How much feed is given per session ? _____ mls

**If *Cyclic* feeding occurs**

1. How long is each feeding session ? _____
2. How much feed is given per session ? _____
3. What is the current rate of feeding ? _____ mls per hour

**Amount of feed used**

1. How many Mls of feed are *prescribed* per day (e.g. how many cans \ bottles) _____
2. How many Mls of feed (on average) is *administered* per day _____
3. How many Mls of water is administered per day _____

**What type of feed is used at present?**

_____

**Where are feeds obtained?**

1. Local Pharmacy
2. HB Pharmacy
3. Other

**Are the feeds**

1. Delivered
2. Collected
3. DK

1. Light
2. Dark
3. DK

**Where are the feeds stored?**

1. At room temp
2. Above room temp
3. Below room temp
4. DK

**Is storage place for feeds & equipment a problem?**

1. Yes
2. No
3. DK
4. NA

**How often do you obtain feeds?**

1. Once per week
2. Twice per week.
3. More than twice per week
4. Once per fortnight
5. Once per month
6. Other (Specify)

**Is the transport of feeds a problem?**

1. Yes*
2. No
3. DK
4. NA

***If YES , in what way?**_____

**Is the following equipment used?**

| | | |
|---|---|---|
| Pump | | Type |
| Giving set | | Type |
| Reservoir | | Type |
| Pump stand | | Type |
| Pump carrier bag | | Type |
| Other equipment | | Type |

**If a *Pump* is used, who provided the feeding pump?**

1. Company ☐ Name_____
2. Hospital ☐ Name_____
3. Nursing Home ☐ Name_____
4. Other ☐ Name_____

**Has the pump ever broken down?**

1. Yes
2. No
3. DK
4. NA

**Who contacted if pump breaks down?**

1. GP
2. Hospital dietitian
3. Company dietitian
4. Company rep
5. PHN
6. Other (specify)

**Do you find the pump too noisy?**

1. During the day
2. During the night
3. Neither
4. Both

**If *Giving Sets* used, where are they obtained?**

Local Pharmacy
Health Board Pharmacy
Other

**Are Giving Sets?**

1. Delivered
2. Collected
3. DK

**How often are the giving sets collected \ delivered?**

More than twice per week
Twice per week.
Once per week
Once per fortnight
Once per month
Other (Specify)

**If Giving Sets are collected: Is the collection of giving sets a problem?**

1. Yes ☐ 2. No ☐ 3. DK ☐

**If YES, in what way?**

_____

_____

**How often are the giving sets changed?**

1. Every 24hrs
2. Every 48hrs
3. Every 72hrs
4. Other (Specify)

**Are Giving Sets recycled \ reused?**

1. Yes*
2. No
3. DK

***If YES, Why do you recycle your Giving Sets?**

_____

_____

**Have there been difficulties acquiring**

Feeds
Pump
Giving sets
Other equipment (specify)

**What kind of difficulty was encountered?**

**How often is tube flushed?**

1.Before and after every feed
2.Before every feed only
3.After every feed only
4.Other (specify)

**What fluid is used to flush the tube?**

1.Warm tap water
2.Cold tap water
3.Warm boiled water
4.Cold boiled water
5.Bottled water
6.Sterile water
7. Other

**Are connectors used for flushing?**

1. Yes
2. No
3. DK

**What volume is used to flush the tube (i.e. per flush)?**_____Mls

**What volume of water is used daily to flush tube**_____*(calculate)*

**NG fed patients only**

*Dressings*

**Is the tube secured onto the patients face with dressing**

1. Yes ☐ 2. No ☐ 3. DK ☐ 4. NA ☐

**If YES, then what dressing material is used?**

_____

**How many times per day is the tape changed?**_____

*Position of the NG tube*

**Is the position of the NG tube checked at home?**

1. Yes ☐ 2. No ☐ 3. DK ☐

**If YES, Is it checked before the administration of every feed?**

1. Yes ☐
2. No ☐
3. DK ☐

**If NO, how often is the position of the tube checked?**

_____

**How is the position of the NG tube checked at home?**

1. Litmus paper / pH method ☐
2. Auscultation method ☐
3. X ray ☐

**Patients with stoma only**

**Are gauze dressings used on the stoma site at the present time?**

1. Yes* ☐
2. No ☐

**How often is the stoma site washed**?**

1. Daily ☐
2. Every two days ☐
3. Weekly ☐
4. Depends ☐
5. DK ☐
6. Other ☐

***If YES, how often are they changed?**

_____

****What is the site washed with?**

_____

| **Is there any pain around the stoma site?** | **Yes** | **No** | **DK** | **Is it present more than 50% of the time?** |
|---|---|---|---|---|
| 1. Is there any erythema (superficial reddening of the skin) around the stoma site? | | | | |
| 2. Is there any discharge around the stoma site at present ? | | | | |
| 3. Has there been any infection around the stomas site at present? | | | | |
| 4. Has there been any leakage of feed around the stoma site at present? | | | | |

**Was your home modified in any way for provision of HETF?**

1. Yes* ☐ 2. No ☐ 3. DK ☐ 4.NA ☐

***If YES, In what way?**

_____

_____

***If YES, who paid, and were the costs recovered?**

_____

| | Yes | No | DK |
|---|---|---|---|
| Has the feeding tube ever been replaced? | | | |
| If Gastrostomy tube used, was an NG tube replaced by the Gastrostomy tube in the community? | | | |
| Is the tube (NG) removed on a regular basis? | | | |

**Where does replacement of displaced feeding tubes take place if necessary?**

1. Home
2. GP surgery
3. OPD in hospital
4. A&E dept. in hospital
5. Other (specify)
6. NA

**Who replaces the tube?**

1. PHN
2. Hospital doctor
3. Hospital nurse
4. Other (specify)
5. GP
6. NA

**Is there any oral intake at the present time?**

1. Yes**
2. No
3. DK

**Is the consistency of the food eaten modified**

1. Yes*
2. No
3. DK
4. NA

***If "Yes", then how is it modified?**

1. Soft consistency
2. Semi-Solid consistency
3. Set consistency
4. NA

**** If there is oral intake**

1. How many calories (on average) per day _____
2. How much protein (on average) per day _____

## Section 4 : Review of the regimen in the community

**Has the patient been reviewed while at home in the community? (i.e. Is the patients nutritional status, nutritional requirements and nutritional intake assessed, and the feed changed if necessary, or has there been any phone calls regarding the feed)**

1. Yes ☐ 2. No ☐ 3. DK ☐

**If yes, then in what way was the patient reviewed?** By Whom?

Was the patient weighed
Was the feed regimen reviewed
Was the patients intake assessed

**Have there been any changes* made to the *feed /feeding schedule* since last discharge from hospital**

1. Yes
2. No
3. DK

**If Yes*, was the change made to**

1. Type of feed
2. Feeding schedule
3. Volume of feed
4. Other

** "Change", meaning, change in rate of flow of feed, feed volume, feed type, feeding schedule etc.*

**If Yes, the who made the change**_____

## Section 5: Medical information

**Diagnosis \ underlying indication for artificial nutrition?**

**Other significant medical conditions:**

**From where was the Patient discharged (i.e. *where was feeding tube inserted)?***

Hospital
Nursing Home
Other

Name

**Current Drug \ Medications taken by Patient (State whether in liquid form or not)**

**Are drugs taken**

1. Orally
2. Via tube
3. Both
4. Depends
5. DK

**If BOTH, does method of administration depend on form in which drug available (i.e. Liquid or Tablet Form)**

1. Yes
2. No
3. DK

**Are the following drugs taken**

Laxatives
Enemas
Suppositories

Bowel Openings _____per week

**Are drugs taken?**

1. With feed
2. Between feeds
3. DK

**If tablets are administered via the tube, are they crushed before administration?**

1. Yes
2. No
3. DK

**If YES , What is used to crush the pills?**

1. Pill Crusher
2. Other

**Is the feeding tube flushed *before* medications are administered?**

1. Yes
2. No
3. DK

**Is tube flushed *after* medications are administered?**

1. Yes
2. No
3. DK

**What fluid is used to flush the tube after *medications* are administered?**

Warm tap water
Cold tap water
Warm boiled water
Bottled water
Sterile water
Cold boiled water
Other

## Section 6: Physiological and other problems

**Have any of the following been experienced by the Patient while receiving nutrition support at home ? Was anybody contacted to help deal with the problem, and if so, who was contacted ?**

| Problem | Problem Experienced Yes | Problem Experienced No | Contact Anyone Yes | Contact Anyone No | Professional Contacted |
|---|---|---|---|---|---|
| 1. Nausea | | | | | |
| 2. Vomiting | | | | | |
| 3. Abdominal distention | | | | | |
| 4. Constipation | | | | | |
| 5. Diarrhoea | | | | | |
| 6. Regurgitation of feed | | | | | |
| 7. Tube blockage | | | | | |
| 8. Tube displacement | | | | | |
| 9. Nasal discomfort | | | | | |
| 10. Pharyngeal discomfort | | | | | |
| 11. Aspiration pneumonia* | | | | | |
| 12. Cough | | | | | |
| 13. Fever | | | | | |
| 14. Wheeze | | | | | |
| 15. 16. Peritonitis | | | | | |

***If patient has had aspiration pneumonia, did this require**

1. Hospitalization ☐
2. Treatment by GP only ☐
3. Other ☐_____

**Has HETF caused difficulty with travel?**

1. Yes ☐
2. No ☐
3. DK ☐
4. NA ☐

**Has HETF disrupted social activity?**

1. Yes ☐
2. No ☐
3. DK ☐
4. NA ☐

**In general do the feeding times suit the Patients lifestyle**

1. Yes ☐
2. No ☐
3. DK ☐
4. NA ☐

**If YES, in what way?**

_____

_____

_____

**If YES, in what way? (e.g. Swimming, walking)**

_____

_____

## Section 7: Education regarding HETF

**Where was the educated re HETF carried out?**
1. At home \ N. Home ☐
2. In discharge hospital ☐
3. Both of above ☐
4. Other Specify ☐

**Was there a home visit prior to discharge?**
1. Yes* ☐
2. No ☐
3. DK ☐

**Were the following involved in the education program ?**

| | Yes | No |
|---|---|---|
| 1. Hospital dietitian | ☐ | ☐ |
| 2. Hospital doctor | ☐ | ☐ |
| 3. Hospital nurse | ☐ | ☐ |
| 4. Hospital OT | ☐ | ☐ |
| 5. Local pharmacy | ☐ | ☐ |
| 6. Company dietitian | ☐ | ☐ |
| 7. Company rep | ☐ | ☐ |

***If YES, then by whom?**_____

_____

**Did you receive an instruction manual for HETF?**
1. Yes ☐
2. No ☐
3. DK ☐

**If YES, from whom?**
1. Hospital dietitian ☐
2. Hospital nurse ☐
3. Hospital doctor ☐
4. Company dietitian ☐
5. Company rep ☐

**Did you have confidence in your GP's knowledge of HETF ?**
1. Yes ☐
2. No ☐
3. DK ☐

**Did you have the enteral feed available at home on the day of discharge?**
1. Yes ☐
2. No ☐
3. DK ☐

**On finishing education was the Patient / Carer able to**

| | Yes | No | DK | NA |
|---|---|---|---|---|
| Check tube position (NG) | | | | |
| Secure the tube adequately | | | | |
| Prepare the feed for administration | | | | |
| Connect the feed to the giving Set | | | | |
| Connect the giving set to the pump | | | | |
| Program & operate the feeding pump | | | | |
| Administer bolus feed down the tube | | | | |
| Administer medication down the tube | | | | |
| Disconnect the feed and flush water down the tube | | | | |
| Contact the appropriate health professional when necessary | | | | |
| Clean and care for the syringes | | | | |
| Irrigate a blocked tube | | | | |
| Change malfunctioning parts of the tube | | | | |
| Clean & care for the pump | | | | |
| Deal with the pump alarm | | | | |

| **Was the Patient \ Carer satisfied with the level of education received re HETF** | Yes | No | DK | NA |
|---|---|---|---|---|
| | | | | |

| | | | | |
|---|---|---|---|---|
| In hospital | | | | |
| At home | | | | |
| **Do you think that HETF could be improved by** | | | | |
| More equipment adapted for home use | | | | |
| Better equipment (change in present design) | | | | |
| Better maintain service for equipment | | | | |
| Structural alterations to home ( to provide greater storage space) | | | | |
| Better education in hospital | | | | |
| Better education at home | | | | |
| Transfer to home logistics | | | | |
| Support service at home | | | | |
| Other (specify) | | | | |

**Would you like to have more frequent contact with a health professional?**

1. Yes
2. No
3. DK

**If "yes" then with whom?**

1. Hospital. dietitian
2. Company dietitian
3. Hospital. doctor
4. Company rep
5. Other

## Section 8 : Payment for HETF

Does the Patient have a medical card?
Does the Patient have a long term illness book?
Does the Patient use the drug cost subsidisation scheme?

## Section 9: Miscellaneous data

**In opinion of Carer does the Patient have a good quality of life on HETF at present?**

1. Yes
2. No
3. DK

**Since the start of HETF? Has primary caregiver experienced:**

| | Yes | No | DK | NA |
|---|---|---|---|---|
| 1. Employment disruption | | | | |
| 2. Anxiety | | | | |
| 3. Depression | | | | |
| 4. Fatigue | | | | |

## Section 10: Length of time spent on HETF

Date on which NG / PEG inserted _____
Date of Discharge into the community _____
Date of Interview _____
Duration of feeding in the community _____
Number of admissions into hospital after initial discharge on HETF _____
Reasons for re-admittance _____

## Section 11. anthropometric data

| | | Measured directly | Measured indirectly |
|---|---|---|---|
| Actual weight (Kg) | | | |
| Usual weight (Kg) | | | |
| Height (m) | | | |
| BMI | | | |
| IBW(Kg) | | | |

| Skinfold | No. 1 | No. 2 | No. 3 | Average | % Ile |
|---|---|---|---|---|---|
| Biceps | | | | | |
| Triceps | | | | | |
| Subscap | | | | | |
| Suprailiac | | | | | |
| Total | | | | | |

Calorie requirements (Schofield) _____ Kcals per day

Calorie intake:

A. Oral intake _____ Kcals per day

B. ETF intake _____ Kcals per day

Total _____ Kcals per day

| | Measurement | %Ile |
|---|---|---|
| MUAC (cm) | | |
| Calf circumference | | |
| Knee height (cm) | | |
| Armspan (cm) | | |
| *Mid arm muscle circumference | | |
| *Mid arm muscle area | | |
| *% Body fat | | |
| *% Ideal body weight | | |
| Time over which weight was lost | | |

* *calculated from equations*

Hand grip

1st attempt _____

2nd attempt _____

3rd attempt _____

*Take best attempt*

## Section 13. Barthel Index

Methods to assess functional status and/or quality of life

**Barthel ADL index**

| Function | Score | Description |
|---|---|---|
| bowels | 0 | Incontinent (or needs to be given enemas) |
| | 1 | Occasional accident (less than once a week, max once a day) |
| | 2 | Continent |
| bladder | 0 | Incontinent or catherised but unable to manage |
| | 1 | Occasional accident |
| | 2 | Continent for over 7 days |
| grooming | 0 | Needs help with personal care |
| | 1 | Independent. Implements can be provided by helper |
| toilet use | 0 | Dependent |
| | 1 | Needs help but can do something alone (including wiping self) |
| | 2 | Can reach toilet, undress sufficiently, clean self and leave |
| feeding | 0 | Unable |
| | 1 | Needs help in cutting up food, spreading butter etc., but feeds self |
| | 2 | Independent (food cooked, served and provided within reach, but not cut up). Normal food. |
| transfer | 0 | Unable, no sitting balance, 2 to lift |
| | 1 | Major help: physical help, 1 strong or 2 normal. Can sit. |
| | 2 | Minor help: 1 person easily or supervision for safety |
| | 3 | Independent (may use aid) |
| mobility Indoors | 0 | Immobile |
| | 1 | Wheelchair independent |
| | 2 | Help of one trained person, including supervision |
| | 3 | Independent (may use aid) |
| dressing | 0 | Dependent |
| | 1 | Needs help but can do half unaided |
| | 2 | Independent including buttons, zips, laces etc |
| stairs | 0 | Unable |
| | 1 | Needs help (verbal/physical, carrying aid) |
| | 2 | Independent up and down, carrying any walking aid) |
| bathing | 0 | Dependent |
| | 1 | Independent (Bath: must get in and out unsupervised and wash self shower: unsupervised/unaided) |

**Section 14. modified norton Scale**

| | | | | |
|---|---|---|---|---|
| **A** | **Mental condition** | | **B** | **Activity** |
| | 4 | Fully orientated | 4 | Ambulant |
| | 3 | Occasionally confused | 3 | Walks with help |
| | 2 | Cannot answer adequately | 2 | Chairbound |
| | 1 | No contact | 1 | Bedridden |
| **C** | **Mobility** | | **D** | **Food Intake** |
| | 4 | Full | 4 | Normal |
| | 3 | Slightly limited | 3 | Insufficient |
| | 2 | Very limited | 2 | Parenteral/Enteral |
| | 1 | Immobile | 1 | No intake |
| **E** | **Fluid intake** | | **F** | **Incontinence** |
| | 4 | Normal | 4 | None |
| | 3 | Insufficient | 3 | Occasional |
| | 2 | Parenteral | 2 | Usually urine |
| | 1 | No intake | 1 | Double |

**G** **General physical condition**

4 Good
3 Fair
2 Poor
1 Very bad

**Patient Name** _____
**MRN** _____
**Address** _____
**Tel No** _____
**Consultant** _____
**Date** _____
**Study number** _____

*Cut along line to protect the identity of the patient*

## Section 1: Demographics

**Study Number** _____
**Date of birth** _____
**Age at time of interview** _____

**Sex** **Male** ☐ **Female** ☐

**Fathers occupation** _____
**Mothers occupation** _____
**Childs schooling** _____

**Patients speech communication**

1. Normal ☐
2. Slight Impairment ☐
3. Difficulty ☐
4. Major Difficulty ☐
5. Infant ☐
6. Nil ☐

**Patients mobility level**

1. Able to walk unaided ☐
2. Able to walk with aid ☐
3. Unable to walk ☐
4. Infant ☐
5. Other ☐

**Does the patient *normally* leave the place of residence?**

1. Yes ☐
2. No ☐

**Does the patient/carer *currently* have home help?**

1. Yes* ☐
2. No ☐
3. NA ☐

**How frequently does the patient leave their place of residence?**

1. Daily ☐
2. Weekly ☐
3. Fortnightly ☐
4. Monthly ☐
5. Every few months ☐
6. Few times per year ☐
7. Never ☐
8. Other ☐

***If "yes" then what kind of home help?** _____

***If "yes" then how often do you have home help?**

1. ____times per week 2. On an ad hoc basis ☐ 3. NA ☐

## Section 2: Primary carer details

**Who (generally) administers the feed?** _____

**Name** _____

**Age** _____

**Sex of Carer** **Male** ☐ **Female** ☐

**Relationship to Patient** _____

## Section 3: Patients feeding regimen

Date on which tube inserted _____

Date of initial discharge on tube feeding into the community _____

Duration of feeding in the community _____

Length of time on feeding in the hospital before discharge _____

**PEG changes:**

| Date tube changed | from: | to: |
|---|---|---|
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |

**Is there any oral intake at the present time?**

1. Yes ☐
2. No ☐
3. DK ☐

**Is the consistency of the food eaten modified?**

1. Yes ☐
2. No ☐
3. DK ☐
4. NA ☐

**If "Yes", then how is it modified?**

1. Soft consistency ☐
2. Semi-Solid consistency ☐
3. Set consistency ☐
4. NA ☐

**If there is oral intake**

1. How many calories (on average) per day _____
2. How much protein (on average) per day _____

**What is the current principle objective of the nutrition support?**

1. Palliative Care ☐
2. Supplementary nutrition (expected short term) ☐
3. Supplementary nutrition (expected long term) ☐
4. Full nutrition support (expected short term) ☐
5. Full nutrition support (expected long term) ☐

**Feeding route**

| | | | |
|---|---|---|---|
| 1. Nasogastric | | 5. Gastrostomy (Foley Cath | |
| 2. Nasoduodenal | | 6. Jejunostomy (endoscopic) | |
| 3. Gastrostomy (endoscopic) | | 7. Jejunostomy (surgical) | |
| 4. Gastrostomy (surgical) | | 8. Low profile gast | |

**Type of feeding tube (brand)** _____

**What type of feed(s) is used at present?** _____

**Feeding schedule administration**

| | |
|---|---|
| 1. Continuous drip | |
| 2. Bolus feeding | |
| 3. Cyclic feeding | |
| 4. Varies | |

**Does feeding occur during**

| | |
|---|---|
| 1. Day only | |
| 2. Night only | |
| 3. Both | |
| 4. Depends | |

*i.e. The enteral feed is given as a constant infusion over 16 -24 hours via a fine bore tube)*
*i.e. The administration of 300-400 mls of feed at once)*
*i.e. Feed given over less than 16 hours in the day e.g. night time feeding)*

**If *Continuous* feeding occurs**

1. What is the duration of the feeding session? _____
2. What is the rate of feed administration? _____
3. How much feed is given per session? _____

**If *Bolus* feeding occurs**

1. How often is bolus feed administered? _____
2. How long does feed take to administer? _____
3. How much feed is given per session? _____

**If *Cyclic* feeding occurs**

1. How long is each feeding session? _____
3. How much feed is given per session ? _____
4. What is the current rate of feeding ? _____

**Amount of feed used**

1. How many Mls of feed are *prescribed* per day (e.g. how many cans \ bottles) _____
2. How many Mls of feed (on average) is *administered* per day _____
3. How many Mls of water is administered per day _____

## Section 4: Feed and Equipment

| | |
|---|---|
| **Where are the feeds obtained?** | |
| **How often do you obtain feeds?** | |

**Are the feeds:**

1. Delivered ☐
2. Collected ☐

**Is storage for feeds & equipment a problem?**

1. Yes ☐
2. No ☐
3. DK ☐
4. NA ☐

***Is the transport of feeds a problem?**

1. Yes ☐
2. No ☐
3. DK ☐
4. NA ☐

***If "Yes", in what way?**_____

**Is the following equipment used?** Type

1. Pump _____
2. Giving set _____
3. Reservoir _____
4. Pump stand _____
5. Pump carrier bag _____
6. Syringes _____

**If a *Pump* is used, who provided the feeding pump?** Name

1. Company _____
2. Hospital _____
3. Nursing Ho _____
4. Other _____

**Has the pump ever broken down?**

1. Yes ☐
2. No ☐
3. DK ☐
4. NA ☐

**Do you find the pump too noisy?**

1. During the day ☐
2. During the night ☐
3. Neither ☐
4. Both ☐

| | |
|---|---|
| How many times have you need assistance with the pump since discharge on feeding? | |
| Who would/does the Carer contact if pump breaks down? | |

**If *Giving Sets* used, where are they obtained?**_____

**Are Giving Sets?**

1. Delivered to home ☐
2. Collected* ☐

**How often are the giving sets collected/delivered?**

1. More than twice per week ☐
2. Twice per week. ☐
3. Once per week ☐
4. Once per fortnight ☐
5. Once per month ☐
6. Other ☐

***Is the collection of giving sets a problem?**

1. Yes ☐
2. No ☐
3. DK ☐
4. NA ☐

***If YES, in what way?**

_____

_____

**How often are giving sets changed?**

1. Every 24hrs ☐
2. Every 48hrs ☐
3. Every 72hrs ☐
4. Other ☐

**Are Giving Sets recycled/reused?**

1. Yes* ☐
2. No ☐

***If YES, Why do you recycle your Giving Sets?**

_____

_____

| Have there been difficulties acquiring | *Yes | No |
|---|---|---|
| 1. Feeds | | |
| 2. Pump | | |
| 3. Giving sets | | |
| 4. Other equipment | | |

***What kind of difficulty was encountered?**

_____

_____

## Section 5: Care of the tube and stoma site

**Describe how often the tube is flushed?**

_____

_____

**What fluid is used to flush the tube?**

1. Warm tap water ☐
2. Cold tap water ☐
3. Warm boiled water ☐
4. Cold boiled water ☐
5. Bottled water ☐
6. Sterile water ☐
7. Other ☐

What volume is used to flush the tube (i.e. per flush)? _____

What volume of water is used daily to flush tube _____

What type of syringe do you use? _____

How many syringes do you dispose of per week? _____

Where do you get your syringes? _____

***Dressings (NG fed patients only)***

| Is the tube secured onto the patients face with dressing? | | Is the position of the NG tube checked at home? | | If YES, Is it checked before every feed? | |
|---|---|---|---|---|---|
| 1. Yes* | | 1. Yes*** | | 1. Yes | |
| 2. No | | 2. No** | | 2. No | |
| 3. DK | | 3. DK | | 3. DK | |
| 4. NA | | 4. NA | | 4. NA | |
| | | | | | |

***If YES, then what dressing material is used?** _____

**How many times per day is the tape changed?** _____

****If NO, how often is the position of the tube checked?** _____

******If YES How* is the position of the NG tube checked at home?** _____

**Patients with stoma only**

**Are gauze dressings used on the stoma site?** 1. Yes ☐ 2. No ☐

**If YES, how often are they changed?** _____

**How often is the stoma site washed?** _____

**What is the site washed with?** _____

| **Is there any:** | At present | In Past | >50% time | Never | DK |
|---|---|---|---|---|---|
| **Pain around the stoma site** | | | | | |
| **Erythema around the site** | | | | | |
| **Discharge around the stoma site** | | | | | |
| **Infection around the stomas site** | | | | | |
| **Leakage of feed** | | | | | |

**Has the feeding tube ever been replaced?**

1. Yes ☐
2. No
3. DK

**If G-tube used, was an NG tube replaced by the G-tube in the community?**

1. Yes ☐
2. No
3. DK

**Is the tube (NG) removed on a regular basis?**

1. Yes ☐
2. No
3. DK
4. NA

**Where does replacement of displaced feeding tubes take place?**

1. Home ☐
2. GP surgery
3. OPD in hospital
4. A&E dept. in hospital
5. Other
6. NA

**Who replaces the tube?**

1. PHN ☐
2. Hospital doctor
3. Hospital nurse
4. Other
5. GP
6. NA

## Section 6: Review of the patients nutritional status

| | Yes | No | DK |
|---|---|---|---|
| **Has the patient been reviewed by a dietitian since the first discharge into the community?** | | | |
| **Has the patient been weighed since the first discharge into the community?** | | | |

**How often have you telephoned your dietitian since the discharge?**

1. _____times
2. Never
3. 1-5 times
4. 6-10 times
5. 10+ times

**How often have you visited the hospital OPD since discharged on the feed?**

1. To see the doctor? _____
2. To see the Dietitian? _____
3. To see an other professional in relation to the feed? _____

**How often have you needed to attend A&E since discharged on the feed?**

| Date | Indication for A&E visit |
|---|---|
| | |
| | |
| | |

**How often had your child been admitted to hospital since discharge on tube feeding?**

| Date | Indication for admission | LOS |
|---|---|---|
| | | |
| | | |
| | | |
| | | |

**Have there been any changes made to the feed/feeding schedule since last discharge from hospital?**

1. Yes **
2. No
3. DK

**If Yes, was the change made to**

1. Type of feed
2. Feeding schedule
3. Volume of feed
4. Other*

*Specify_____

**If Yes, the who made the change?_____

## SECTION 7: Medical Information

**Diagnosis/underlying indication for artificial nutrition?** _____

**Other significant medical conditions** _____

_____

**Current Drugs/Medications taken by Patient (State whether in liquid form or not)**

| Drug | Tube or orally | Liquid or Tablet | Time taken in relation to feed |
|---|---|---|---|
| 1. | | | |
| 2. | | | |
| 3. | | | |
| 4. | | | |
| 5. | | | |
| 6. | | | |
| 7. | | | |
| 8. | | | |
| 9. | | | |
| 10. | | | |

**Are the following drugs taken?**

1. Laxatives
2. Enemas
3. Suppositories

**Are tablets crushed before administration?**

1. Yes
2. No
3. DK

**If YES, What is used to crush pills?**

1. Pill Crusher
2. Other

| | Yes | No |
|---|---|---|
| **Is the feeding tube flushed *before* medications are administered?** | | |
| **Is tube flushed *after* medications are administered?** | | |

**What fluid is used to flush the tube? when *medications* are administered?**

1. Warm tap water
2. Cold tap water
3. Warm boiled water
4. Cold boiled water
5. Bottled water
6. Sterile water
7. Other

## SECTION 8: Physiological and Other Problems

**Have any of the following been experienced by the Patient while receiving nutrition support at home ? Was anybody contacted to help deal with the problem, and if so, who was contacted ?**

| | problem experienced | | contact anyone? | | |
|---|---|---|---|---|---|
| | YES | NO | YES | NO | person contacted |
| 1. Nausea | | | | | |
| 2. Vomiting | | | | | |
| 3. Abdominal distention | | | | | |
| 4. Constipation | | | | | |
| 5. Diarrhoea | | | | | |
| 6. Regurgitation of feed | | | | | |
| 7. Flatulence | | | | | |
| 8. Tube blockage | | | | | |
| 9. Tube displacement | | | | | |
| 10.Nasal discomfort | | | | | |
| 11.Pharyngeal discomfort | | | | | |
| 12.Aspiration pneumonia* | | | | | |
| 13. Cough | | | | | |
| 14. Fever | | | | | |
| 15. Wheeze | | | | | |
| 16. Sleep Disturbance | | | | | |

**If patient has had aspiration pneumonia, did this require**

1. Hospitalization
2. Treatment by GP only
3. Other

**Has HETF caused difficulty with travel (e.g. school, holidays etc.)?**

1. Yes*
2. No
3. DK
4. NA

**Has HETF disrupted social activity?**

1. Yes**
2. No
3. DK
4. NA

**If YES, in what way?**

_____

_____

**If YES, in what way? (e.g. Swimming, walking)**

_____

_____

**In general do the feeding times suit the Patients lifestyle?**

1. Yes
2. No
3. DK

## SECTION 9: Education Regarding HEN

**Where did the main educated re HETF take place?**

1. At home
2. In discharge hospital

**Was there a home visit prior to discharge?**

1. Yes*
2. No
3. DK

***If YES, then by whom?**_____

**Were the following involved in the education program ? (tick as appropriate)**

1. Hospital dietitian
2. Hospital doctor
3. Hospital nurse
4. Hospital OT
5. Local pharmacy
6. Company dietitian
7. Company rep

**Was the Patient/Carer satisfied with the level of education received re HETF?**

1. Yes
2. No
3. DK

**How many days/weeks did it take you to get familiar to the feeding system at home?**

_____

| **During your education regarding Home Tube Feeding:** | **Yes** | **No** | **DK** |
|---|---|---|---|
| 1. Were you confident in the hospital team that planned your \ your relatives discharge ? | | | |
| 2. Was there a relaxed, quiet area suitable for private discussion of the treatment? | | | |
| 3. Were you able to express your fears and expectations of the treatment? | | | |
| 4. Did you receive an instruction manual/written instructions for home tube feeding? (apart from a pump manual) | | | |
| If YES, from whom? | | | |
| 5. Were you confident you would be able to cope with enteral feeding at home? | | | |
| 6. Do you think you could have benefited from a longer period of training? | | | |
| 7. Were you aware of the responsibilities of each health care professional involved in your childs care? | | | |
| 8. Do you have confidence in your GP's knowledge of HETF ? | | | |
| 9. Do you have confidence in your PHN knowledge of HETF? | | | |
| 10. Did you have a written prescription for the enteral feed (and other prescribable items) on discharge | | | |
| 11. Did you have the enteral feed available at home on the day of discharge? | | | |
| 12. Did you know the names and telephone numbers of health care professionals to contact in case of emergency day or night? | | | |
| 13. Were any arrangements made for the nutritional follow up of the patient? | | | |

| **Do <u>you</u> think that Home Tube Feeding could be improved by:** | **Yes** | **No** | **DK** |
|---|---|---|---|
| 1. More equipment adapted for home use | | | |
| 2. Better equipment (change in present design) | | | |
| 3. Better maintenance service for equipment | | | |
| 4. Structural alterations to your home to provide greater storage space) | | | |
| 5. Better education before discharge | | | |
| 6. More support services at home | | | |
| 7. Are there other ways to improve HETF that you can think of? | | | |

| **On finishing education were you able to:** | **Yes** | **No** | **DK** |
|---|---|---|---|
| Pass the feeding tube | | | |
| Check tube position | | | |
| Prepare the feed for administration | | | |
| Connect the feed to the giving set | | | |
| Connect the giving set to the pump | | | |
| Program & operate the feeding pump | | | |
| Administer bolus feed down the tube | | | |
| Administer medication down the tube | | | |
| Disconnect the feed and flush water down the tube. | | | |
| Clean and care for the syringes | | | |
| Fix a blocked tube | | | |
| Change broken parts of the tube | | | |
| Apply the principles of hygiene and cleanliness when feeding | | | |

| **Since the start of HETF Primary caregiver experienced:** | **Yes** | **No** | **DK** |
|---|---|---|---|
| Employment disruption | | | |
| Anxiety | | | |
| Depression | | | |
| Fatigue | | | |

**Would you like to have more frequent contact with a health professional?**

1. Yes
2. No
3. DK

**If "yes" then with whom?**

| | |
|---|---|
| Hospital dietitian | |
| Hospital doctor | |
| Company dietitian | |
| Company rep | |
| Other | |

## SECTION 10: Payment for HETF

| | **Yes** | **No** | **DK** |
|---|---|---|---|
| **Does the Patient have a medical card?** | | | |
| **Does the Patient have a long term illness book?** | | | |
| **Does the Patient use the drug cost subsidization scheme?** | | | |

**Community Care Area of Patient** _____

**Local health centre** _____

**GP Name and Address** _____

**PHN name and center** _____

## Section 11. Psychological aspects of tube feeding

**Before PEG tube insertion:**

Which word best describes how you felt when you first heard that your child needed a feeding tube?_____

| | Yes | No | DK |
|---|---|---|---|
| Were you initially opposed to the idea of a feeding tube being inserted? | | | |
| Was the decision to proceed to have a feeding tube inserted difficult to make? | | | |
| Do you think the health professionals were sensitive to you and your child's feelings when they told you your child would need a feeding tube? | | | |
| Before the tube was inserted, did you worry that your child was not getting enough food? | | | |
| Do you find it easy to talk to health professional about your child's feeding? | | | |
| Before the tube was inserted did feeding times take up a lot of your time?* | | | |

*If yes, how long did dinner take for example? _____

**Since tube insertion has your child put on weight?**

Yes ☐
No ☐
Don't know ☐

**Since tube insertion has your child become taller?**

Yes ☐
No ☐
Don't know ☐

**Since tube insertion is your child;**

Happier than before tube feeding? ☐
No different with regards to happiness ☐
Less happy ☐

**Since tube insertion is your child:**

More active since tube feeding commenced ☐
No different with regards to activity level ☐
Less active since tube feeding commenced ☐

**Since the feeding tube was inserted would you say that your child's "well being" has**

Improved ☐
Remained the same ☐
Disimproved ☐

**Would you say that your child is:**

Very bothered about by the tube ☐
Sometimes bothered by the tube ☐
Not bothered at all by the tube ☐

**Do you think the tube feeding has improved or disimproved your child's quality of life?**

Improved ☐
Disimproved ☐

**Do you think a support group for Patients and their Carers would be beneficial?**

Yes ☐
No ☐

Quality of life has remained the same ☐ Don't know ☐

**Was opting for tube feeding the right decision to make?**

Yes ☐
No ☐
Don't know ☐

**Did you feel any sense of loss when the feeding tube was inserted?**

Yes* ☐
No ☐
Don't know ☐

*What kind of loss did you feel?

_____

Would you say that the advantages of tube feeding (that is weight gain, knowing your child's nutritional requirements have been met) outweigh the losses (that is the comfort of food for your child, the bond between parent and child when feeding)

| | Yes | No | DK |
|---|---|---|---|
| Has your attitude toward the feeding tube changed since you first heard it would be necessary? | | | |
| Do you miss mealtimes with your child? | | | |
| Do you feel more in control of your child's nutrition now that they have a PEG tube? | | | |
| Do you or other members of the family eat in other rooms to avoid upsetting the child? | | | |

**On finishing education/preparation for discharge:**

| | Yes | No | DK | NA |
|---|---|---|---|---|
| Did your child *smell* differently after the tube was inserted? | | | | |
| If "yes", were you aware that he/she would? | | | | |
| Were you aware of the importance of oral hygiene for children on exclusive tube feeding? | | | | |

**In a few words, what is the best thing about the feeding tube?**

_____

**In a few words, what is the worst thing about the feeding tube?**

_____

_____

**Did you talk to other parent of children on tube feeds before your discharge into the community?**

Yes ☐
No ☐

**If yes: Did you find it useful to talk to other parents?**

Yes ☐
No ☐

**If no: Do you think it would have been useful to talk to other parents?**

Yes ☐
No ☐

What advice would you give parents who have been told their child needs a feeding tube?

Do you think that you were adequately prepared for feeding your child at home?

| | Yes | No | DK |
|---|---|---|---|
| **Psycologically** | | | |
| **Practically** | | | |

**Appendix III:** Commercial Companies involved in the manufacture and distribution of enteral feed and enteral feeding products in Ireland

| Company | Pump | Feeds | Admin. sets | PEG kits | NG\NJ kits |
|---|---|---|---|---|---|
| 1. Abbott Laboratories | ✓ | ✓ | ✓ | ✓ | ✓ |
| 2. Baxter Healthcare | ✓ | ✓ | ✓ | × | × |
| 3. Cow and Gate Nutricia | ✓ | ✓ | ✓ | × | ✓ |
| 4. PEI | ✓ | × | ✓ | ✓ | ✓ |
| 5. Merck Biomaterials | × | × | × | ✓ | ✓ |
| 6. Technopharm Ireland Ltd | ✓ | ✓ | ✓ | ✓ | ✓ |

# Home Enteral Tube Feeding
# Assessing the Practices & Attitudes of Irish hospital Dietitians

**Name** _____

**Place of employment at present** _____

_____

_____

_____

_____

**How long have you been working in clinical practice?**

**Job title**

Principal Dietitian \ Clinical Nutritionist ☐

Senior Dietitian \ Clinical Nutritionist ☐

Basic Grade Dietitian \ Clinical Nutritionist ☐

**Size of hospital of employment**

Small ( 200 Beds or Less ) ☐

Medium ( 201 - 499 Beds ) ☐

Large ( 500 Beds or More ) ☐

**Hospital type**

Teaching ☐

Paediatric ☐

Geriatric ☐

Orthopaedic ☐

General ☐

Private ☐

Regional ☐

Other (Please Specify) ☐

**Number of new patients that *You Personally* on average discharge on home enteral tube feeding**

☐ per Fortnight

☐ per Month

☐ per Two Months

| | |
|---|---|
| | per Quarter |
| | Other ( Please Specify) |

**Regarding patients being discharged into the community, (either to residential homes or to patients own home) who is responsible for the following in your place of employment? Tick the appropriate individual (s).**

| | | | |
|---|---|---|---|
| Rep | *Company Representative* | ST | *Speech Therapist* |
| WS | *Ward Sister* | CN | *Clinical Nutritionist* |
| HDr | *Hospital Doctor* | SW | *Social Worker* |
| Nr | *Nurse* | Oth | *Other, ( Please Specify)* |

| | Rep | WS | HDr | Nr | ST | CN | SW | Oth |
|---|---|---|---|---|---|---|---|---|
| Determining patients nutrient requirements | | | | | | | | |
| Determining patients fluid requirements | | | | | | | | |
| Selecting enteral feeding formula | | | | | | | | |
| Selecting the feeding access route | | | | | | | | |
| Determining the patients feeding schedule | | | | | | | | |
| Contacting primary carer re education | | | | | | | | |
| Teaching the patient to administer feeding | | | | | | | | |
| Teaching patient to operate feeding pump | | | | | | | | |
| Teaching the patient to flush the tube | | | | | | | | |
| Teaching the patient to care for the tube site | | | | | | | | |
| Teaching patient to recognise formula intolerance | | | | | | | | |
| Teaching patient to avoid complications associated with tube feeding | | | | | | | | |
| Teaching patient to administer medications via tube | | | | | | | | |
| Contacting DCC* to ensure funding for disposable equipment | | | | | | | | |
| Ensuring supplies at home for patient on discharge | | | | | | | | |
| Ensuring home environment suitable for artificial feeding | | | | | | | | |
| Contacting local pharmacy if patient is going to **Own** Home | | | | | | | | |
| Contacting local PHN | | | | | | | | |
| Contacting company rep | | | | | | | | |
| Contacting liaison officer | | | | | | | | |

***DCC = Director of Community Care***
***PHN = Public Health Nurse***

**What is the average time spent by you on the education of patients \ carers before discharge on home enteral tube feeding?**

| | |
|---|---|
| <1 Hr | |
| 1 Hr | |
| 2 Hrs | |
| 3 Hrs | |
| 4 Hrs | |
| 5 Hrs | |
| 6 Hrs | |
| > 6 Hrs | |
| Other ( Please Specify) | |

**Do you feel that the length of time that you spend educating these patients/carers is limited due to other work commitments?**

| | |
|---|---|
| Yes | |
| No | |

**When educating a patient \ carer re. home enteral tube feeding , on average, over how many days is the education carried out, before the patient is discharged ?**

| | |
|---|---|
| 1 Day | |
| 2 Days | |
| 3 Days | |
| 4 Days | |
| 5 Days | |
| 6 Days | |
| 7 Days | |
| Other ( Please Specify) | |

**Has a patient ever been discharged before your education of that patient \ carer was complete ?**

| | |
|---|---|
| Yes | |
| No | |

**If YES, approximately how many times would this happen, say, for every 10 patients you send home?**

_____
10

**Do you ever receive phone calls regarding patients you have sent home or to residential institutions on nutrition support?**

| | |
|---|---|
| Yes | |
| No | |

**If YES, approximately how many times would this happen, say, for every 10 patients you send home?**

_____
10

**From whom do you receive these calls?**

| | Yes | No |
|---|---|---|
| GP's | | |
| PHN's | | |
| Patients \ Carers | | |
| Other (Please specify) | | |

**What kinds of inquiries do you receive over the telephone regarding these patients?**

| | |
|---|---|
| Inquiries regarding pump | ☐ |
| Inquiries regarding feeding schedule | ☐ |
| Inquiries regarding funding for feeds etc. | ☐ |
| Inquiries regarding blocked tubes | ☐ |
| Inquiries regarding physiological problems | ☐ |
| Other (Please Specify) | ☐ |

_____

**In your opinion, do you think that the process of transferring patients from hospital to home \ nursing home \ residential institution could be improved?**

Yes ☐
No ☐

If **YES, then in *What Way* in your opinion, do you think it could be improved? Please mark the following in order of their importance.**

**1 = Poorest way to improve...** **7 = Best way to improve...**

| | | |
|---|---|---|
| A | Provision of national guidelines outlining the responsibilities of each of the health professionals involved in the education & transfer of patients into the community. | ☐ |
| B | The availability of a hospital nurse specialised in the education training of patients \ carers regarding home enteral nutrition before discharge into the community. | ☐ |
| C | Making the funding for, and access to, disposable equipment required for home enteral nutrition more readily available. | ☐ |
| D | The availability of an educational package for education of GP's and PHN's regarding home enteral nutrition. | ☐ |
| E | Provision of community dieticians to continue the care of these patients after discharge into the community | ☐ |
| F | The setting up of a self help group for patients receiving nutrition support at home and their carers. | ☐ |
| G | The setting up of a national register of patients receiving home nutrition support. | ☐ |

**Additional comments on the subject of home nutrition support are welcome**

_____

_____

_____

_____

_____

## Home Enteral Tube Feeding
## Assessing the Practices & Attitudes of the Nutritional Company Representative

### Section 1. General information about the nutritional company representative

Date of interview

1. Subject number
2. Company of employment at present
3. Work base
4. Years working as nutritional company rep
5. Job title
6. Hospitals / Institutions covered by rep.

### Section 2. The role of the rep in the education of patients/carers

| | Yes | No |
|---|---|---|
| Do you educate patients or carers on the subject of home enteral tube feeding? | | |

1. What subjects or topics does your education focus on? Explain.

# Home Enteral Tube Feeding
# Assessing the Practices & Attitudes of the Nutritional Company Representative

## Section 1. General information about the nutritional company representative

Date of interview _____

1. Subject number _____
2. Company of employment at present _____
3. Work base _____
4. Years working as nutritional company rep _____
5. Job title _____

6. Hospitals / Institutions covered by rep. _____

## Section 2. The role of the rep in the education of patients/carers

| | Yes | No |
|---|---|---|
| Do you educate patients or carers on the subject of home enteral tube feeding? | | |

**1.** What subjects or topics does your education focus on? Explain.

_____

_____

_____

_____

3. Where do you visit patients?

| | | |
|---|---|---|
| Home only | | |
| Hospital (before discharge) only | | |
| Both always | | |
| Either/depends | | |
| Other | | |

4. How long does it take you to educate a patient/carer, on average?

5. In nursing homes, what level of education do nurses have with respect to enteral feeding, in your opinion? (If answer is "it varies", then describe differences seen)

6. If educating nurses in a nursing home re enteral feeding, how many nurses do you educate at a time?

7. How often do you see patients during their education regarding tube feeding?

a) Before discharge

b) After discharge

8. How many *new* patients would you see for education on average per month?

9. Who normally contacts you to ask you to educate the patient \ carer regarding tube feeding? (if it "varies" explain how it varies)

## Section 3. Equipment

1. What is the average cost of

*a) Your company pump(s)*
1.
2.
3.

*b) Your company enteral feeds*
1.
2.
3.
4.

2. Other equipment available from your company for use in home enteral tube feeding?

3. How many pumps (i.e. *belonging to <u>your</u> company*) are in the community at present? (i.e. used or unused)

4. Do you know where all your pumps are located in the community at present?

Yes
No
Unsure

5. Do you provide manuals for patients or carers to keep after education is complete?

☐ Yes*
☐ No
☐ Sometimes

6. *If, "yes" what kinds of manuals do you provide?

a) For adult patients?

*Name* _____

*Cost* _____

b) For paediatric patients?

*Name* _____

*Cost* _____

c) For nursing staff?

*Name* _____

*Cost* _____

7. What happens to your pump when the patient using it dies or discontinues feeding?

_____

_____

## Section 4. Role of the Rep

1. How many patients on home enteral tube feeding does *your company* have contacts with at present?

_____

| | | At Home | In Nursing Homes |
|---|---|---|---|
| **a) Adults** | *Male* | | |
| | *Female* | | |
| **b) Children** | *Male* | | |
| | *Female* | | |

*Note: Quote an estimated number (est), exact number (ext), or don't know (DK)*

2. Do you liase with the following individuals? **Yes** **No**

| | | |
|---|---|---|
| **a) GP** | | |
| **b) PHN** | | |
| **c) Hospital dietitians** | | |
| **d) Community Pharmacists** | | |
| **e) Community Dietitians** | | |

3. Why do you need to liase with these individuals and in general do you contact them regarding patients, or do they contact you?

*a) GP's*

*b) PHN's*

*c) Hospital dietitians*

*d) Pharmacists*

*e) Community dietitians*

4. Do you ever change or review patients feeds (i.e. feeding schedule, type of feed, rate of feed, volume of feed used) in the community, in the course of your work?

5. What kinds of things would you/ have you changed about feeds?

6. How would you describe your "**role**" in relation to patients on home tube feeding or could you define the service you provide to patients/clients?

7. Do you liase with reps from other companies about patients?

8. Do you visit patients who use your pumps routinely, or only if someone contacts you to see them?

9. Are any written records kept on patients on home enteral tube feeding by company reps ?

10. What are the most common medical conditions requiring feeding that *your* patients have in the community?

**Section 5. Problems with HETF**

1. Do you see problems in the community with home enteral tube feeding?

2. What are the problems experienced by patients at home? List.

3. What are the problems experienced by patients in nursing homes? List.

4. What are the problems experienced during the discharging procedure? List.

5. Are you aware of other problems relating to home enteral tube feeding the community? List.

6. In your opinion, does the provision of HETF in Ireland need to be improved?

7. Do you have any ideas on how it could be improved?

8. In your opinion how do families cope generally with home enteral tube feeding?

9. In your opinion how do nursing homes cope generally with enteral tube feeding?

# General Practitioners and Home Enteral Nutrition

**Name (*optional*)**

---

**What is the current number of patients on your General Practice list? *Please tick.***

| | | | |
|---|---|---|---|
| **0 - 300** | ☐ | **600 - 700** | ☐ |
| **300 - 400** | ☐ | **700 - 800** | ☐ |
| **400 - 500** | ☐ | **800 - 900** | ☐ |
| **500 - 600** | ☐ | **900+** | ☐ |

**Does your work involve visits to nursing homes?**

**Yes** ☐ **No** ☐

**Have you *ever* had a patient in your care in the community, ( i.e. at home or in nursing homes / residential institutions), who was fed using artificial methods of feeding , i.e. NG (nasogastric) feeding, or PEG (percutaneous endoscopic gastrostomy) feeding?**

**Yes** ☐ **No** ☐

**Do you <u>*currently*</u> have a patient of this type in your care in the community?**

**Yes** ☐ **No** ☐

**What is the approximate number of *adult and paediatric* patients in your care currently receiving home nutrition support (i.e. at home or in nursing homes / residential institutions)?*Please tick.***

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| **Adults** | 0 | ☐ | 1 | ☐ | 2 | ☐ | 3 | ☐ | 3+ | ☐ |
| **Children** | 0 | ☐ | 1 | ☐ | 2 | ☐ | 3 | ☐ | 3+ | ☐ |

*Thank you for completing the questionnaire. Please return in the stamped addressed envelope provided. All responses to this questionnaire will be treated in confidence. Respondents names will not be linked to the information on our computer database.*