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Percutaneous Endoscopic Gastrostomy (PEG) at home: An exploratory study of family carers' experiences and the relationships between their perceptions and distress.

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by

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ABSTRACT

Background: As PEG techniques have improved, its use within the community has increased. There is limited research exploring the effects of PEG care on family members that carry out the process. Small qualitative studies have found that caring for an individual with a PEG can have psychosocial effects and can cause distress. Despite this finding there is little understanding of the psychological impact that carers' experience with the introduction of PEG. This study aims to understand the possible relationships between family carers' perceptions of the PEG and their psychological distress. **Method and Results:** This explorative cross sectional study measured carers' perceptions and distress. An open-ended questionnaire was also administered verbally. Data on 39 family carers was gathered. Approximately half had some level of clinical distress. The majority perceived that their relative's PEG would remain for a long time. Perceptions of negative PEG identity and emotional representations were found to relate to increased guilt. No relationships were found between perceptions and anxiety or depression. Carers reported that they often felt under prepared and alone when their relative was discharged with a PEG. In time carers described that they adapted and accepted the changes involved in home PEG care. **Conclusions:** The five perception constructs of the SRM appear to be relevant to PEG carers. Despite the lack of significant relationships between perceptions and distress, carers describe cognitive behavioural patterns within their descriptions of PEG experience. Methodological triangulation is used to discuss the findings and the rationale behind service suggestions are presented.

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Chapter One: Introduction

1.1 Malnutrition and Artificial Methods of Support

Patients with various underlying illnesses can become malnourished for a diverse number of reasons. Adequate dietary intake is very important with nutritional problems being responsible for undue mortality in some patients (Martyn, Winter, Coles & Edington, 1998; Todorovic, Russell, Stratton, Ward & Elia, 2003). Improving a patients' nutritional status can aide both clinical and psychological health (Keys, Brozek, Henschel, Mickelson & Taylor, 1950; Martyn, Hansen & Jen, 1984).

If a patient is malnourished due to inadequate or unsafe oral intake (e.g. dysphagia [an inability to swallow]), then non oral (artificial) methods of nutritional support may be required (National Institute of Clinical Excellence [NICE], 2006). Non oral methods can prevent further weight loss and improve weight gain in some patients (Elia, 1995). There are several artificial methods of nutritional support. These are incorporated within parenteral and enteral methods. Enteral methods involve the provision of nutrition through a tube into the gastrointestinal tract, parenteral administration involves intravenous delivery (American Society for Parenteral and Enteral Nutrition [A.S.P.E.N], 2005) Two commonly used enteral feeding methods include Nasogastric (NG) and Percutaneous Endoscopic Gastrostomy (PEG).

Enteral methods are preferred over parenteral methods where possible. This is because they are associated with fewer psychosocial and physical difficulties (NICE, 2006; Padilla & Grant, 1985). Enteral feeding also allows the possibility of reversal as there is less likelihood of gut atrophy (Lanza-Jacoby, Sitren, Stevenson, & Rosato, 1982).

Nasogastric methods of enteral feeding are more likely to be provided to patients who require short-term nutritional support (less than 4-6 weeks), as this is the least invasive method (NICE, 2006). O'Tool (2003) describes the nasogastric administration as a process where a tube, which enters the body through the nostril, instills liquid nutrition to the stomach for gastric decompression. If diagnosis suggests the patient will require longer term support it is unlikely that nasogastric feeding will be introduced / continued. This method has been found to be less physically and psychologically tolerable than PEG (Baeten & Hoefnagels, 1992).

1.2 The PEG Process

PEG provides nourishment that occurs via a tube at a stoma site, which leads either straight into the stomach or jejunum (Loser et al., 2005). Feeds are administered using either a pumping device (pump method) which propels feeds into the feeding tube, or relies on the force of gravity to discharge the feed from a syringe into the tube (bolus method). The endoscopic procedure of fitting a feeding tube was introduced in 1980 (Gauderer & Ponsky, 1980) and allows rapid placement (approximately 15 minutes) without invasive surgery. The tube is endoscopically inserted through the abdominal wall into the stomach and requires only local anesthesia or intravenous sedation (Gauderer & Ponsky, 1980; NICE, 2006). This technique has superseded open surgical techniques of inserting the tube, and has been found to be advantageous to both the patient and the health system (Loser et al, 2005; Loeser, Von Herz , K uchler, Rzehak & M uller, 2003). Advantages include economic benefits, comparatively low complication rates, reduced levels of discomfort and

relatively simple management (Loser, Wolters & Folsch, 1998; Riera, Sandiumenge, Calvo, Bordas, Alobid, Llach & Bernal 2002).

PEG supports people with a range of underlying illnesses / disorders. The British Artificial Nutritional Survey (BANS, 1999) defined these diagnoses as:

Cerebral Palsy, Congenital Handicap and Congenital Malformation, Cystic Fibrosis, Inborn Error of Metabolism, Cerebral Trauma, Faltering Growth, Cerebro-Vascular Disease, Cancer: Oesophageal, Oropharyngeal, gastric, head and neck and other, Neurological: Multiple Sclerosis, Parkinson's Disease, Motor Neurone Disease, Dementia and Respiratory: Emphysema and other Chronic Obstructive Disorders, Pulmonary disease. (BANS, 1999)

A PEG should only be recommended by a physician if the patient has a reasonable life expectancy (at least several months) (Loser et al, 2005; National Confidential Enquiry into Patient Outcome and Death [NCEPOD], 2004). Home Enteral Tube Feeding (HETF) allows patients to receive enteral nutrition at home. This is a popular choice with patients, possibly because they perceive that it will allow them to get on with everyday life and be with their family (Loeser et al, 2003). This may not be a realistic expectation as only a small percentage (14-16%) of patients fitted with a PEG will undertake usual everyday activities (Elia et al., 2001).

The provision of PEG in the home is continually on the increase, with a rise of approximately 10,000 patients using HETF in the United Kingdom between 2000 and 2002 (Glencorse, Meadows & Holden, 2003). PEG is the most common method of HETF with 84% of new patients being supported in this way (Glencorse et al, 2003).

1.3 Physiological Research of PEG Patients

The functional and physical consequences of PEG have been researched extensively. It is generally accepted that there are few complications associated with the technique (Gutt, Held, Paolucci, & Encke 1996). PEG has been found to permit a reduction in hospital stays compared with other forms of tube feeding (Marik & Zaloga, 2004; Pritchard, Duffy, Edington & Pang, 2006). As with all methods of HETF, PEG is not without physical complications and these include wound infections, separation of the stomach from the abdominal wall, bleeding, diarrhoea, aspiration, tube blockage / dislodgement, excoriation of the skin, and ischaemic pressure necrosis (Holmes, 1999; Roberge et al., 2000). Complications occur in between 2–57% of patients who are provided with enteral nutrition (Hinsdale et al., 1985; Waitzberg et al., 1986). The broad range of physical complications are assumed to be related to the nature of the population who have an array of underlying illnesses, pre treatment nutritional states and advancing age (Heitkemper & Shaver, 1989; Saunders, Carter, D'Silva, James, Bolton & Bardhan, 2000). Physical adjustments have been developed to address these complications (including changing formulas, taking medication, adjusting feed rates (Oley, 1997). Once patients have become established on the procedure the mortality rates associated with the PEG are low (0.3-1%) (Grant, Rudberg & Brody, 1998).

1.4 Psychosocial Research of PEG Patients

Quality of life is thought to involve three distinct domains of health; physical, psychological and social (Testa & Simonson, 1996). Thus, for an individual to have

adapted well to PEG intervention, there are other aspects of adjustment that need to be considered.

There has been a theoretical framework created by nursing therapies, which aims to take into account different types of research (Heitkemper & Shaver, 1989). This framework gives consideration of the factors associated with, or leading to, positive or negative patient adjustment to enteral feeding. The model purports that there are various risk factors and vulnerabilities that may bias the person to develop negative responses to enteral feeding.

The external risk factors arise from the environment and can be physical or social. Social risk factors include a lack of support and the inaccessibility to culturally acceptable food. A physical risk factor could involve an inability to use feeding equipment successfully, or a lack of food availability. Internal risk factors, which exist within the person, can also be assessed. Vulnerability factors are considered to be fixed (i.e. gender, age and disease state) or modifiable (psychological). These are described as anxiety, knowledge deficit and tension. 'Environmental risk factors' and 'Modifiable Vulnerability factors' are areas that can be addressed to improve adaptation (Heitkemper & Shaver, 1989).

Research has concentrated mainly on the pathological physical responses. Emotional responses are less well represented (Heitkemper & Shaver, 1989). Depression and anger are two of the emotional responses to tube feeding in Heitkemper & Shaver's (1989) work. Later studies have indicated that approximately 25% of patients who have PEG, experience depression (Rickman, 1998 [22%]); Roberge et al., 2000 [29%]). The psychosocial factors that appear to be implicated in these reactions include issues surrounding: body image (Gilchrist, Phillips, Odgers & Hoogendorp, 1985; Grindel,

Whitmer & Barsevice, 1996; Oley, 1997; Padilla & Grant, 1985; Rickman, 1998; Roberge et al., 2000); sexual interaction (Grindel et al, 1996; Holmes, 2004; Oley, 1997; Rickman, 1998), social interaction (Rickman, 1998; Roberge et al., 2000); and loss of the ability to eat, including the full experience of food such as social interaction and taste (Brotherton, Abbott & Aggett, 2006; Oley, 1997; Padilla & Grant, 1985; Rains, 1981; Roberge et al., 2000). Heitkemper & Shaver (1989) found other demographic factors, such as amount of time since the initiation of enteral feeding and also that the disease process affected such responses.

Research of behavioural adaptation was found to be particularly limited (Heitkemper & Shaver, 1989). Behavioural adaptations are placed into two categories: physical adaptations (e.g. changes in sleep patterns) and social adaptations (e.g. changes in role or dependency). This kind of research is routine in health psychology, to highlight the effect of disease and interventions. Whilst it is recognised that the presence of a feeding tube suppresses everyday activities such as being house bound (Elia et al, 2001), the psychological issues are less researched and do not seem to be fully understood.

1.4.1 Limitations of Current Research

As described above there are several avenues of research into PEG feeding. Whilst the research clearly illustrates that PEG is a clinically efficient way of providing nutrition to malnourished patients, the evidence indicates this method is not as sound in its psychological tolerance (Liley & Manthorpe, 2003; Roberge et al., 2000).

There are several studies which discuss the psychosocial impacts of nutritional support for the patient. Much of this research has been conducted abroad in various

different countries which limits its generalisability to the United Kingdom, due to differences in health service systems.

Methodological difficulties limit generalisation. Many studies have concentrated on various types of nutritional support methods using an umbrella term of 'artificial feeding' or 'enteral feeding', which have different demands and requirements. Few concentrate exclusively on patients being nourished using one particular method (Loeser et al, 2003; Roberge et al., 2000). This inclusion criterion has also allowed samples, which do not distinguish between those who are tube fed at home from those who are tube fed in hospital or residential settings (Rickman, 1998).

The psychosocial impact of enteral feeding for patients has been explored using quality of life measures (Loeser et al, 2003; Roberge et al., 2000; Schneider et al., 2000) including the EORTC H, N35 (Bjordal et al., 1994), Quality of life Index (Spitzer, Dobson, Hall, et al, 1981), and The Karnofsky index (Karnofsky & Burchenal, 1949). Such instruments do not seem to be ideal tools for measuring an individual's adaptation to PEG. Whilst these aim to measure quality of life (QoL) which is influenced by experiences, beliefs, expectations and perceptions (Testa & Simonson, 1996) the conceptual bases for these measures are still being developed due to difficulties in defining what constitutes QoL (Abbott, Webb & Dodd, 1997). This has caused differences between the measures subscale domains which are used to measure QoL (Abbott et al, 1997). The measures are also non specific to the PEG process and are rigid, which could have implications in a heterogeneous population where the effect of other factors such as treatment processes or life events need to be controlled for. QoL has been found to be lower in HETF patients than those matched for age and sex from the general population, yet it has been found that one of the predictors

of QoL in patients fed using artificial methods is their underlying disease (Malcolm, Robson, Vnderveen & O'Neil, 1980; Schneider et al, 2000). These measures do not seem to be able to distinguish the psychosocial effects of other treatment modalities, such as chemotherapy or life events such as previous care responsibilities from that of the PEG. This is because the score is compared to a 'norm' population rather than a population of chronically ill individuals (Liley, 2001).

Other issues that affect the reliability of past research include little regularity in the data collection techniques. Roberge et al (2000) points out that measures previously used to research the patient on enteral feeding's QoL were not specifically developed for this population and had not been validated.

More recent attempts to explore QoL in patients that are PEG fed have used qualitative methods taking an experiential approach. Qualitative interviews involve questions on 'feelings' towards PEG feeding (Brotherton et al, 2006; Liley, 2000). Due to the rigidity of quantitative measures, the qualitative approach was felt to be more useful (Brotherton et al, 2006; Liley, 2001). However, this approach is also limited as it relies on the subjective reports of symptoms (Peteet, Mederios, Slavin & Walsh-Burke, 1981; Rains, 1981; Sami, Saint-Aubert, Szawlowski, Astre & Joyeux, 1990). It is therefore hoped that qualitative work may allow the development of a more discriminant and meaningful tool (Brotherton et al, 2006).

1.5 Shift from Acute to Community Care

In the previously known East Yorkshire Community NHS Trust there has been an increase from 6 patients receiving HETF in 1995 to 117 HETF patients in the merged Hull and East Yorkshire Community Health NHS Trust at the end of 2000 (Liley, 2001).

The change from hospital care to home environments is partially due to a result of the technical and medical advances in the methods of PEG feeding. Progression has allowed a reduction in the number of physical complications that occur as a result of the procedure, making HETF more feasible. Advances have also allowed the process to be simpler and more practical for home use. Political and economic drivers are also responsible for the care shift supporting the increased use of HETF. It is estimated that the NHS saved approximately £200 million by 1994 when 3,200 patients received enteral feeding at home rather than remaining in hospital (Liley, 2001). Savings were attributed to factors such as bed occupancy costs (Dhoot, Georgieva, Grottrup, Mahdavian, Poh & Hindle, 1994; Elia, 1995).

1.6 Carers

The care that some family members provide in order for their relatives to continue living at home would previously have been considered so involved that it was the responsibility of acute hospital care (Liley, 2001; Pickard, Jacobs & Kirk, 2003).

It was noted in Liley and Manthorpe's (2003) study that patients and their carers had different perspectives of the tolerance to the tube. Brotherton et al's (2006) study also found carers were more negative than the patient in their perceptions of QoL since their relative had been fitted with a PEG. It was also found that 22% more carers than patients

felt that they required additional care support around PEG (Rickman, 1998). This appears to suggest high levels of carer burden, which suggests that study of them in their own right is required. However, many studies do not discriminate between descriptions given by the patient and that which has been given by the carer (Loeser et al, 2003). Further, the opinions of paid carers are not distinguished from those of family carers (Liley & Manthorpe, 2003).

1.6.1 Government Policy

The NHS and Community Act followed by subsequent government policy have striven for efficiency and value for money (Audit Commission, 2007; Department of Health [DoH], 1990; Gershon, 2004). Since these initiatives, more patients, who are judged to be competent or have competent family, are discharged to the community whilst being dependent on technology for ongoing support (Liley, 2001). This move can only be successful if the patient can be efficiently cared for and more costs are not incurred by the deteriorating health of the patient or the development of ill health in the family carer. Hence it is important to consider the patients' families involved in caring. Currently policies around decision making highlight the need to consider the patient's own wishes, yet the decision of the future carer does not seem to be weighted with as much importance (Loeser & Muller, 1998; Niv & Abuksis, 2002).

At the last UK Census in 2001 5.9 million informal carers (unpaid) were recorded (Office for National Statistics [ONS], 2001). Most provided care for less than 20 hours a week but approximately 20% reported a provision of 50 hours or more (ONS, 2001). Family members, who act as carers, provide support and care as part of an emotional

relationship. Caring may provide a means of expressing their feelings for the patient or may be because the family member believes that it is their duty (Pickard et al, 2003). This family care is not time limited and will be delivered regardless of environment or circumstance. Care in the community has been reliant on this type of carer who is accountable for the bulk of care giving (DoH, 1989).

Government policy recognises the difficulties with which carers are faced and has developed guidelines to reiterate the importance of supporting carers (Pickard et al, 2003). All national service frameworks published to date have stressed the need to support carers (Audit Commission, 2000; DoH, 1995; 1999a; 1999b; 2001; 2004). It is acknowledged that the user and carer experiences should be explored and understood in order to allow the provision of useful provision.

Since the introduction of 'The Carers' (Recognition and Services) Act of 1995 all family carers are entitled to an assessment of need, which provides established pathways of gaining extra help in terms of respite and care. Subsequent policies have echoed the need for carers to have a break from caring.

'A break from caring is invaluable in reducing the psychological and emotional stress faced by many carers. Access to support services and breaks can also help carers to continue providing the support they give to a sick, disabled or elderly person.'

(DoH, 1999a; p.58)

1.6.2 Carer Distress

Current research indicates that the carers' health can be affected negatively by their responsibilities. Such evidence indicates that carers require support (Victor, 1997). The Princess Royal Trust for Carers concurs with this research and shows that the carer may

suffer physically, mentally, socially and financially, if adequate support is not provided (Shooter, 2004).

Literature relating to cancer patients states that care givers not only take on physical care demands but that they also assume roles which would have previously been the responsibility of the patient (Rose, 1998). In some cases the introduction of the PEG may coincide with the occurrence of the illness, PEG being a dimension of the changes involved. For others it becomes an additional care demand that may shift roles and requirements. Hogan, Lisy, Savannah, Henry, Kuo and Fisher (2004) report that family carers' roles change and that this can have a negative affect upon them. Regardless of the negative consequences, such as changes in living arrangements and employment, carers continue to provide their relative with the support they require.

Symptoms, dependency levels and needs for assistance have been found to contribute to carers' psychological reactions to an illness over time (Oberst, Thomas, Gass & Ward, 1989). The introduction of PEG may have an impact on all of these factors, resulting in the PEG itself having a direct impact on the carer's mental health.

1.6.3 The Nature of Caregiver Distress

One-third to one-half of family carers experience significant psychological distress (Oyebode, 2003). Anxiety is one form of distress that is known to result from care giving (Oyebode, 2003). The onset of clinical anxiety often occurs when individuals are experiencing stressful life circumstances, where the individual perceives there is a danger to themselves or their loved ones (Hawton, Salkovskis, Kirk & Clark, 1998). The danger that the person perceives in their current circumstances seems to result in the anxious

response. This reaction is often exaggerated due to misperceptions of the danger involved in their circumstances (Beck, Emery & Greenberg, 1985). Carer's anxiety is rated as one of the most severe problems in informal cancer carers (Ramirez, Addington-Hall & Richards, 1998). In some carer populations the prevalence is reported to be almost 50% (Ramirez et al, 1998) and this may be related to perceptions of their current circumstances.

Guilt is a common form of emotional distress and may be particularly relevant to family care relationships due to its social nature (Baumeister, Stillwell & Heatherton, 1994). Strong forms of this emotional distress are most likely to arise and continue in relationships where there is an expectation of mutual concern. It is in these relationships where humans' innate response to others' suffering can result in guilt (Baumeister, Stillwell & Heatherton, 1994; Hoffman, 1982).

Depression disturbs many aspects of daily functioning including behavioural, motivational, affective, cognitive and somatic performance (Beck et al., 1979). There does not seem to be any single causal or maintaining factor that can explain depression. Instead there seem to be a variety of variables that can be implicated, including environmental and psychosocial factors (Hawton et al, 2004). The lifestyle changes involved in caregiving may explain the high prevalence reports of depression in carers (39% in informal cancer carers) (Oyebode, 2003; Ramirez et al, 1998).

1.7 Research on Carers of PEG Patients

Carer burden was a strong theme in Brotherton et al's (2006) study of PEG patient carers. Research indicates that enteral feeding can have significant effects on the carer's everyday life. This may be because the demands placed on these carers are particularly time

intensive (Verhoef & Van Rosendaal, 2001) and involve a level of care complexity that necessitates the rapid development of skills in order to cope (Brotherton et al, 2006; Liley, 2001).

Some carers were found to continually assess and monitor the patient's weight, adjusting the prescribed feeding regimes according to their observations. Whilst family carers are provided with technical training to aide them with the provision of such care, the formal programme may not prepare the carer for the psychological and physical demands of PEG feeding (Liley, 2001).

Pedersen, Parson & Dewey's (2004) study showed that parents who had children fed via PEG, had higher levels of stress than those parents who cared for children with enduring illnesses such as diabetes mellitus. Carers of adults with PEG also reported feeling guilty, stressed and depressed with half Rickman's (1998) sample being afflicted. Over half of the Rickman (1998) sample of carers reported feeling anxious and all stated that they were experiencing a feeling of loss since the PEG placement. Half of Rickman's (1998) carers also reported feeling sadness. It seems that the psychological morbidity of carers is equal to or greater than that of the patients in all of these areas.

Rickman (1998) also identified that whilst a third of carers reported being distressed with the outcome of PEG, none of the patients in the sample felt this way. This finding was supported in a later discovery. Whilst all patients agreed they would have PEG again, 30% of the caregivers said that they would not want the same decision to be made (Verhoef & Van Rosendaal, 2001).

1.8 Implicated Psychosocial Areas of Impact for PEG Patient Carers

A review of the research seems to indicate that some of the issues (issues around food and eating, sexuality, relationship changes, body image and socialising), which are known to affect efficient patient adaptation to HETF, may also affect the family carers (Brotherton et al, 2006; Liley, 2001).

1.8.1 Eating and the Meaning of Food

Good practice guidance has emphasised the importance of mealtimes in providing mutual enjoyment for the patient and carer (Crawley, 2002). Even in those patients who are unable to eat independently there can be intimate and interactive experiences for both individuals involved (Bayley, 2000; Manthorpe & Watson, 2003).

There is evidence to suggest that individuals with PEG placements are less likely to engage in social nourishment ('hooking up' in public). Roberge et al (2000) found that HETF was reported to reduce social interaction opportunities, such as participating in mealtimes at children, family and friends homes. Tube feeding can reduce the likelihood of patient involvement at mealtimes, not only because they are attaining nourishment in an unfamiliar manner but also because they are 'feeding' at unusual times.

Two qualitative studies suggest that when a patient returns home with a PEG, their carer will also experience a change in their eating habits (Brotherton et al, 2006; Liley, 2001). The carer's self report suggests that food is linked to guilty feelings about their ability to eat and enjoy nourishment (Liley, 2001).

The PEG patient's inability to participate in meals (including those associated with seasonal / other celebrations) also seems to affect the carer. Research suggests that the carer

no longer experiences food as a marker of time, or as a pleasurable experience involving social interactions. This loss appeared to be extremely relevant to the carer (Brotherton et al, 2006; Liley, 2001).

The inextricable link between food and care, where the provision of nutrition is understood to bring the receiver pleasure, health and comfort, may also add to the significance of this area for PEG patient carers. This conceptualisation of food is developed in childhood and is consolidated throughout adult life (Lipman, 2003). Whilst Liley (2001) states that PEG is not the cause of the inability to eat, the return home after a PEG placement may result in the carer losing an important caring strategy.

This loss may be under prepared for, as the medical terminology 'enteral nutrition' or 'nutritional support' has the potential to occlude the carer from the possible difficulties associated with the loss of food in the caring process (Lipman, 2003). Such terms may build on the carers' food associations, creating positive connotations about the intervention including nurturing, nourishing and supporting (Lipman, 2003). As discussed, the experience of being discharged with the PEG may have converse connotations for carers. This may be due to the discrepancy between the understanding of PEG and the reality of the experience. This may explain the findings that some carers feel they have made the wrong decision in allowing the procedure to go ahead (Verhoef & Van Rosendaal, 2001).

1.8.2 Appearance

The presence of tubing, the insertion site and other equipment associated with a gastrostomy feeding tube is known to affect patient's body image (Gilchrist et al, 1985; Oley, 1997; Rickman, 1998; Roberge et al., 2000). Jenks, Morin & Tomaselli (1997)

defines body image as the individual's perception of their physical appearance and function of their body. The addition of an enteral feeding tube produces a change in body appearance and function. Altered body image occurs when changes in the body ideal, reality or presentation is caused by disease, injury, or disability overwhelms coping strategies (Price, 1995).

Society places huge importance on having a body which is aesthetically and functionally pleasing, causing body image to be an important part of everyday life (Salter, 1997). Similarly carers may be affected by the changes to their relative appearance. In aesthetic procedures, surgery has been found to impact not only on the individual's appearance but also the perceptions of them by others (Kalick, 1979). There is little research in the area of medical surgical interventions and partners perceptions. Much of the cancer research describes that the reduction in sexual activity is due to patient issues (physical difficulties in love making, a lack of desire) or the partners fear at potentially hurting the patient (Finger, 2006). Whilst it is mentioned that the patient may feel that their partner is "put off" due to changes in appearance, there appears to be little research where the reality of this assumption is tested.

Social difficulties can arise as a result of alterations in body image. With regards to PEG patients these difficulties appear to be contributed to by a lack of awareness in the general public. A consumer focus group identified that HETF can cause misattributions about function, instigating staring and questioning about the equipment. Patients avoid being perceived as disabled and describe being reluctant to be in public because they feel that they would not be able to fit in (Newell, 1999; Oley, 1997).

Whilst there is some description of how the HETF patient feels the general public perceive the PEG, there is no information that this researcher could find regarding the family carers' perception of their relatives' appearance after PEG placement.

1.8.3 Socialising

Family carers may be reluctant to leave the PEG fed individual because of anxieties surrounding the technological aspects of PEG. One-third of Rickman's (1998) sample reported anxiety about the therapy related complications of PEG feeding. This anxiety may prevent carers enjoying time apart from their relative. Rickman (1998) found that all carers involved in her study felt they had experienced loss of time for themselves since the introduction of enteral nutrition.

It is not solely feelings of anxiety which inhibit the carer's opportunity to have time to themselves or with others. PEG is a huge commitment in terms of the carer's time (Pedersen et al, 2004; Rickman, 1998; Verhoef & Van Rosendaal, 2001). The feeding regime requires the carer to be available to set up the feeds and problem solve for the period whilst the patient is hooked up. Over a half of the caregivers provided at least 15 hours of care per week. Verhoef & Van Rosendaal (2001) felt that this level of burden may not have been anticipated by the caregivers and it was the time pressures that the carer found to be the most negative aspects of the PEG experience.

Whilst government policies aim to support carers in these situations, there are still high levels of psychological morbidity and respite difficulties (Rickman, 1998). Carers' reports indicate that there are considerable levels of unmet needs in terms of support from health professionals.

The carer of a patient with PEG can often find that they are more knowledgeable than many health care professionals (Liley, 2001; Pickard et al, 2003). This means that finding individuals who have the necessary knowledge of the PEG procedure to substitute the family carer is very difficult. Reports from carers who recognised poor comparisons of care in respite revealed that the use of available provisions caused further levels of distress (Rickman, 1998).

Preferable, non formal alternatives of care are also unavailable to carers, with family and friends untrained to cope with PEG procedures and unable to cope should any complication arise. Evidence suggests that relatives previously involved in care before the introduction of other forms of artificial feeding became anxious in the presence of equipment involved and began avoiding the individual (Perl et al., 1980). Pedersen et al's (2004) study highlights these issues, noting that when technological support is introduced constant care demands are placed on the parent, and the level of support provided by the parent's social network is reduced, whilst the severity of the child's illness / disability remains.

As well as the inability to leave the patient due to anxieties about technology and time intensive regime, the carer may also feel unable to leave the house as a result of all of the equipment involved in the PEG procedure (Oley, 1997). This was often noted to prevent families going out together or taking vacations (Brotherton et al, 2006; Grindel et al, 1996; Liley, 2001; Rickman, 1998).

As well as the practical issues surrounding the carers' ability to leave the home and socialise there also appear to be psychological factors involved. As discussed above, many patients with a PEG experience a change in their body image which may affect their desire

to socialise. It is possible that if the carer is reluctant to leave the patient, due to anxieties surrounding the technology, the carer also becomes unable to leave the home.

As a result, many people who care for patients with PEG spend most of their day caring for their relative without suitable respite. There is little or no opportunity for them to have a break, and this may have implications on caregivers' stress levels.

1.8.4 Relationships Between the Carer and Others

Time restrictions and reduced opportunities to leave the home, may also reduce the carers' ability to contact their family and friends. Roberge et al's (2000) found that 15% of HETF patients felt they had become detached from their family. Less is known about the effect on carers' social network, but limited time away from care giving and limited socialising opportunities, are likely to have an impact on their relationships. These factors also restrict carers' ability to attend employment (Rickman, 1998), further reducing the carers social network. Such factors may result in social exclusion.

1.8.5 Relationships Between the Carer and the PEG Patient

Smith, Giefer & Bieker (1991) found that the relationships and roles of individuals and the family carers changed with the introduction of parenteral feeding. This was beyond the changes that had taken place as a result of the underlying illness. It is less clear, if or how, the carer's relationship with their relative changes once a PEG is introduced.

1.8.6 Sexual Relationships

The issue of sexuality has been considered with the aim of gaining a greater depth of understanding regarding the carer's perception of a loved one's appearance and their relationship with them after a PEG placement.

Holmes (2004) found that some individuals who are artificially fed report sexual dysfunction and loss of libido, which can cause reductions in intimate contact (Grindel et al, 1996; Rickman, 1998). This can be a significant issue for the individual with the PEG placement and their partner, as sexual relations can be a fundamental part of a person's sense of self and everyday life (Oley, 1997; Weerakoon, 2001). Whilst the western cultures' media portrays sex as being predominantly an issue for young, non-disabled populations, equal rights suggest that all individuals be entitled to a full right for sexual relations (Weerakoon, 2001).

Many of the concerns described to be associated with a reduction in sexual initiation for patients, (including fears of dislodging the equipment or tangling the tubing during sexual activity) may equally affect the spouse carer (Oley, 1997, Rickman, 1998). Currently there is limited literature on the perspective of the partner, but emerging explanations appear to be related to feelings about the equipment (Oley, 1997; Rickman, 1998).

Sexuality and sexual function are often 'hidden' problems in technology-dependent patients with physicians being found to neglect discussion of sexual issues at the time of discharge (Oley, 1997; Weerakoon, 2001). It is probable that this issue is frequently overlooked by physicians because of the other in-depth medical issues and technology training that is being addressed at this time (Oley, 1998). It is likely that the generation of more appropriate and valid information regarding sexual issues would allow the physician

to support couples by highlighting potential difficulties and problem solving possibilities (Oley, 1997; Weerakoon, 2001).

1.9 PEG Carer Research Limitations

Whilst psychosocial areas of concern for carers can be speculated upon using information drawn from PEG patient research and other areas, the issues discussed above can only arguably be implicated in the caring experience. They have not all been specifically denoted by any study identified by the researcher.

The review of the literature has indicated that available research in this area is limited. Some studies include carers when patients are unable to participate. This may affect how they participate (possibly giving an account of how they believe the PEG affects the patient rather than their own experiences) (Schneider et al, 2000). Whilst research of children with PEG has involved studies dedicated to family carers (Holden et al., 1991; Michaelis & Warzak, 1992; Pedersen et al, 2004), there are no identified studies which are dedicated purely to the carers of adult patients with a PEG. Studies which involve patients and carers have only involved small sample numbers from both populations and often do not distinguish between paid and family carers (Liley, 2001; Rickman, 1998; Verhoef & Van Rosendaal, 2001).

The current limitations in research may impact on national and local guidelines, which concentrate on the needs of the patient, using carers as an extension of hospital care, training them in technical methods. There is little awareness of the effects on carers and their emotional needs have been largely ignored (Liley, 2001). As more patients are discharged to the community, whilst being dependent on technology for ongoing support, a

further understanding of the psychosocial issues experienced would be useful, given the indications of emotional disturbance in carers' self reports. To date, as far as this author is aware, there is no other study which explores the experience of the PEG family carers' distress using a psychological model.

1.10 Models of Caregiver Distress

In accordance with other stress theories (Lazarus, 1990; Lazarus & Folkman, 1984), care giving stress process models incorporate appraisal, coping resources and methods of coping (Knussen, Tolson, Swan, Stott & Brogan, 2005). Pearlin Mullan, Semple & Skaff (1990) model was developed from work with carers of individuals with dementia, but has been adapted to gain an experiential understanding of people with different care giving circumstances (Pearlin et al, 1990).

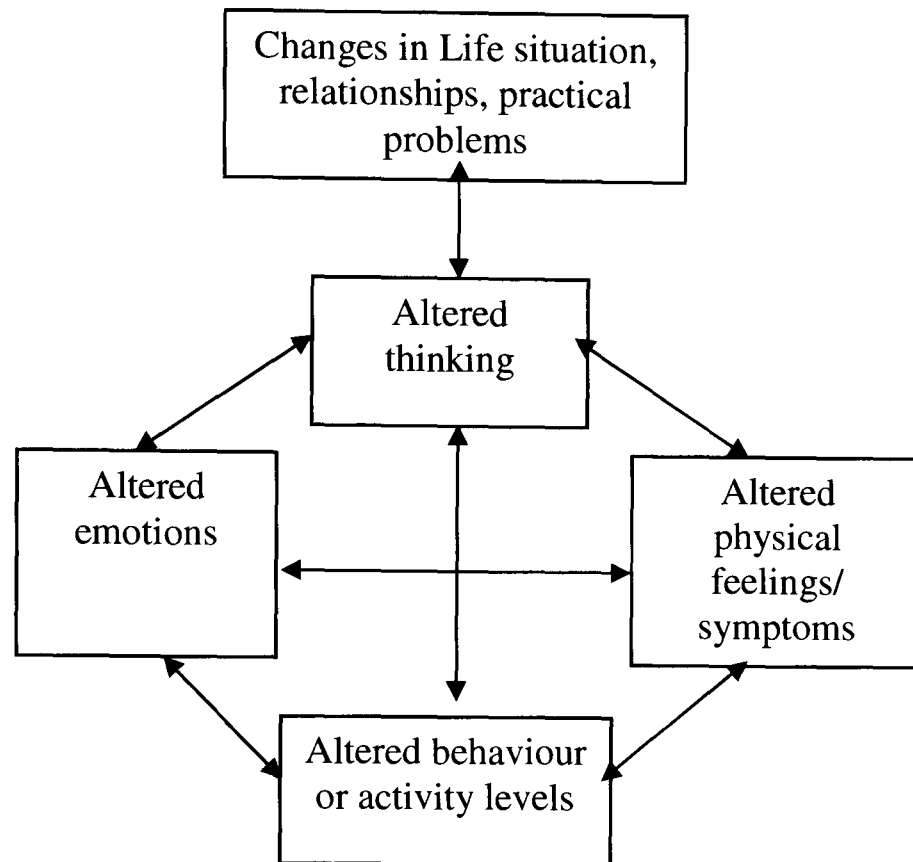
The characteristics of the patient are understandably a central focus of caregiver stress process models. Such characteristics include the underlying illness and the level of physical dependency. Pearlin et al (1990), termed these as 'objective' primary stressors. This type of stressor has been found to directly influence carer well-being (Alspaugh, Stephens, Townsend, Zarit & Greene, 1999; Desbiens, Mueller-Rizner, Virnig & Lynn, 2001). Objective stressors can also affect carers' well-being indirectly. The caregiver's appraisal or perception, and reaction to 'objective stressors', is also known as 'subjective stressors'. This pathway of affect is also predicted by the Lazarus model (Goode, Haley, Roth & Ford, 1998; Joyce, Leese & Szmukler, 2000).

1.11 Cognitive Behavioural Perspectives

The cognitive behavioural model of understanding is increasingly popular within clinical interventions (Williams & Garland, 2002). In essence the approach is a psycho educational style of psychotherapy, which has a clear underlying model (Williams & Garland, 2002). The key cognitive behavioural principle is that people's perceptions of their current situation affect their emotional and physical feelings, impacting on their behaviour (Garland, Fox & Williams, 2002).

Cognitive behavioural interpretation of distress appears to link in with Pearlin et al's (1990) model of carer distress. The cognitive behavioural model regards the 'target problem' to be 'unhelpful thinking', rather than simply the objective stressor (Williams & Garland, 2002). Thus, if a carer has very negative perceptions of their relatives PEG, this may be regarded as influencing their distress. A cognitive behavioural approach would therefore work with an individual's perception of the PEG with the aim of reducing distress.

The 'Five Area Model' (see figure 1.1) (Williams, 2001) is a cognitive behavioural model of distress, which illustrates the influence of life situation, relationship and practical problems on thoughts, feelings and emotions. Using this interpretation, the introduction of PEG (as an isolated factor), like other problems or life situations, can have a huge impact for the carer, affecting how they think about the PEG. Negative cognitive representations of the PEG may have an impact on their emotional and physical state. It is therefore possible that the carer's perception of this medical intervention can influence their levels of distress.

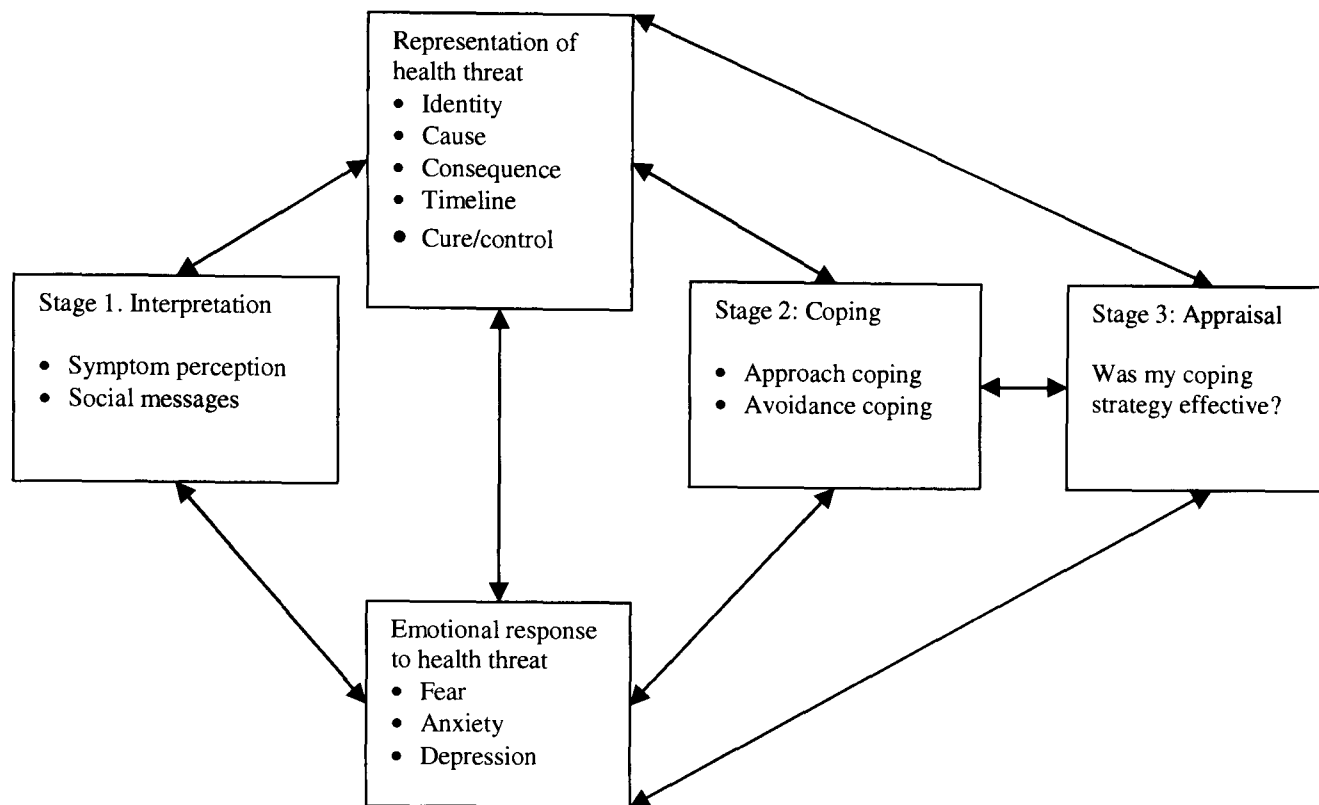
Figure 1.1 Williams' (2001). Five Areas Model of Distress

Leventhal, Meyer and Nerenz's (1980) Self Regulation Model highlights the link between thoughts, feelings and behaviour. This is described in a parallel processing relationship of cognitions and emotions; the way that the carer thinks about their relative's illness influences their emotional state, and the way they behave in order to cope.

1.12 Self Regulation Model (SRM)

The SRM is a health psychology model, grounded on problem solving frameworks. In this model, illnesses are understood as problems. The illness causes a change in the individual's equilibrium from their 'normal' healthy status. The model is comprised of three stages; interpretation, coping and appraisal. The use of these stages persists until coping has been assessed as successful and a new equilibrium is achieved (Ogden, 2000). This model is portrayed in Figure 1.2.

Figure 1.2 Leventhal et al's (1980, 1997) Self Regulation Model (SRM)



The SRM was developed through understandings of illness representations (Leventhal et al., 1980, 1997). Illness representations are the cognitive conceptions of the condition, which create a framework that provides the individual with a personal understanding of their illness. Illness schemas are comprised of cognitive representations and can be defined as:

A distinct, meaningfully integrated cognitive structure that encompasses (a) a belief in the relatedness of a variety of physiological and psychological functions that may or may not be objectively be accurate, (b) a cluster of sensations, symptoms, emotions and physical limitations in keeping with that belief, (c) a naïve theory about the mechanisms that underlie the relatedness of the elements identified in (b) and (d) implicit or explicit prescriptions for corrective action. (Lacroix, 1991, p.197)

According to the most recent revision of the SRM, illnesses are interpreted through the development of cognitive representations on the following five dimensions; 'Timeline' (duration), 'Consequence', 'Identity' (symptoms and labels), and 'Causes' and the latterly added 'Controllability' component (Lau & Hartmann, 1983). These components were

identified through multidimensional scaling of symptoms, illness labels (Penrod, 1980) and open ended interviews. Factorial methods suggest that each component feature is independent yet research indicates that they are inter-related (i.e. changes in one perceptual dimension implicates changes in others).

Initial work, influential in the development of this model, suggests independent processing of cognitive and emotional representations. The nature of the cognitive understanding 'illness representations' has, however, been found to affect the individuals' emotional response to their illness. The combination of emotional and cognitive representations of the illness affects coping (Ogden, 2000). Coping strategies are used by the individual to try to return to a 'normal' state (Ogden, 2000). Appraisal then aims to determine whether coping has been useful and whether to continue coping in this manner or to select another strategy.

Family carers of patients with a PEG have received limited attention within research and government policy. Their thoughts surrounding PEG are not clearly understood. Despite a thorough review of the literature, there does not appear to be a psychological model which fits neatly with the circumstances of this population and would allow for the exploration of carers perceptions of their relative's PEG. Despite PEG being a medical intervention, the SRM's conceptualisation of illness seemed to be a useful framework for exploring PEG perceptions and distress. This was more fitting than the model's interpretation of medical interventions (as a health related behaviour or a coping response). The carer's perception of the PEG intervention, using Lacroix's (1991) definition of an illness schema, could feasibly be perceived in a similar manner to an illness as their relative's PEG appears to have many similar qualities. PEG carer research to date suggests

that this may include changes in the carer's thoughts about their relative's physical and psychological functioning as well as the additional symptoms that may result from the new feeding process. The application of this model was also felt to be useful given that the emerging research suggests that carers conceptualise the introduction of PEG as negative, this is akin to early perceptions of illness (Clipp & George, 2006; Petersen, Kedia, Davis, Newman & Temple, 2006). However, it is important to note that research has also shown that PEG can be perceived as a welcomed relief from the increasingly difficult task of feeding (Brotherton, Abbott, Hurley & Aggett, 2007). It is therefore likely that there would be some difference between family carers' perceptions of an intervention such as PEG and an illness.

Aspects of the five dimensions of illness perceptions appear to fit with findings of the literature review of PEG carers (this is reflected in the items on the tool which measures illness perceptions, the Illness Perceptions Questionnaire – Revised (IPQ-R) (Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002) .The items of the Beliefs about Medicines Questionnaire (BMQ) (Horne & Weinman, 1994) which is the SRM's measure of medical interventions do not appear to be so fitting.

The SRM has also been found to be applicable to carers. Like the patient, research indicates that carers form cognitive representations of the illness of those they support (Heijmans, DeRidder & Bensing, 1999; Helder, Kaptein, Van Kempen, Weinman, Van Houwelingen & Roos, 2002). Leventhal's SRM (Leventhal et al, 1980; 1997) could therefore be used to explore the carer's adjustment to the PEG as an intervention. The perceptions that family carers hold about the PEG could be examined on a number of cognitive dimensions. These dimensions are as follows: the perception of the patient's PEG

associated symptoms, labelled as Identity; perceived duration of use of the PEG, labelled as Timeline; perceived personal consequences of the PEG e.g. socialising (Rickman, 1998); losses around food (Liley, 2001); appearance of their relative (Verhoef & Van Rosendaal, 2001); sexuality (Rickman, 1998); relationships (Rickman, 1998) labelled as Consequences; perceived personal control of the PEG, labelled as Personal Control; perceived emotional reactions to the PEG, labelled as Emotional Representation. As with illness representations, the cognitive representations of PEG may give the process meaning for the carer, which may affect emotional representation and their psychological tolerance to the PEG.

Exploring Carers' perceptions of PEG using the IPQ-R would suggest that high levels of identity and more serious perceived PEG consequences are associated with higher levels of depression and anxiety. Lower levels of control scores would also be assumed to be associated with more depression and anxiety. Such a pattern has been found to occur in a number of illness types (e.g. Heijmans, 1998, 1999; Moss-Morris, Petrie & Weinman, 1996; Petrie, Weinman, Sharpe & Buckley, 1996; Scharloo et al., 2000; Scharloo, Kaptein, Weinman, Willems & Rooijmans, 2000).

Chapter Two: Study Rationale

2.1 Summary

Since the shift of the complex care that PEG involves from acute hospital settings to community settings, family carers have had to undertake and adjust to complex care requirements (Liley, 2001; Pickard, 2003). Despite policy and service drives to provide support for family carers in their own right (DoH, 1999a), it is argued that the psychosocial needs of family carers are not properly understood (Grindel et al, 1996; Liley, 2001; Rains, 1981). This in turn might affect the support they receive in their day to day management of the PEG.

Leventhal's SRM (Leventhal et al, 1980, 1997) is, in this case, being used to explore the carer's adjustment to the PEG as an intervention. This can be examined in terms of a number of cognitive dimensions. This study aims to understand how carers cognitively represent the PEG and the meaning the carer attributes to its use. Relationships between these perceptions and levels of distress will be examined with the aim of gaining an understanding about why some carers are less able to adapt to caring for their relative with PEG and are more vulnerable to psychological morbidity.

2.2 Implications of Results

Gaining an understanding of the possible relationships between family carer perceptions of their relative's PEG and their psychological adjustment and distress related to their relatives PEG, may help to decrease the likelihood of psychological morbidity in this population. This could be achieved by using this study's findings to inform services and develop targeted needs-led assessment and psychosocial intervention.

Current research indicates that certain interventions can improve the well-being of PEG patients. It has been found that patients with parenteral placement who receive information are less likely to experience psychological morbidity (Smith, Curtas, Werkowitch, Kleinbeck & Howard, 2002) Gaining a greater understanding of carer experiences and perceptions will help to provide such information about the support that carers require, which could improve their psychological well-being. The development of interventions may also, in turn have a positive effect on the family's ability to provide care and support. In parenteral patient populations it was found that patients' depression abated as family carers began to manage (Padilla & Grant, 1985). Considering the impact of the carers' psychological well being on the patient, the aim of the study links closely with the recommendations of NCEPOD, which acknowledges that there is a need for more comprehensive national guidelines around PEG patient suitability. Only 18% of discharged patients' homes were visited prior to discharge and few had teams to offer recommended multidisciplinary teams for aftercare (Holmes, 1999).

2.3 Research Questions and Hypothesis

1. What are family carers' perceptions of their relatives' PEG?

This question aims to gain an understanding of the perceptions of PEG which are typically held by the family carer.

2. *How do family carers' perceptions of PEG influence their psychological distress (anxiety, depression and guilt)?*

Question two will examine the relationship between family carers' perceptions of their relatives PEG on the five cognitive dimensions and the different types of distress that are assessed for.

It is hypothesised that the carers' perceptions of: how long PEG feeding will continue (timeline), the amount of symptoms the patient experiences as a result of the PEG (identity), the amount of change in the carers' own life as a result of PEG feeding (consequence), the carer's feeling about the PEG (emotional representation) and the amount of control carers' have over the process of PEG feeding (personal control) will contribute to their level of distress.

3. *What is the phenomenological nature of family carers of PEG patient's perceptions and distress?*

The exploration of question three will involve the use of qualitative methodology.

2.4 Qualitative Methodology Rationale

Qualitative research aims to gain an understanding rather than testing hypotheses (Bryman, 1988). These methods allow the clinician to be close to the phenomena that they are studying. It provides a participant-based understanding of the experience and given the exploratory nature of this study, this methodology was felt to be useful (Barker, Pistrang & Elliot, 2002).

The population of PEG carers is varied in several aspects, including; age, gender, relationship to the patient, length of time caring for the patient. Patients fitted with a PEG are also heterogeneous in many respects (e.g. the nature of their underlying illness, the duration of the illness prior to the fitting). The combination of carer and patient variance supports a qualitative post modernist stance. This perspective posits epistemological pluralism; that there are multiple perspectives of a single event or circumstance, rather than a single objective truth and each perspective is equally valid (Barker et al, 2002).

The literature review illustrates that research dedicated to carers has used solely qualitative methods. This study aims to build upon this research using quantitative methods. However the review also identified a gap in current research, a psychological model has not previously been used to understand the experience of carers and that implicated areas identified have not been specifically addressed. This is the initial attempt at using Leventhal' s SRM (Leventhal et al, 1980, 1997) as a basis for exploration of this area of study.

2.5 Mixed Methods Design

Whilst qualitative research has its own distinct philosophy which contrasts from quantitative approaches, the combined use of the approaches can be complementary in several ways (Barker et al, 2002). The qualitative approach can facilitate the understanding of quantitative results (McLeod, 2001). This is the aim of methodological triangulation in the current study.

2.6 Qualitative Approaches; Grounded Theory and Phenomenology

The aim of Grounded Theory is to collect and analyse data from an area of study to allow the development of a theory which explains the human behaviour (Streubert-Speciale & Rinaldi-Carpenter, 2003). Stemming from a sociological background, the underlying theory is based upon, 'Symbolic Interactionism', which conveys the idea that the understanding of an object or situation determines how people interact.

Grounded theory explores the process of transition or change, seeking to understand the different stages that are involved (Strauss and Corbin, 1988). The researcher starts with a question which aims to understand the process through the participant. Questions evolve and change with the collection of data by giving full consideration to the meaning that the participants' attribute to the phenomena. (Streubert -Speciale & Rinaldi -Carpenter, 2003).

Whilst the introduction of PEG is a transitional period, this study aims to understand the perceptions and experiences of all carers, including those who have been involved in their care for several years and may not anticipate any further change in their circumstances. This factor suggests that a grounded theory approach may not be suitable for this study.

A phenomenological approach studies people's perceptions of their circumstances. An assumption within this stance is that perceptions engender people's thoughts, actions and behaviour. As a result it is the perception of the person's circumstances that is important rather than the factual details. This philosophy appears to fit with the research aims; to understand the carer's perceptions of the PEG and how the perceived meaning affects how they feel.

Whilst there have been some qualitative studies of carers of patients with a PEG, experiential understanding is limited. The phenomenological approach's flexibility allows identification and exploration of previously unknown concepts as it does not restrict the individual's responses. This approach also enables the researchers to form links between several differing components (Griffen & Phoenix 1994). This is useful for this population given the varying factors implicated in their experiences prior to and during PEG placement.

2.7 Interpretative Phenomenological Analysis

There are several different types of research methodology which are based on the phenomenological approach. Interpretive Phenomenological Analysis (IPA) (Smith, Jarman & Osborn, 1999) is a frequently used tool used in the analysis of health psychology research (Golsworthy & Coyle, 1999; Rhodes & Jakes, 2000). This approach generates experiential descriptions of how an important event or object is perceived and how it affects participants' lives (Shaw, 2001).

The process aims to understand the individual's perspective and experience of the phenomena that is being explored. Analysis then brings together this information with the shared contextual components found across participants' descriptions. This allows IPA to produce findings that are reflective of a human experience as they are dependent on the person and the environment that surrounds them (Reason and Rowan, 1981).

The analysis is not restricted as it is not focused on answering research questions or hypotheses. IPA aims to understand the meaning of the area being researched, through the participant's experience. This allows for the discovery of new phenomena.

The process of understanding another individual's 'internal world' is not possible without the involvement of the interpreter's conceptions (Smith et al, 1999). This complicates the analysis process, and can bias results, causing the account to become the researchers' rather than the participant's. However IPA can allow for this difficulty if reflexivity and strict self-monitoring techniques are followed. These techniques have been found to help to prevent biasing. Monitoring involves frequent referral to the original narrative. This process aims to prevent the researcher unconsciously surpassing what has been said by the participant. Reflexivity involves the researcher acknowledging the beliefs and values that they hold, which they feel could affect their interpretation. If these techniques are followed, findings are more likely to be seen as legitimate accounts by those who have knowledge of the focus area (Caelli, 2001). Thus, Heron (1996) suggests that findings are more likely to be valid if participants have been given the chance to confirm, or query interpretations.

IPA gives the researcher the possibility of gaining a thorough understanding of the experience and meanings that care givers attribute to the PEG. As this approach denotes the importance of perceptions and allows for individual variations, it may be useful in methodological triangulation with quantitative data.

Chapter Three: Method

3.1 Study Design

The nature of this research was explorative. It made use of a cross-sectional participant design and employed qualitative and quantitative methods. The study aimed to analyse relationships between self report, quantitative questionnaires on carer perception of PEG and their levels of anxiety, guilt and depression, to examine the research questions. These were completed by participants at a single measurement point.

A qualitative open-ended semi structured questionnaire, derived from the existing literature reviewed above, generated data on the personal consequences of the PEG. This provided experiential data, which assisted with interpretation of the quantitative data on perceptions.

3.2 Participants

The study group consisted of family members actively involved in the PEG patients care. Patients with a PEG were referred either before, or immediately after, PEG fitting, to dietetics. Participants involved in the study were known to dietitians through their relative's contact with services. Recruitment occurred within four Trusts across Britain, the names have been anonymised and are referred to as; Trust one, two, three and four through out. In addition, participants were recruited from Patients on Intravenous Naso-gastric and Nutrition Therapy (PINNT), a charitable support group for patients using enteral and parenteral methods of feeding and their families.

Participants were recruited between July 2006 and March 2007.

Criteria for entry were:

- A family member providing care
- Aged over 18 years
- Have good command of the English language (to avoid the need for translation)
- Undertake an active role in the PEG process. This is defined in the same manner as in Liley's (2001) study i.e. 'assisting in setting up and taking down the feed, starting and stopping the feeding pump (if applicable), and being involved in trouble shooting should problems with equipment arise'.

3.3 Measures

Table (1.1) gives a summary of all measures used in the study

3.3.1 Demographic Questionnaire

Participants filled out a questionnaire (see Appendix 1.1) which required them to answer questions on the following variables:

- Gender
- Age
- Relation to the person using PEG
- PEG patient's condition
- Decision making surrounding PEG
- Methods used to give the tube feed
- Nutrition the patient is able to take by the mouth
- Duration of patient's PEG use
- Duration of HETF

- Time devoted to care of relative
- Frequency of health and social care support

In order to respond, most questions required participants to select the category most applicable to their situation. This questionnaire was based on Liley's (2001) demographic questionnaire.

3.3.2 Measures of Independent Variables

(Perceptions; Identity, Emotional Representation, Personal Control, Consequences, Timeline)

- The Illness Perception Questionnaire – Revised (IPQ – R) *(Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002)*

This is a quantitative measure commonly used in health psychology to measure individual's 'illness representations' as defined in Leventhal's self regulatory model (Leventhal et al, 1980, 1997).

Structure: The revised version of the IPQ is composed of nine sub-categories (Identity, Consequences, Timeline, Cyclical Timeline, Personal Control, Treatment Control, Illness Coherence, Emotional Representation and Causes), which measure the components of illness representations.

Information gathered from the literature review suggested that five subscales were particularly relevant to PEG (Identity, Consequences, Timeline, Personal Control and Emotional Representation). To minimise the number of questionnaire items that participants received, these components were the focus of this study.

This study aimed to use the IPQ-R structure to measure the five aspects of the family carer's perception of their relative's PEG (see Appendix 1.2 for PEG Perception Questionnaire). Items from the relevant subscales were adapted and further items were

added, which focused on consequences (outlined in the introduction). The latter items were not scored but aimed to provide a quantitative measure of specific areas of consequence perception.

Identity –sub category: The 'Identity' sub-category scale lists a number of physical symptoms. The IPQ-R list was replaced with symptoms commonly associated with the PEG process (Holmes, 1999 & Roberge et al., 2000). Participants were asked to identify whether their relative had experienced each of the symptoms in the last month by giving either a yes or no response. They were further asked whether they perceived the symptom to be associated to the PEG.

Identity scores were deduced by summing the number of yes rated responses to PEG associated symptoms. High scores suggest negative Identity beliefs, i.e. a number of symptoms associated with the PEG.

Other sub-categories: Items related to the remaining four components were assessed using a five point Likert scale comprised of 'strongly disagree', 'disagree'; 'neither agree nor disagree', 'agree' and 'strongly agree'. A score value ranging from one to five is attached to the Likert category. The scores for each item are comprised to give an overall rating of the component.

Table 3.1 reports the marking scheme for the IPQ-R once it has been adapted for PEG carers (PEG Perception Questionnaire [PPQ]).

Table 3.1 Summary of IPQ- R subscales adapted for PEG patient carers

PEG Perceptions Questionnaire	Scoring
PPQ Identity Scale 9 Item, Score 0-1: No/Yes	0-9 High score = negative perception about the number of symptoms identified with the PEG
PPQ Consequences Scale 5 Item scale 5 point Likert scale: Strongly Agree – Strongly disagree	5- 25 High score = perception that the PEG has major consequences on the carer's life
PPQ Timeline Scale 6 Item scale 5 point Likert scale: Strongly Agree –Strongly Disagree	6-30 High score = perception that the PEG will remain in place for a long time
PPQ Personal control Scale 5 Item scale 5 point Likert scale: Strongly Agree –Strongly Disagree	5-25 High Score = perception that the carer does not have control over the PEG
PPQ Emotional Representation Scale 6 Item scale 5 point Likert scale: Strongly Agree –Strongly Disagree	6-30 High score = perception that the PEG is associated with a negative emotional impact on the carer

Reliability and Validity: Principal Components Analysis using a large sample of participants (711) from different diagnosis populations allowed item selection of the IPQ-R (Moss-Morris et al, 2002). Research has provided confirmation of the factorial structure (Hagger & Orbel, 2005), validity and reliability. All subscales in the IPQ-R demonstrate good internal consistency with Cronbach's alpha ranging from 0.79 to 0.89 (Moss-Morris et al, 2002). The IPQ-R has been found to be psychometrically valid for use with carers (Heijmans et al, 1999; Helder et al, 2002) and has been successfully used after disease specific adaptation has been made (Richards, Fortune, Chong, Mason, Sweeny, Main, & Griffith, 2004).

Three healthcare professionals, who have regular contact with individuals who care for relatives with PEG, provided face validity for this adapted measure. A pilot study incorporating all measures was completed with a family carer. The aim of this process was to ensure that carers felt the measures were relevant to their circumstances and feelings. The procedure was felt to be necessary given that some of the questionnaires were designed specifically for this study, and that other measures had never been used with this population. Feedback from the pilot study involved some criticism of the PPQ. A general comment suggested that the PPQ was too negative. The carer also highlighted some specific items, which she felt were difficult to understand. With the aim of trying to protect the original validity of the IPQ-R the items which were taken directly from this measure were altered as little as possible. However to tackle these issues several steps were taken: Further additional items (E, I, K) were added which were phrased in a positive manner. The wording of items (PP13) was also changed from 'What I do can determine whether my relatives PEG related situation gets better or worse' to 'What I do can determine whether the PEG helps my relative or not'. Item (PP15) was rephrased from 'Nothing I do will affect my relatives PEG' to 'Nothing I do will affect whether the PEG is useful or not'.

3.3.3 Measures of Dependent variables

- Hospital Anxiety and Depression Scale (HADS). (*Zigmond & Snaith, 1983*)

This measure is a brief self report assessment of anxiety and depression. It is frequently used in health psychology research as it is brief and has been found to have good internal consistencies using Cronbach's alpha, 0.8 for anxiety and 0.81 for depression.

Retest reliability of $r > 0.8$ indicates that it is not affected by situational influences and has adequate long-term sensitivity for mood fluctuations (Herrmann, 1997).

The measure consists of 14-items, with one subscale for anxiety and another for depression. All items in each of the subscales have scores that range from 0 to 3. The sum of each subscale can range from 0 to 21, with 0-7 indicating a normal level of anxiety and depression, 8-10 mild clinical disorder, 11-14 moderate clinical disorder, and 15-21 a severe clinical disorder.

- General Health Questionnaire (GHQ – 28) (Goldberg, 1972)

This is a frequently used tool which is designed to screen the general population as a measure of clinical caseness for psychological distress. This measure has a 28 item scale. Scoring for each item is based on a Likert scale. Items are scored individually using a marking scheme (0-3). Binary scores can also be used for each item, using scores 0-0-1-1 to correspond to the four items on the Likert scale. A total score can be derived from summing the scores from each item and a binary scored total which indicates caseness using a threshold score of 4/5 for discrimination.

Subscale scores totals assess somatic symptoms, anxiety and insomnia, social dysfunction and severe depression.

The measure is recognised to have a good level of validity, with gender, age and level of education having no significant effects on validity levels (Goldberg et al, 1997). A survey of the general population recorded an internal consistency coefficient of 0.93 (Makowska & Merez, 2000). Studies of family carers, which focus on various populations, have also used the tool as a measure of psychological distress (Chipase & Lincoln, 2001).

The tool is highly regarded within this population and has been used to assess the construct validity of other measures of care giving stress (Joyce et al, 2000).

- Guilt measure (Woods, 1997)

This 10 item measure, with a 5 point Likert scale and score range of 0-40, is designed for people who care for individuals with a memory problem. It has been used in studies of family caregivers (Ingleton, 2000), and is validated in comparison to other measures of family carer distress (Relative Stress Scale; Greene, Smith, Gardiner & Timbury, 1982) with a correlation coefficient of $r=0.60$. The measure has been chosen for this study as it allows quantification of guilt which has been reported subjectively in self report interviews of PEG patient carers. It is a useful tool for the study as it is suitable for use with carers across the age range from varied backgrounds (Ingleton, 2000). A good level of reliability is reported with an internal consistency of 0.86 using Cronbach's alpha (see Appendix 1.3).

3.3.4 Experiential Qualitative Measure

This questionnaire is a qualitative and quantitative measure, which focuses on the 'consequences' construct of illness representation. This construct is measured in the PPQ measure, but due to its quantitative nature is unable to obtain the rich detailed information that the qualitative approach can achieve.

Quantitative element: Carers are asked to rate the level of change they perceive has occurred for each of the areas identified as relevant to the carer by the literature (i.e. losses around food and eating (Liley, 2001), sexuality (Rickman, 1998), relationship changes (Rickman, 1998), appearance of loved one (Verhoef & Van Rosendaal, 2001) and

socialising (Rickman, 1998). The extent of the change was measured using a Likert scale ranging from 0-7, with 0 equating with no change, and 7 indicating a complete change. Participants were then asked to indicate the direction of any change (i.e. increased satisfaction, no change in satisfaction or decreased satisfaction).

Qualitative element: The questionnaire contains qualitative open-ended items which do not restrict the carer's response. These items aim to allow a greater understanding of the carers' experiences and needs since their relative was fitted with a PEG. As well as more general sections, areas are also provided for participants to write / discuss their thoughts and feelings about each of the areas discussed above. No psychometric validation of this measure was deemed necessary as it was used primarily for qualitative data collection. However literature on interview schedules was consulted in the development of this measure. Issues which were deemed to be more personal or sensitive in its nature were addressed later in the questionnaire (Smith & Osborn, 2003). (See Appendix 1.4)

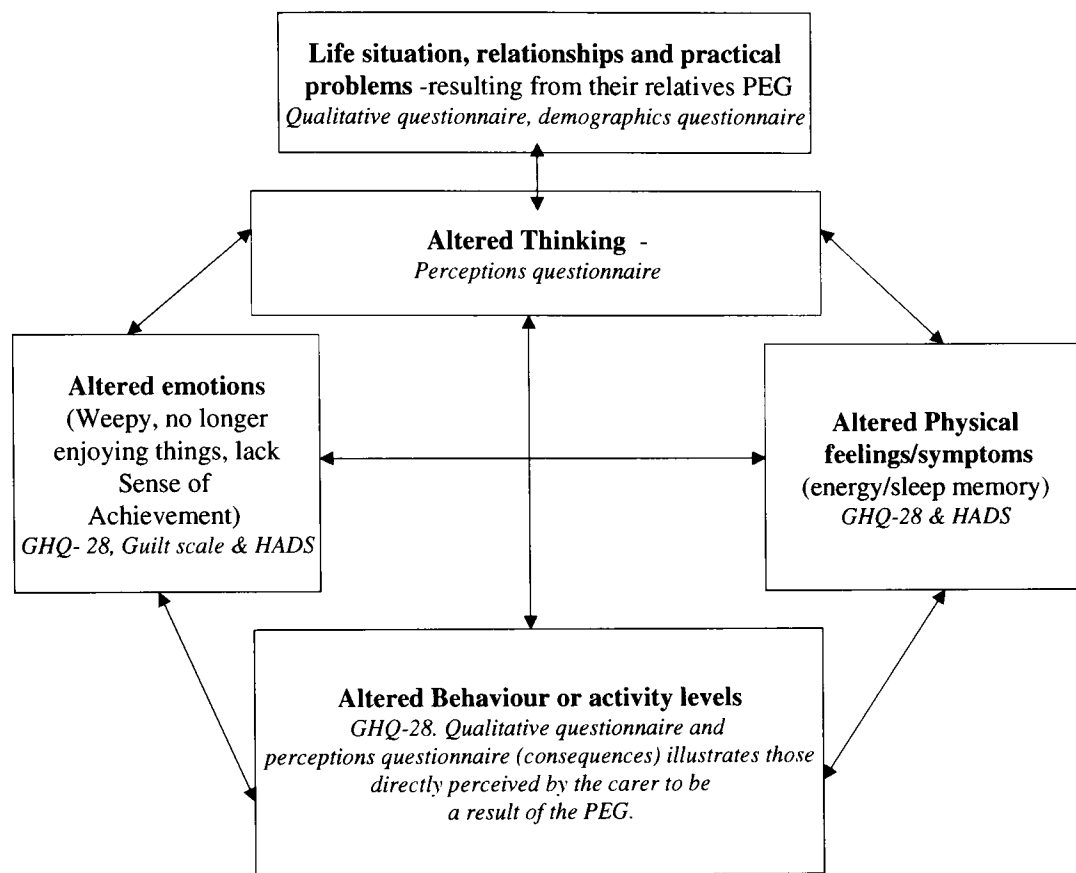
Table 3.2 provides a summary of the measures used in the study.

Table 3.2 Summary of Measures used in the Study

Measure	Marking scheme
Adapted Illness Perception questionnaire	
(PPQ) Consequences scale	5 Item, Score 1-5
(PPQ) Timeline scale	6 Items, Score 1-5
(PPQ) Personal Control scale	5 Items, Score 1-5
(PPQ) Emotional Representation scale	6 Items, Score 1-5
(PPQ) Identity scale	9 Item, Score 0-1
Hospital Anxiety and Depression	
Sub scale: Anxiety	7-Items, Score 0-3
Sub scale: Depression	7-Items, Score 0-3
General Health Questionnaire 28	
Somatic	Symptoms 7 Items, Score 0-1
Anxiety and Insomnia	7 Items, Score 0-1
Social Dysfunction	7 Items, Score 0-1
Severe Depression	7 Items, Score 0-1
The Guilt Scale	10 - Items, Score 0-4
Demographics Questionnaire	12 Items, Categorical Selection
Experiences Questionnaire	9 Items, Qualitative 6 Items, Categorical Selection 6 Items, Score 1-7

Figure 3.1 gives an overview of how the measures were used to understand whether the relationships between caregivers' perceptions and distress fit within Williams' (2001) cognitive behavioural framework.

Figure 3.1 Williams' (2001). Five Areas Model Including Measures for Exploring Carers' Reactions to PEG



3.4 Procedure

3.4.1 Ethical Procedure

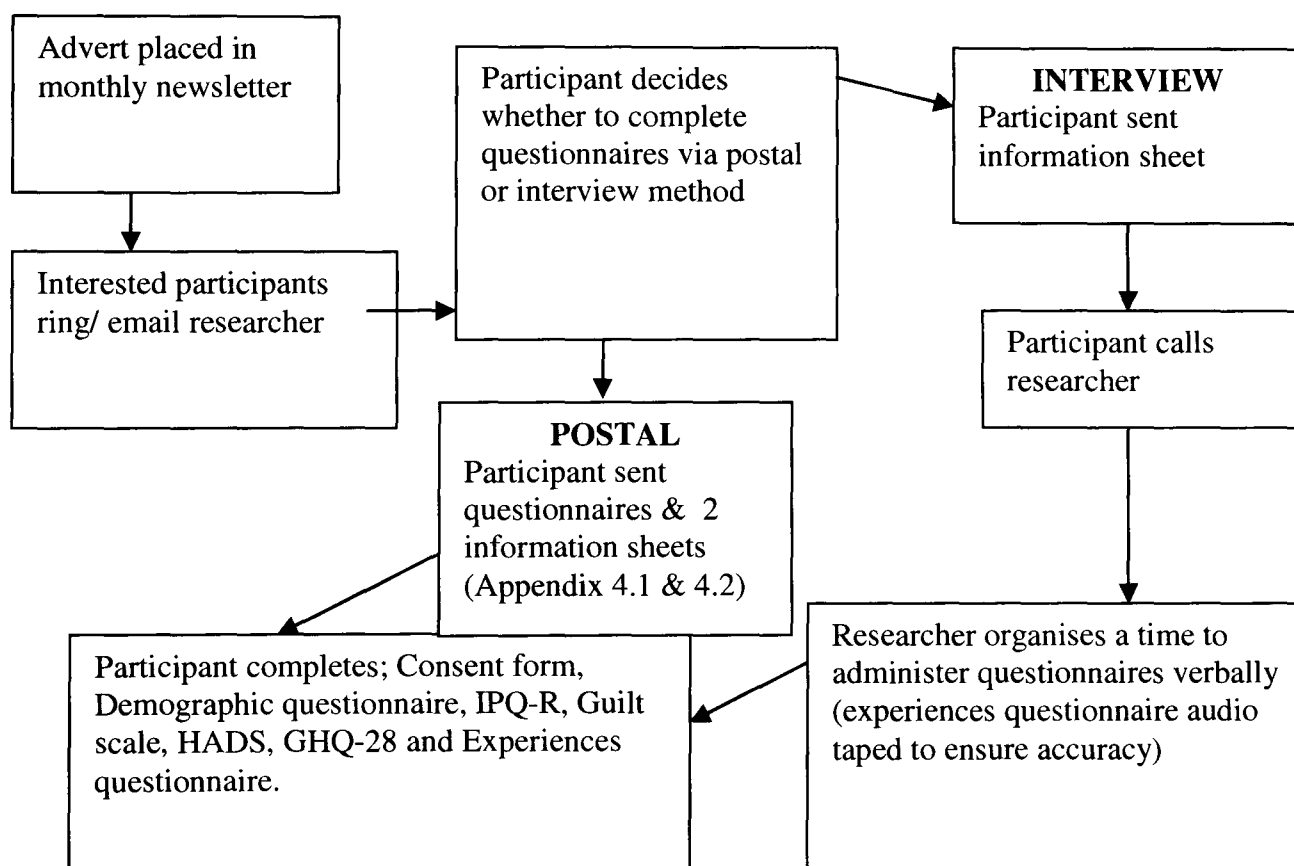
Ethical approval for the study was obtained from Hull and East Riding Research Ethics Committee prior to the commencement of data collection (see Appendix 2.1). Agreement to access patients' family carers was sought from an 'Enteral Feeding Dietitian' from Trusts one (Research and Development approval was obtained before contact was made with participants) (see Appendix 2.2). Following participant recruitment difficulties a further 20 dietitians from different Trusts were approached via email (see Appendix 3). Three further Trusts showed interest in involvement. A substantial amendment form was submitted to ethics to allow recruitment from these Trusts. The amendment was approved in August 2006. Research and Development approval was then achieved from the other Trusts.

3.4.2 The Process

Access to family carers was obtained through 'Enteral Feeding Dietitians' and a charitable organisation. The researcher liaised with dietitians from four Trusts as well as the co-coordinator of the charitable organisation. This involvement provided the researcher with the opportunity to explain the research to staff and gain their agreement to help recruit participants.

Charitable sample: Figure 3.2 provides a summary of the charitable sample, data collection procedures.

Figure 3.2 Summary of Charitable Sample Procedure.

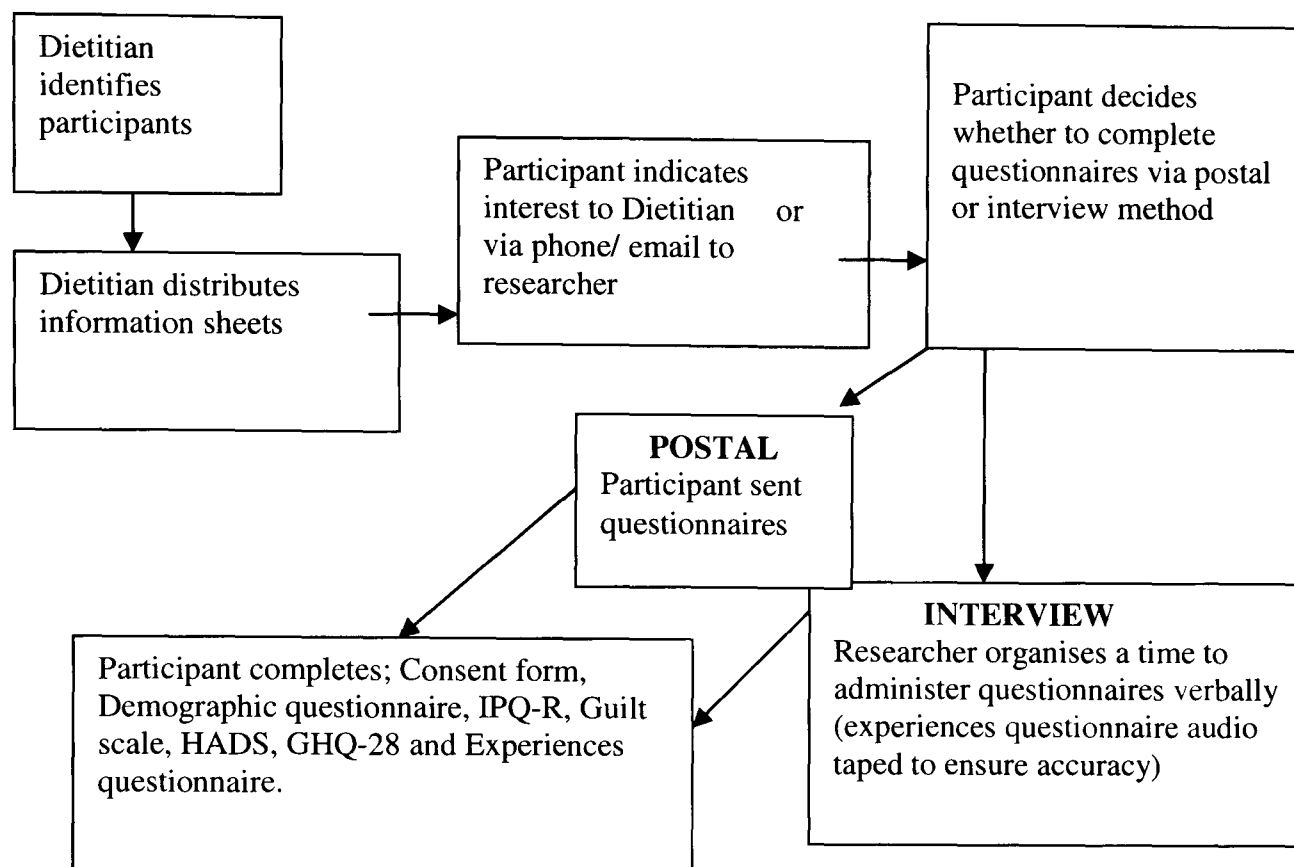


Participants recruited through the charitable organisation were recruited through advertisement in the organisations magazine (see Appendix 5). This advert contains the researcher's contact details, which allowed interested individuals to contact the researcher. Participants were asked whether they would prefer to complete the questionnaires through postal or verbal administration methods. Two methods of administration were offered after

speaking to the dietitians who described the varied lifestyle restrictions of carers. After considering these difficulties it was felt that a single method of administration may negate some carers taking part. Some carers were described as having many health professionals entering their home, a verbal interview could be seen as a further intrusion, for these participants postal methods may be preferred. Other participants are involved with time intensive care which may negate their desire to tackle the questionnaires during their free time. Those who wished to participate through postal contact were then sent the information sheets, the consent form and the six questionnaires as well as a stamped addressed envelope for participants to return questionnaires to the researcher's work address at the University of Hull.

Those participants who requested an interview were sent information sheets and were asked to ring back if they were still interested in participating on receipt of the information sheets. Those participants who called back organised a suitable appointment time with the researcher. The appointment involved the completion of the consent form followed by the verbal administration of the six questionnaires (the open-ended questionnaire was recorded to ensure that the researcher was able to document all of the information given).

Clinical sample: Figure 3.3 below gives a summary of the procedures used in clinical data collection

Figure 3.3 Summary of Clinical Sample Procedure

Dietitians reviewed their case load of patients to identify which individuals were currently making use of PEG feeding from home with the help of a family carer. Family carers were known to the dietitians through their contact with patients. Potential participants who met the inclusion criteria (which was provided to the dietitians by the researcher) were given the information about the study on routine contact with the families identified. If family members were told of the study over the telephone, dietitians sent out the information sheets to the family member and patient through the post (researcher paid postage). Interested participants would then contact the researcher directly using the contact details given on the information sheets or would telephone the dietitian, who in turn informed the researcher of the participants contact details. Those participants who opted to complete the questionnaires by verbal administration in an interview organised an appointment time during this conversation. At the interview, participants were initially

asked to complete the consent form. The researcher then administered the six questionnaires verbally.

Participants who preferred the postal method were posted a package of questionnaires, which included the consent form, the six questionnaires and a stamped addressed envelope to allow the participant to send back the completed questionnaires to the researcher.

On completion of data analysis all participants received a summary of the study's findings.

3.5 Consent

3.5.1 Postal Administration

Participants choosing to participate in the study using the postal method were informed by the researcher that by completing the package of questionnaires and returning them (including the consent form) in the stamped addressed envelope they were giving their consent to participate in the study.

3.5.2 Verbal Administration

Verbal consent to be involved in the study was gained by the researcher over the phone, when personal details were taken (telephone number and address) to organise the interview.

Prior to beginning the interview the researcher gave the participant a self-administered consent form to complete (see Appendix 6).

3.6 Analysis of Quantitative Data

3.6.1 Statistical Analysis

As a consequence of the exploratory nature of this study, a range of sample size calculations (based on varying values of R-squared for regression modelling of the dependent variables [distress]) were examined in a power analysis. A sample of 54 was decided upon, based on educated guesses for the values of the R-squared statistic. This can achieve 80% power to detect a change in R-Squared of 0.15 attributed to 5 independent variables; identity, emotional representation, timeline, consequence, personal control, using an F-Test with a significance level (alpha) of 0.05. The regression coefficients are tested against zero. The variables tested were adjusted for an additional 3 independent variables, medical/ elective placement, oral intake status and length of time caring for individual with PEG, with an R-Squared of 0.30. These were independent variables whose influence was removed from experimental error.

As the IPQ-R has been adapted to allow suitability for PEG patient family carers, Cronbach's alpha was used to assess the co-variances of all items in a scale with each other. This allows overall scale reliability to be estimated (Barker et al 2002).

3.6.2 Analysis of Question One

Descriptive and frequency analysis was used to gain an understanding of the typical perceptions of PEG in family carers.

3.6.3 Analysis of Question Two

Family carers were assessed on measures of anxiety and depression and guilt. General Linear Model analysis aims to understand the effects of predictor variables on dependent variables. This method of analysis appeared to be consistent with the objectives of the study, which aimed to understand the relative contribution of the independent variables: 5 constructs of PEG perception, decision making and oral feeding capabilities, on the dependent variable for distress (HADS anxiety /depression and the guilt scale).

3.7 Analysis of Qualitative Data

Data were analysed according to whether the response was given in writing (through postal methods) or verbally (through a verbal administration interview).

3.7.1 Interpretive Phenomenological Analysis (IPA)

The experiences questionnaire, administered verbally allowed a semi structured interview structure for data collection. This gave the researcher insight into the participant's perceptions, experiences and feelings. Such a framework is commonly used in qualitative analysis of data (Smith, Harre & Van Langerhore, 1995; Willig, 2001).

Sandelowski's (1995) work on sampling in qualitative research encouraged the researcher to consider the aims of the qualitative aspect of this study. The questionnaire's main aim was to understand typical consequence perceptions and caring experiences of a family PEG patient carers. Analysis of all the questionnaires using IPA would not be feasible within the time constrictions of this study. Ten open-ended questionnaires were analysed in order to adequately determine important factors. A random selection technique was felt to be possible as all the transcripts were felt to be of equal quality and due to the

varied experiences of carers, they were felt to be equally valid descriptions. The use of a manual selection technique was incorporated. Coolican's (1999) description of this process was followed, open-ended questionnaires were numbered and the corresponding numbers placed in a box for selection. All of the questionnaires selected that were from participants who had taken part using the verbal administration process were analysed using IPA methods.

Interviews were transcribed by the researcher and IPA analysis was carried out in the manner described by Smith Jarman & Osborn (1999). This description outlines several stages of analysis. These are described below.

To begin, each transcript was read several times. This aimed to allow the researcher to interpret the meaning of the text. Broad notes developed from the analyser's reactions to the thoughts and feelings expressed in the text were made to the left of the narrative. Specific segments were highlighted if they were felt to encapsulate the thoughts or feelings annotated to the left.

At the right of the transcript prose, keywords were noted, which aimed to label the identified essence of that segment of text. Each transcript allowed the development of a list of quotes and labels. These sheets can be used to allow within participant clustering, to generate specific themes. During this process the context of the quotes was frequently checked within the body of the original transcript. This process ensured themes were supported by the raw data and also helped to prevent theme distortion due to researcher bias.

Each transcript was analysed individually. At the beginning of analysis of a new transcript, previous participant themes were set aside. Once all transcripts were analysed

across cases, the researcher identified convergent and divergent themes (Smith & Osborn, 2003). Convergent themes were then categorised into groups of similar themes. This allowed the generation of sub and super-ordinate themes.

Quality: The process of IPA involves methodology, which ensures the validity of analysis. The increased use of qualitative methods in psychological research has instigated the development of guidelines, which aim to ensure credibility (Elliot, Fischer & Rennie, 1999). These include transparency which demonstrates a sound connection between theory and method (Salmon, 2003), as well as sensitivity to context, where themes are grounded in examples (Elliot et al, 1999).

Reflection is also an important factor which enables the researcher to consider how their understanding has been developed. The researcher should be aware of themselves within the analysis. The values and preconceptions that they have brought to the process should, where possible, be considered and made explicit (Willig, 2001). The researcher aimed to ensure this by keeping a detailed research reflection diary, which was regularly referred to. Key concepts were detailed within the reflexive statement (section 3.7.3).

To further ensure the validity of interpretation, a second Trainee Clinical Psychologist, external to the study, read the transcripts. The findings were discussed and agreed. Additionally, a Clinical Psychologist who was a member of the IPA group was involved in analysis. The group which was regularly attended was used to ensure quality. The Clinical Psychologist who was familiar with IPA methods, was given access to some of the data, which facilitated discussion and ensured that themes had not been distorted by researcher bias.

Generated themes were also given to two of the dietitians involved in recruitment and a participant who expressed interest in analysis.

3.7.2 Triangulation

Methodological triangulation is the analysis of data using multiple methods, this technique can be used to gain a greater understanding of the focus area (Denzin, 1970). In this case triangulation refers to the analysis of different modalities of data (qualitative and quantitative). For the purpose of the current study qualitative data were used to support and provide further meaning to quantitative results. This use of qualitative data methods has been successfully achieved in the past (McLeod, 2001).

3.7.3 Reflective Statement

In accordance with good practice guidelines (Elliott et al, 1999) this section aims to provide the reader with information that could have coloured the researcher's analysis. This is hoped to provide the reader with information about the possible influences of the researcher within the context of her analysis. It is also hoped that by acknowledging and understanding any personal perspectives and experiences the implications of the researcher's view points on analysis and conclusions will have been minimised, as is suggested by phenomenological theory (Elliot et al, 1999).

To allow a comprehensive understanding of the possible biasing influences, this section will begin by looking at the personal factors that have motivated this piece of research. It will end with the researcher's viewpoint of HETF with a PEG following contact with the participants involved in this study. To prevent the problems associated with

retrospect, a reflective diary has been kept throughout the research process. This has been used to aid writing. To make clear the intentions of this section, which involves the discussion of the researcher's personal opinions and values, the writing style will change to adopt the first person.

Prior to clinical training I was employed as a teacher's aide at a school for individuals with complex physical and learning disabilities. It was at this time that I first became aware of the PEG feeding process. One of the children who I supported used the pump method of PEG feeding. There were only a few staff that knew how to use the PEG feed equipment and this would often cause difficulties. Other staff that were unfamiliar with the process would worry if they were left in charge of the boy especially if the pump machine beeped. Their worries and attempts to get assistance often affected the young man involved. He appeared to be concerned about what was happening around him. After working at the school for a number of months I met with his family. They described the difficulties in finding suitable respite and the unexpected difficulties associated with the PEG feed.

At a later date the family began to send in a small chocolate mousse for the young man which they asked me to feed him at lunch time. During the lunchtimes the young man who was often in a lot of pain due to his physical condition, 'lit up'. It was very rare that he would manage the full mousse but the interaction that this process allowed was relished by both the boy and myself.

When beginning on the Clinical Psychology Doctorate training course and generating ideas of possible research areas, I began to think about PEG feeding. After speaking to a nurse and finding out about the process I began to think about the many

different areas of psychological research where there was a lack of evidence base. I began to consider the numerous conversations I had with the young man's family.

Teaching we were given about psychoanalytic and psychodynamic theory led me to consider how PEG as an artificial form of feeding had impacted on the family's everyday life. My understanding of Cognitive Behavioural theory emphasised the links between the family's thoughts about the PEG and their feelings. This is a key concept within this research.

When looking through my research diary and reviewing the many obstacles that faced the recruitment process, I became aware of a frequent professional response to my research proposal. This viewpoint was that the carers of individuals had no choice but to deal with the PEG as it was an essential intervention. As they perceived the PEG as a useful medical intervention it seemed that they could not see that the PEG would have any independent effects upon the lives of carers.

This stance appeared to contribute to an unexpected carer reaction to the beginning of the interview process. Carers were initially, reluctant to discuss any negative thoughts or experiences surrounding the PEG. Often, carers backed up any negative descriptions with a positive statement about the benefits the PEG had provided for their relative. I was struck by the increased responsibilities and restrictions that were placed upon the carers when a PEG was placed. Carers often considered the difficulties from their relative's perspective rather than their own. This drove me to meet more carers across several Trusts to ensure that this research provided a more representative picture. I hope that this is more likely to increase health professional's awareness of carers' thoughts and feeling surrounding PEG, allowing the alternative viewpoint which considers the carers needs to be developed. It

seems to me that a shift in the professional's attitude to HETF will give carers a voice so that they feel able to voice their opinions and concerns.

Chapter Four: Results

4.1. Sample Recruitment Routes

Despite considerable recruitment attempts, using several different services, it was not possible for the researcher to gain the sample size proposed by the original power calculation. A sample size of 39 participants was recruited. Most participants, (95% (n=37)) chose to take part using the interview option. The sample composition is displayed in Table 4.1.

Table 4.1 Participant Recruitment Routes

Trust/ Organisation	Participants Recruited	Method of participation	
		<i>Interview method</i>	<i>Postal method</i>
PINNT	n = 3/39 (7.7%)	N= 2/39 (5.1%)	n= 1/39 (2.6%)
Trust one	n = 2/39 (5.1%)	n = 2/39 (5.1%)	n = 0/39 (0.0%)
Trust two	n = 10/39(25.6%)	n = 10/39 (25.6%)	n = 0/39 (0.0%)
Trust three	n = 12/39(30.8%)	n = 12/39 (30.8%)	n = 0/39 (0.0%)
Trust four	n = 12/39(30.8%)	n = 11/39 (28.2%)	n = 1/39 (2.6%)

Note. The number of carers who received the PINNT newsletter was 50 but this figure includes members who are supporting a relative who is a child or who is fed using NG.

4.2. Revised Power Analysis

As the proposed sample size was not achieved, a further power calculation was made preceding data analysis. This calculation was made using the PASS statistical software (Hintze, 2001). It aimed to assess the implications of the achieved sample size on power. This analysis is adjusted for 2 independent variables (decision making about the PEG placement and oral intake status). It did not control for the influence of 'length of time caring for individual with PEG' as 85% (n= 33) of the sample had cared for their relative with a PEG for over 10 months. The sample of 39 was found to achieve 80% power for the

following scenario: a change in R-Squared of 0.20 attributed to the 5 independent variables, using an F-Test with a significance level (alpha) of 0.05. This assumed an R-Squared of 0.30 when controlling for the influence of the two independent variables.

4.3. Sample Characteristics

The sample demographic characteristics are presented in Table 4.2. This shows a higher ratio of females to males in the sample. This is a slightly higher proportion of females (64%) than is typical in the gender distribution of carers in the United Kingdom (ONS, 2001).

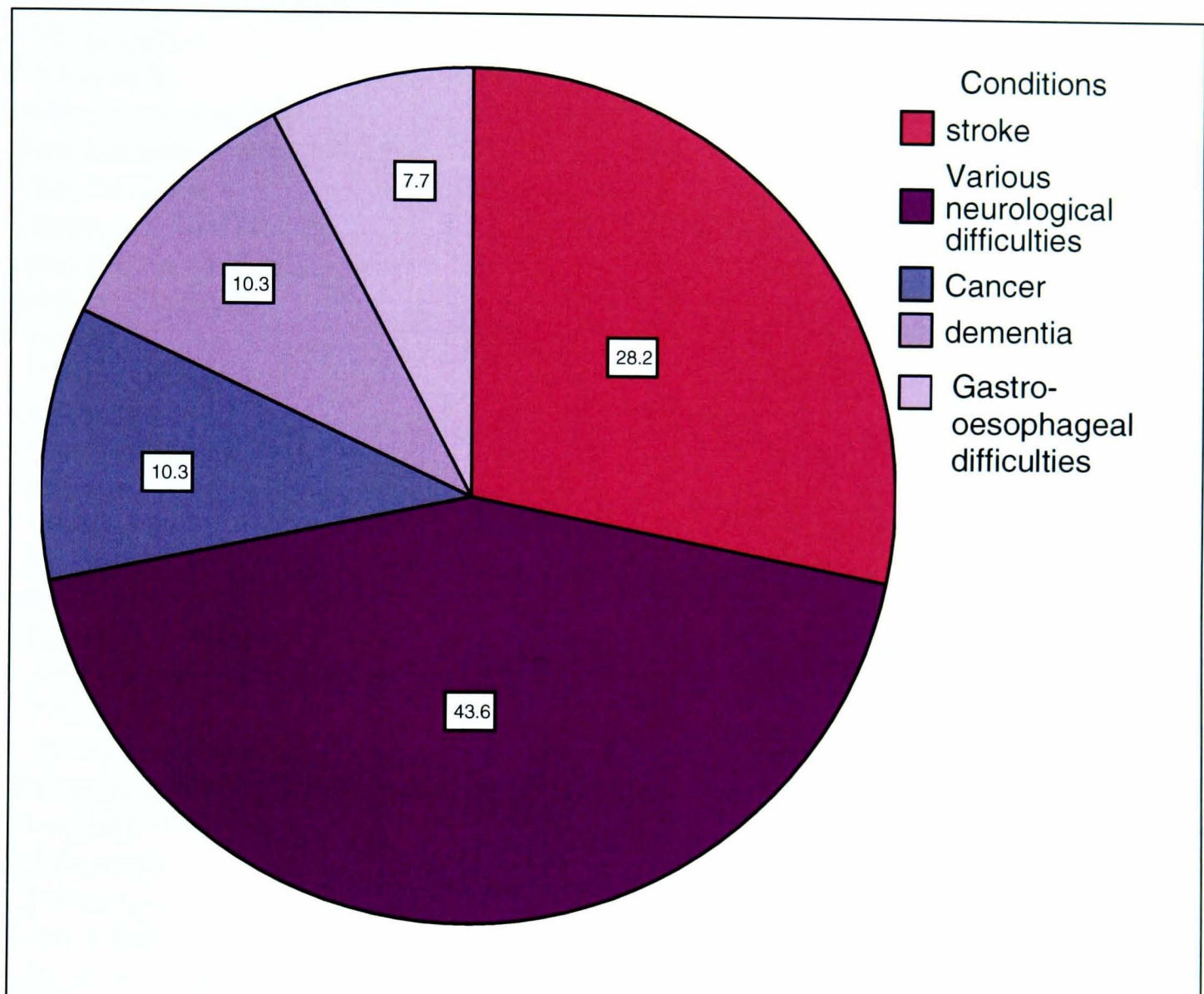
Table 4.2. Participant Demographic Characteristics

Demographic domain	Results
Gender	
Female	n = 25 (64.1%)
Male	n = 14 (35.9%)
Age	
45-64 years old	n = 22 (56.4%)
65-84 years old	n = 15 (38.5%)
18-44 years old	n = 2 (5.1%)
Relationship	
Spouse	n = 20 (51.3%)
Parents	n = 13 (33.3%)
Offspring	n = 6 (15.4%)
Hours of care	n = 37 (94.9%)
More than 20 hours of care	n = 2 (5.1%)
5-10 hours of care	
Regular professional Involvement	n = 25 (64.1%)
Yes	n = 14 (35.9%)
No	

The underlying conditions that necessitated the use of PEG in carer's relatives were heterogeneous. The researcher grouped conditions into categories to represent the range of

conditions causing dysphagia. Figure 4.1 depicts the distributions of categorised conditions.

Figure 4.1. Pie Chart of Relatives' Underlying Conditions Necessitating PEG Placement



Demographics relating specifically to the PEG were more homogenous. Most participants had provided care for their relative before the PEG placement (64%, [n= 25] reported that their relative had been ill for more than 10 months before tube insertion). Table 4.3 displays the samples' characteristics relating to the PEG.

Table 4.3. Characteristics Relating to the PEG

Demographic domain	Results
Illness duration prior to PEG placement	
No illness prior to PEG placement (emergency procedure)	n = 4 (10.3%)
3-6 months	n = 9 (23.1%)
7-9 months	n = 1 (2.6%)
More than 10 months	n = 25 (64.1%)
Decision surrounding the PEG	
Not involved	n = 9 (23.1%)
Relative involved	n = 4 (10.3%)
Relative and carer involved	n = 26 (66.7%)
Method of feeding	
Bolus	n = 14 (35.9%)
Pump feeding	n = 25 (64.1%)
Oral Intake	
Fluid and normal food	n = 4 (10.3%)
Fluid and soft/ liquidised food	n = 12 (30.8%)
Fluids only	n = 2 (5.1%)
Nothing	n = 21 (53.8%)
PEG duration	
Less than 3 months	n = 2 (5.1%)
3-6 months	n = 3 (7.7%)
7-9 months	n = 1 (2.6%)
10 months or more	n = 33 (84.6%)
Duration of home PEG feeding	
Less than 3 months	n = 2 (5.1%)
3-6 months	n = 3 (7.7%)
7-9 months	n = 1 (2.6%)
10-18 months	n = 6 (15.4%)
More than 18 months	n = 27 (69.2%)

4.4 Reliability Testing

The alterations made to the IPQ-R to make it specific to PEG carers, may have affected the measure's reliability. Cronbach's alpha was completed to ensure that all items used to assess a construct, were measuring the same concept. This analysis was carried out for each of the 5 perception constructs. Table 4.4 displays the reliability of each of the items. A Cronbach's Alpha score of between 0.7 to 0.9 would be regarded as a good level

of reliability (Streiner & Norman, 2003). Scores above this level would suggest that all the items are asking the same question (Streiner & Norman, 2003).

Table 4.4. Reliability Scores of Items on the PPQ

Perception	Cronbach's Alpha	Cronbach's Alpha if item deleted
Identity	0.58	
PEG Fullness		0.49
PEG Regurgitation		0.57
PEG Nausea		0.53
PEG Vomiting		0.53
PEG Diarrhoea		0.56
PEG Constipation		0.59
PEG Flatulence		0.58
PEG Stoma Irritation		0.57
PEG Sleep Disturbance		0.51
Timeline	0.85	
PP1		0.78
PP2		0.80
PP3		0.79
PP4		0.78
PP5		0.79
PP18		0.96
Consequences	0.75	
PP7		0.68
PP8		0.69
PP9		0.71
PP10		0.71
PP11		0.75
Control	0.63	
PP12		0.44
PP13		0.45
PP14		0.81
PP15		0.58
PP16		0.50
Emotional Representation	0.63	
PP33		0.50
PP34		0.50
PP35		0.59
PP36		0.63
PP37		0.63
PP38		0.64

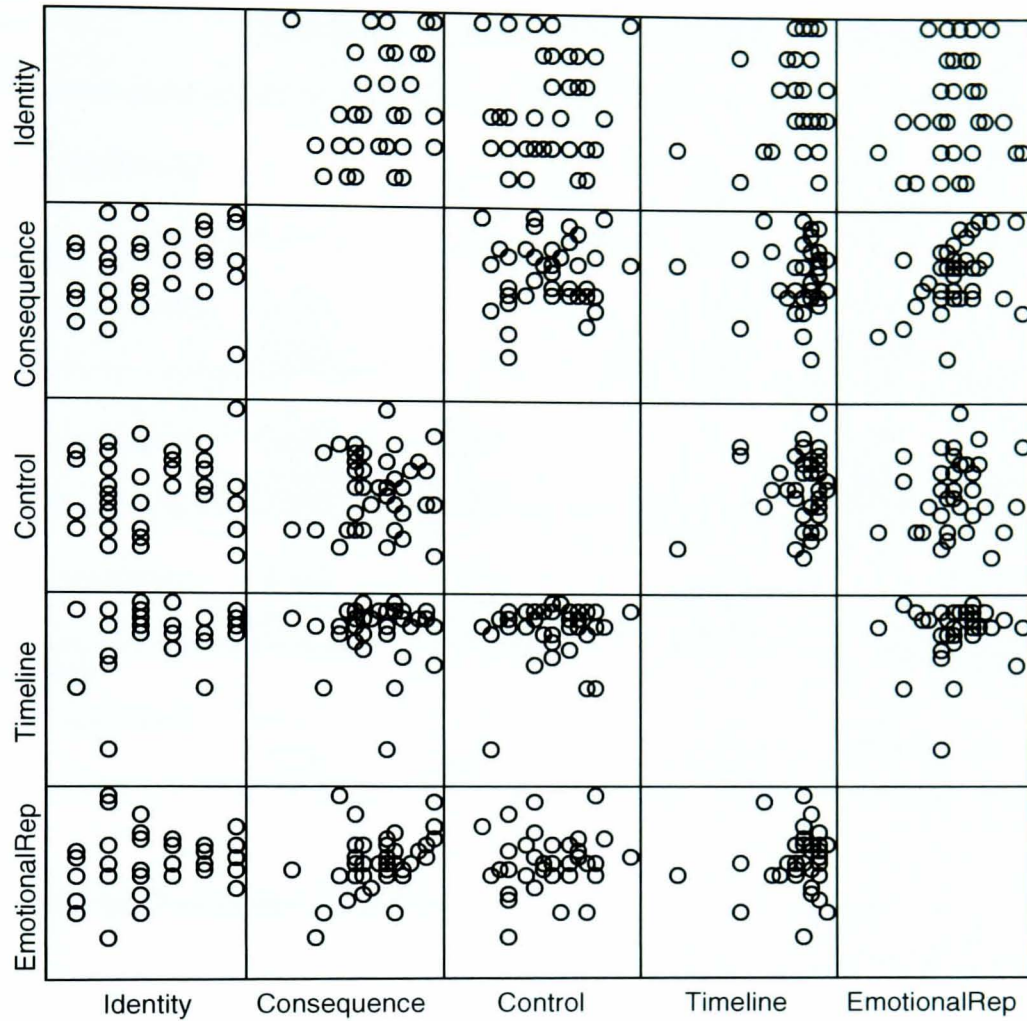
'Identity' has the lowest level of reliability. However, if a carer considers their relative to have one of the PEG related symptoms, it does not follow that they would perceive their relative to have the other symptoms listed. Therefore this method of reliability testing may not be the most appropriate analysis for this construct.

Items measuring 'Time line' and 'Consequence' have a good level of reliability. 'Control' would also be considered as reliable if item 14 was removed. 'Timeline' would have a Cronbach's Alpha of 0.96 if item 18 was removed. This may suggest that items one to five are asking the same question repetitively.

Cronbach's Alpha indicates that items for each construct are related to each other. A correlation was then completed to ensure that the perception subscales were measuring separate constructs. If a correlation between two of the components is very high it suggests that they are measuring the same construct.

As reliability analysis used Cronbach's Alpha (which is based on Pearson's correlation rather than rank correlation), Pearson's Correlation was used to ensure that each construct was distinct. Figure 4.2 illustrates the correlations between the five perceptions.

Figure 4.2 A Matrix Scatter Plot of Correlations Between Perception Construct Subscales



There were significant correlations between the constructs ‘Consequences’ and ‘Emotional Representation’. The value was positive, suggesting that a participant who is negative in their perception of consequence is likely to be negative in their emotional representation of the PEG. Table 4.5 shows correlations between perception areas. These correlations suggest that all perception constructs are distinct as none of the relationships are close to 1.

Table 4.5 Correlations Between Perception Constructs

<i>Perception Construct</i>	<i>Identity</i>	<i>Consequence</i>	<i>Control</i>	<i>Timeline</i>	<i>Emotional Rep.</i>
<i>Identity</i>					
Pearson's Correlation	1	0.23	0.09	0.06	0.15
P Value		0.16	0.60	0.70	0.36
<i>Consequence</i>					
Pearson's Correlation	0.23	1	0.07	-0.02	0.37
P Value	0.16		0.68	0.90	0.02
<i>Control</i>					
Pearson's Correlation	0.09	0.07	1	0.07	0.14
P Value	0.60	0.68		0.70	0.40
<i>Timeline</i>					
Pearson's Correlation	0.06	-0.02	0.07	1	0.09
P Value	0.70	0.90	0.70		0.59
<i>Emotional Rep.</i>					
Pearson's Correlation	0.15	0.37	0.14	0.09	1
P Value	0.36	0.02	0.40	0.59	

4.5 Independent Variables Measure

Carers most commonly perceive that their relative has 1 somatic symptom as a result of the PEG (28.2%, *Mdn*=1). The most commonly reported symptoms were stoma site irritation (51.3%, *n*=20), vomiting (35.9%, *n*=14), flatulence (25.6%, *n*=10) and diarrhoea (25.6%, *n*=10).

The mean scores for each of the other perception constructs are presented in table 4.6. A high mean score indicates that the individuals in the sample are generally negative in their perception about the PEG.

Table 4.6. Perception Construct Scores

Construct Subscale	Result
Consequence	Mean = 12.9 , SD = 4.3
Control	Mean = 11.6, SD = 3.8
Timeline	Mean = 26.7, SD = 3.7
Emotional Representation	Mean = 14.3, SD = 4.6

The participants in this sample were most negative in their perceptions of time line ($M = 4.58$, $SD = 0.80$) and did not believe that their experience would improve over time ($M = 3.33$, $SD = 1.13$). Many participants strongly agreed that their relatives PEG will remain for a long time (74.4%, $n = 29$) and 69.2% ($n = 27$) believed that the PEG would remain for the rest of their relative's life.

Their emotional representation of the PEG was neither positive nor negative ($M = 2.57$, $SD = 1.28$). Carers were also neutral on their perceptions of personal control over the PEG ($M = 2.47$, $SD = 1.17$). There was more negativity about the consequences associated with the PEG ($M = 2.94$, $SD = 1.23$). Participants who felt that there were PEG related consequences, were strong in their convictions; 36% ($n = 14$) of participants strongly agreeing that the PEG had major consequences on their life.

The additional consequence items that were not included within the total scores showed that carers were most negative in their perception of their ability to enjoy eating, with 56.4% agreeing or strongly agreeing that their mealtime enjoyment had decreased ($M = 3.6$, $SD = 1.20$). Over half of all participants (54.6%) agreed or strongly agreed that the frequency with which they completed social activities had changed ($M = 3.5$, $SD = 1.39$).

4.6 Perception of Change and Satisfaction in PEG Consequence Areas

The quantitative results from the open-ended consequences questionnaire are displayed in Table 4.7.

Table 4.7. The Perception of Change and Satisfaction in PEG Consequence Areas

Consequence area	Mean change rating	Satisfaction rating		
		Less	No Change	More
Appearance	3.5	N= 6 (15%)	n = 14 (36%)	n= 19 (49%)
Eating	4.2	n = 21 (54%)	n = 16 (41%)	n = 2 (5%)
Relationship with others	2.5	n = 11 (28%)	n = 26 (67%)	n = 2 (5%)
Relationship with patient	1.8	n = 5 (13%)	n = 25 (64%)	n = 9 (23%)
Socialising	3.6	n = 26 (67%)	n = 11 (28%)	n= 2 (5%)
Sexual relationship	1.9	n = 5 (13%)	n = 12 (31%)	n=0 (0%)

Note .Three participants who were patients' spouse did not want to answer questions about sexual relations

Mean scores showed that carers perceive some change in all of the consequence areas. This appears to suggest that the areas identified by the literature review are relevant to family carers of PEG patients. The areas which were perceived to have changed most since the introduction of the relatives PEG, were eating, socialising and appearance. The majority of carers felt less satisfied with their eating habits and ability to socialise since the introduction of PEG. Participants were more satisfied with their relative's appearance since they were fitted with a PEG.

Correlations were performed for the total consequence change score on the open-ended questionnaire against the guilt scale total score, the HADS total score and the HADS anxiety and depression subscale scores. There were no significant relationships between the Consequence change total score and the HADS total (0.187, $p = 0.253$), HADS depression (0.054, $p = 0.743$) or anxiety subscale scores (0.278, $p = 0.086$). There was a significant relationship between the Consequence change total score and the Guilt scale total score (Pearson's Correlation = 3.99, $p = 0.012$). The positive value of the Pearson's correlation suggests that the more change the participant believes is a consequence of the PEG, the more guilt they feel. The IPQ-R Consequence subscale was not found to have a significant

relationship with guilt. This suggests that there is a difference in carer responses surrounding PEG consequence according to the method of questioning used.

4.7. Dependent Variables Measures

The distribution of scores on the HADS questionnaire shows that the average depression ($M = 5.2$, $SD = 3.6$) score is lower than the anxiety mean ($M = 7.4$, $SD = 3.7$). These scores correspond to normal levels of distress. Table 4.8 displays the sample frequencies for the HADS clinical categories.

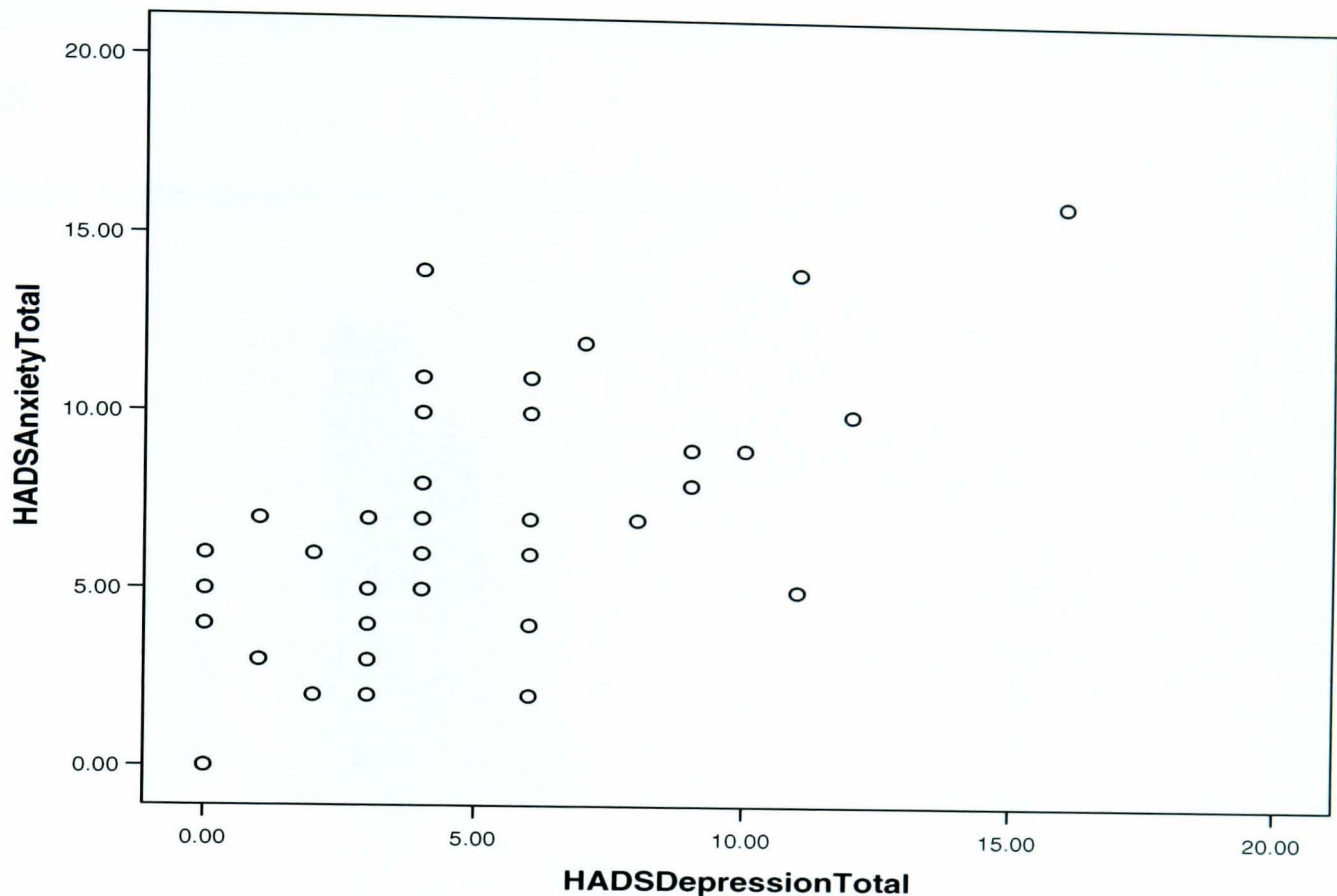
Table 4.8. Clinical Categories on the HADS Questionnaire

Subscale	Result
Anxiety	
Normal	22 (56.4%)
Mild	9 (23.1%)
Moderate	7 (17.7%)
Severe	1 (2.6%)
Depression	
Normal	31 (79.5%)
Mild	4 (10.3%)
Moderate	3 (7.7%)
Severe	1 (2.6%)
Total (Anxiety and Depression)	
No clinical distress	20 (51.3%)
Some level of clinical distress	19 (48.7%)

Despite the low average scores, nearly half of the sample scored within, one of the clinical categories for anxiety or depression. The same participant who scored within the 'severe' category on the depression scale also scored in the anxiety severity range. This appears to be typical of the sample, as anxiety and depression scores are significantly correlated (Pearson's Correlation = 0.61, $p < 0.001$). Figure 4.3 depicts the correlation

between HADS anxiety and depression subscale scores.

Figure 4.3 Scatter Plot Illustrating the Correlation Between HADS Anxiety and Depression Subscale Totals



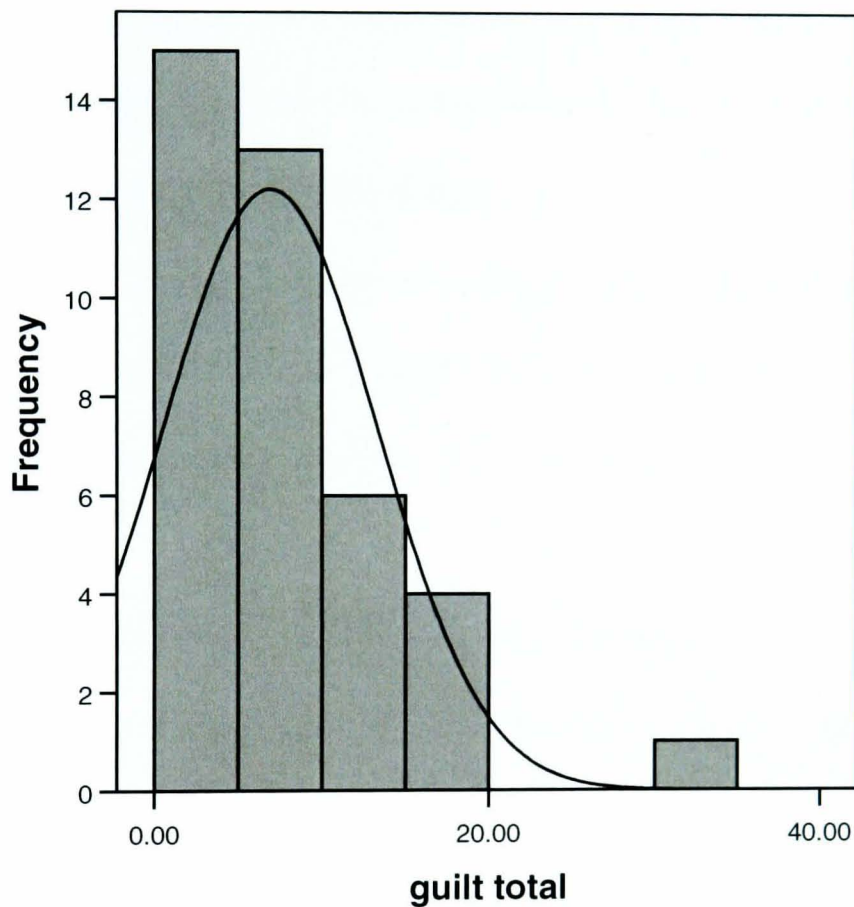
Scores on the GHQ-28 show a lower level of sample distress caseness (12.8%) than the HADS. Table 4.9 shows the mean scores of each of the GHQ-28 subscales using binary scores. The most highly scoring subscale was 'somatic symptoms'. The most highly scored items were A1 ($M = 1.36$, $SD = 0.71$) and A2 ($M = 1.38$, $SD = 0.94$), which asked carers about any changes in their own health and their need for a good tonic. However these mean scores fit within the 'same as usual' category.

Table 4.9. Scores on the GHQ 28 Subscales

Subscale	Result
Somatic Symptoms	Mean = 0.54, SD = 1.19
Anxiety and Insomnia	Mean = 0.33, SD = 0.84
Social Dysfunction	Mean = 0.21, SD = 0.61
Severe Depression	Mean = 0.03, SD = 0.16

The mean score on 'The Guilt Scale' was 6.9 (SD = 6.4) out of a maximum of 40. The high level of standard deviation and the large range of scores (minimum score = 0 and maximum = 31) suggests that there is a large amount of spread in guilt scores (see figure 4.4).

Figure 4.4 *Histogram Depicting Skewed Sample of Guilt Scores*



Despite frequent reports of guilt within verbatim (see section 4.10) the mean score on the guilt scale measure was felt to be comparatively low. A more in depth analysis of guilt scale items showed that questions 1 ($M = 1.00$, $SD = 1.12$), 4 ($M = 1.08$, $SD = 1.20$) and 6 ($M = 1.00$, $SD = 1.12$) were on average the most highly scoring items. The means of these items fit within the 'sometimes' category. The content of these items suggests in general, carers sometimes feel guilty because they feel that they might have unintentionally hurt their relative's feelings. They also feel guilt as a result of the time and care demands

involved in PEG care, with 31% ($n = 12$) of participants reporting that they sometimes feel trapped by the responsibility they feel they have for their relative and 23% ($n = 9$) sometimes accusing themselves of neglecting other people, because of the time they spend with their relative.

Participants reported least guilt about items 2 ($M = 0.28$, $SD = 0.72$) and 10 ($M = 0.28$, $SD = 0.51$) which would be rounded into the 'never' category. Typically carers never felt guilty about letting their relative down or being cruel to their relative. These items are more related to the quality of care provided.

There is a strong correlation between guilt and the HADS total (Pearson's Correlation = 0.468 $P = 0.003$) suggesting that those participants who were more distressed (anxious and depressed) scored higher on the guilt scale.

4.8 Relationships Between PEG Perceptions and Distress

The General Linear Model was used to ascertain whether the carer's PEG perceptions were related to their distress. Table 4.14 summarises the relationships between the perception constructs and scores on the standardized distress measures.

There were no significant relationships between any of the five perception constructs and participant's HADS total scores (see table 4.10). After allowing for the two controlled variables, perceptions were found to produce a non significant change in R-Squared.

Table 4.10. Details of General Linear Model Analysis of HADS Total

<i>Dependent Variable</i>	<i>R</i> ² 7 variables	<i>R</i> ² 5 variables	<i>F</i>	<i>df</i> (change)	<i>p</i>	<i>Predicting variable</i>	<i>F</i>	<i>df</i>	<i>p</i>
HADS Total	0.130	0.066	0.452	5,30	0.809				
						Emotional rep.	0.638	1, 30	0.431
						Timeline	0.083	1, 30	0.775
						Control	0.136	1, 30	0.715
						Consequence	0.007	1, 30	0.932
						Identity	0.983	1, 30	0.329

Note. *R*² for 7 variables; 5 perception variables plus two variables that were controlled for, *R*² for 5 variables; 5 perception variables, change; statistic for change in *R*² after the five perception variables were added.

Further General Linear Model analysis was conducted to ascertain whether there were relationships between the 5 PEG perceptions and HADS subscale scores. There were no significant relationships between the individual perception constructs and HADS depression scores (see Table 4.11). The perception constructs did not produce a significant R- Squared change on depression.

Table 4.11. Details of General Linear Model Analysis of HADS Depression Subscale

<i>Dependent Variable</i>	<i>R</i> ² 7 variables	<i>R</i> ² 5 variables	<i>F</i>	<i>df</i> (change)	<i>p</i>	<i>Predicting variable</i>	<i>F</i>	<i>df</i>	<i>p</i>
HADS Depression subscale	0.149	0.055	0.388	5,30	0.853				
						Emotional rep.	0.560	1, 30	0.460
						Timeline	0.193	1, 30	0.664
						Control	0.008	1, 30	0.931
						Consequence	0.577	1, 30	0.453
						Identity	0.094	1, 30	0.761

Note. *R*² for 7 variables; 5 perception variables plus two variables that were controlled for, *R*² for 5 variables; 5 perception variables, change; statistic for change in *R*² after the five perception variables were added.

Perception variables produced no significant relationships with carer's anxiety score (see Table 4.12) and did not produce a significant change in R-squared on anxiety.

Table 4.12. Details of General Linear Model Analysis of HADS Anxiety Subscale

<i>Dependent Variable</i>	R^2 7 variables	R^2 5 variables	F	df (change)	p	<i>Predicting variable</i>	F	df	p
HADS Anxiety subscale	0.157	0.119	0.848	5,30	0.527	Emotional rep.	0.493	1, 30	0.488
						Timeline	0.898	1, 30	0.351
						Control	0.560	1, 30	0.460
						Consequence	0.347	1, 30	0.560
						Identity	2.192	1, 30	0.149

Note. R^2 for 7 variables; 5 perception variables plus two variables that were controlled for, R^2 for 5 variables; 5 perception variables, change; statistic for change in R^2 after the five perception variables were added.

Whilst none of the relationships were significant, the change in R-squared was highest for anxiety subscale scores, indicating that perceptions about the PEG have more of an effect on levels of anxiety than depression.

When the Guilt Scale scores were subjected to General Linear Model analysis, significant relationships were identified between guilt and two of the perception constructs (identity ($p = 0.008$), and emotional representation ($p = 0.02$)). There was also a notable relationship between control and guilt, though this was not quite significant ($p = 0.06$) (see Table 4.13). After allowing for the two controlled variables, perceptions were found to produce a statistically significant change in R-Square.

Table 4.13. Details of General Linear Model Analysis of the Guilt Scale

<i>Dependent Variable</i>	R^2 7 variables	R^2 5 variables	F	df (change)	p	<i>Predicting variable</i>	F	df	p
Guilt Scale	0.418	0.355	3.660	5,30	0.01	Emotional rep.	5.663	1, 30	0.024
						Timeline	0.779	1, 30	0.385
						Control	3.802	1, 30	0.061
						Consequence	0.657	1, 30	0.424
						Identity	8.169	1, 30	0.008

Note. R^2 for 7 variables; 5 perception variables plus two variables that were controlled for, R^2 for 5 variables; 5 perception variables, change; statistic for change in R^2 after the five perception variables were added.

Positive parameter estimates ($\beta = 1.73$) indicate that the more negative the carers' perception of identity (the greater the number of symptoms they associate with the PEG) the more guilt they feel. The positive β value between emotional representation and guilt

(beta = 0.52) also suggests that the more negative participants are in their emotional representation of the PEG, the more guilt they experience. The negative beta value of guilt and control (beta = -0.431) suggests that the more control the carer believes they have over the PEG, the more guilt they feel.

Table 4.14. Summary of General Linear Model Relationships Between PEG Perception Constructs and Scores on the Standardised Measures

<i>Measure</i>	<i>R-Squared for the 7 variables</i>	<i>R-Squared for 2 controlled variables</i>	<i>R-Squared for 5 perception variables</i>	<i>Statistic of change in R-Squared after adding the 5 perception variables</i>
HADS				
Total	0.130	0.064	0.066	F (5, 30) = 0.452, p=0.809
Anxiety	0.157	0.038	0.119	F (5, 30) = 0.848, p=0.527
Depression	0.149	0.094	0.055	F (5, 30) = 0.388, p=0.853
The Guilt Scale	0.418	0.063	0.355	F (5, 30) = 3.66, p=0.01

These results suggest that perceptions of the PEG had a significant impact on carers' levels of guilt, but not on other forms of distress (anxiety and depression).

4.9. Relationships Between Other Factors and Distress

Anecdotal evidence suggested that certain demographics affected whether PEG carers were distressed. Many carers discussed guilt around eating. Guilt scores of carers, whose relative was able to eat, were compared with the scores of those carers whose relative was unable to eat. A test of normality was carried out to discern whether the samples guilt scores came from a normal distribution. The Kolmogorov-Smirnov test statistic was 0.163 for those caring for a patient able to eat and 0.143 for those caring for a patient unable to eat. Neither of these were significant $p > 0.2$. It was therefore assumed that

the sample of guilt scores was from a normal distribution. This permitted analysis using a T-test.

Levene's test of equality of variances suggested that equal population variances could be assumed. The T value ($t(37) = 1.08, p = 0.287$) was not significant, which implies that there is no evidence for a difference in a carer's level of guilt as a result of their relative's eating ability.

Carers who used pump feeding with their relative discussed feelings of distress surrounding the machinery (including equipment faults). A test, which compared the distress scores of carers using bolus methods and those using continuous methods, was carried out to distinguish whether the use of advanced technology had any effect on carers' distress levels.

The Kolmogorov-Smirnov tests for normality suggested a skewed sample for method of feeding and anxiety level. There was statistical significance in method of feeding and guilt, depression scores (see Appendix 7 for normality scores). These factors suggested that the samples were not normally distributed. A non-parametric Mann Whitney test was therefore assumed to be more useful.

There were significant relationships between methods of feeding and anxiety (Mann Whitney = 100.5, $p = 0.03$) as well as methods of feeding and depression (Mann Whitney = 108.5, $p = 0.05$). These results suggested that carers using pump feeding methods were significantly more anxious and depressed than those using bolus methods.

Journal articles and anecdotal evidence suggested that training provision and health care provision around the PEG was not consistent across Trusts (Culverwell, 2005; PINNT/Novartis, 2000). Given the small numbers recruited from PINNT and HEY NHS

Trust it was not possible to carry out a statistical comparison of distress across Trust populations. Descriptive analysis shows that the highest level of distress (anxiety [$M=11.67$, $SD=1.45$], depression [$M=9.00$, $SD=1.15$] and guilt [$M=17.00$, $SD=7.57$]) was within the PINNT sample. This may indicate that those who are most distressed by the PEG process seek additional support.

General Linear model analysis was carried out between the three Trusts (Trust two, three and four) that had similar numbers of participants. This analysis was used to determine whether Trust membership affected distress scores on standardized measures. There were no significant relationships between carers Trust origin and their distress. Table 4.15 shows the General Linear Model analysis of relationships between Trust membership and distress.

Table 4.15. General Linear Model Relationships Between Trust of Origin and Scores on Standardised Measures

<i>Distress measure</i>	<i>Statistic</i>
HAD TOT	F (2, 31) = 0.958, p=0.395
HAD Anxiety subscale	F (2, 31) = 1.200, p=0.315
HAD Depression subscale	F (2, 31) = 0.864, p=0.431
Guilt Scale Total	F (2, 31) = 0.161, p=0.852

4.10 Summary of Main Quantitative Results

4.10.1 Independent Variables

- a) The IPQ-R measure adapted for PEG carers (PPQ) was found to have an adequate level of reliability. Questions in each subscale were found to be related and subscale constructs were found to be distinct.
- b) Carers in this sample were most negative about their perceptions of PEG timeline. They were most positive in their perceptions of PEG control.

- c) There was a positive correlation between the consequence and emotional representation subscales.

4.10.2 Dependent Variables

- a) The GHQ-28 and the HADS found different levels of clinical distress within this sample of carers.
- b) Average guilt scores were low. There was a lot of variability within the sample's scores.
- c) A positive correlation was also found between the HADS anxiety and depression subscales. The guilt score total was strongly correlated to the HADS total.

4.10.3 Relationships Between Independent and Dependent Variables

- a) None of the PEG perceptions were significantly related to carers' scores on the HADS (Total, anxiety or depression subscale).
- b) Perceptions about PEG identity and emotional representation were related to carers' guilt. There was also a notable relationship between the perception of Control surrounding the PEG and levels of guilt, this relationship was just short of significance.

4.10.4 Relationships Between PEG Factors and Distress

- a) There was a significant relationship between methods of feeding and anxiety. Method of feeding was also found to be significantly related to depression.

4.11. Qualitative Analysis of the Carers' Perceptions of the PEG

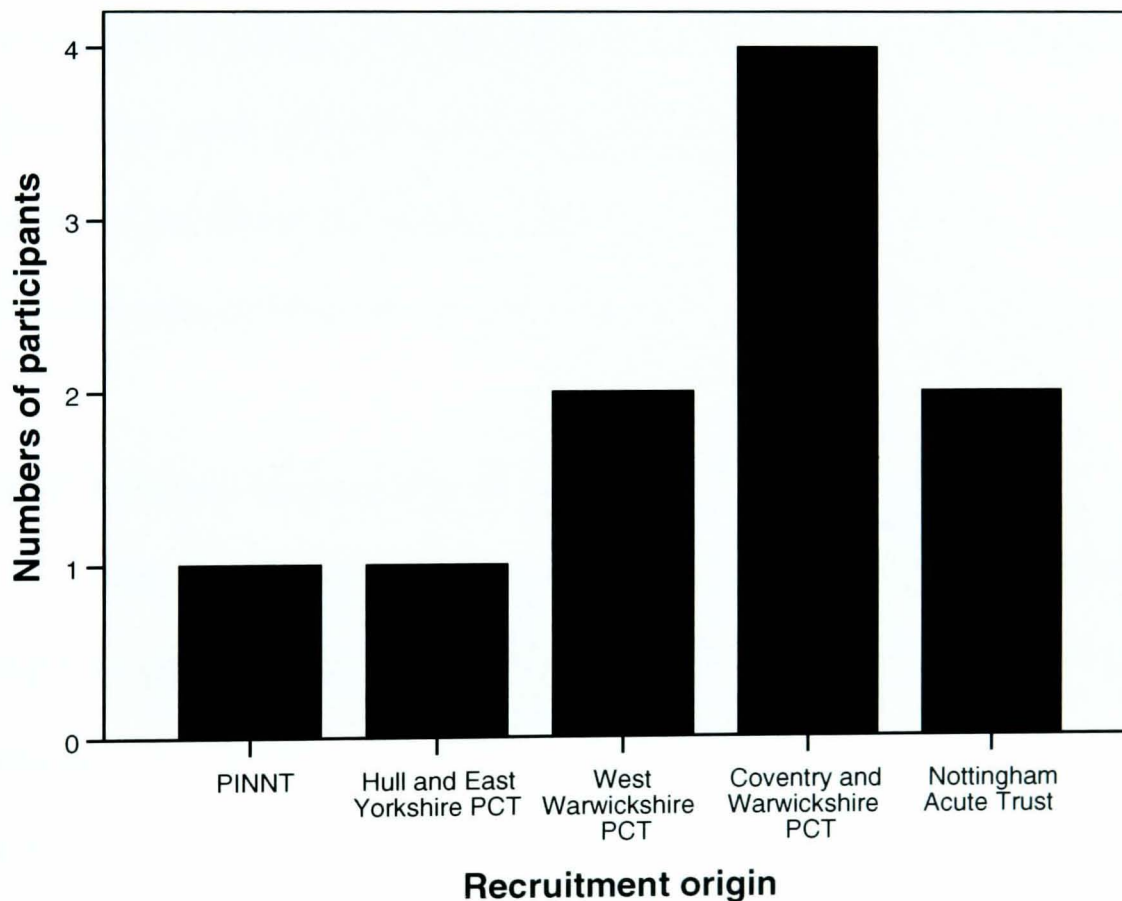
Participants talked about their experiences and perceptions of the PEG in the open-ended questionnaires which were either verbally or postally administered. Ten of these questionnaires were selected randomly for analysis. All ten questionnaires were verbally administered and data from their taped interview were analysed. Table 4.11 presents some of the demographic information about those participants whose interviews were analysed. Their names have been changed to provide anonymity.

Table 4.16 *Demographic Descriptions of Carers who had their Open-Ended Questionnaire Interviews Selected for IPA*

<i>Pseudonym (Participant Number)</i>	<i>Age Category (years)</i>	<i>Relationship with relative with PEG</i>	<i>Method of feeding (PF= pump feed)</i>	<i>Oral Consumption ability</i>	<i>Time at home with PEG (months)</i>	<i>Regular care receipt</i>
Becky	18-24	Wife	PF	Fluids & soft foods	18 +	Yes
April	45-64	Mother	PF	Fluids & normal foods	18 +	No
Fran	45-64	Mother	PF	Nothing	10-18	Yes
Sid	65-84	Husband	Bolus	Fluids & soft foods	18+	Yes
Joy	65 -84	Wife	PF	Fluids & soft foods	18+	Yes
Libby	45-64	Mother	PF	Nothing	18+	Yes
Erica	45-64	Mother	PF	Nothing	18+	Yes
Jessie	65-8	Wife	PF	Nothing	18+	Yes
Harold	65-84	Husband	PF	Nothing	10-18	Yes
Nancy	65-84	Wife	PF	Fluids & soft foods	18+	Yes

This sub-sample of participants had a female bias that was greater than that of the whole sample (16% difference). Compared to the whole sample, a higher proportion of these participants used pump feeding methods (26% difference) and there were a larger number of carers receiving professional involvement (26% difference). The 'oral consumption ability' and 'time home with a PEG' were more representative of the main sample. Figure 4.5 shows the distribution of participants across the organizations of recruitment.

Figure 4.5 A Bar Chart Presenting the Origins of Participant Recruitment



Only one participant from this sample was recruited from the charity. There was no mention of PINNT by other participants within this sub-sample.

Analysis of carers' transcripts suggested that carers could distinguish the PEG from other aspects of their relative's illness and care. It was found that PEG was always

perceived as just one part of 'a bigger picture' surrounding the lifestyle changes involved with their relatives' illness and need for care. A good example of PEG being discussed in this way was one participant's description of how PEG impacted on her family's life within their experiences of their son's illness:

You think it would be horrifying but we dealt with it years ago, that he can do less and less at every stage of the MS. I guess though you think that you couldn't deal with that happening. PEG was upsetting but less upsetting than toileting stuff where he became so exposed.

(Fran: 62-65)

The open-ended questionnaire aimed to understand the carer's perception of the consequence of caring for a relative with a PEG. However there were two opening items which were more general and asked participants about their experiences of the PEG. In general it was found that whilst participants were able to talk about areas of consequence, they were more inclined to talk within a wider context of their PEG experience.

4.11.1 A Review of Emerging Themes

The process of IPA allowed a thematic account of the descriptions given by the ten randomly selected participants. Table 4.12 displays a summary of the themes. The themes presented are not distinct as certain aspects of carer's accounts factor into more than one theme.

Table 4.17. Overview of Thematic Analysis of Carers' Perceptions of PEG

<i>Superordinate theme</i>	<i>Subordinate theme</i>	<i>Theme constructs (where identified)</i>
I'm no expert but it's down to me (n = 10)	Tell me how to do it because I don't know how (n = 10)	Initial training (n = 9) Information (n = 5) Worry (n = 7)
	There is no one else who can do it so I have to (n = 10)	Services (n = 7) Being alone (n = 8) Overwhelmed (n = 3) Worry (n = 8)
My life has changed: socialising and eating (n = 9)	I don't like to do it because they can't (n = 8)	Guilt (n = 6) Avoidance (n = 7) Enjoyment (n = 4)
	I have to be there for them (n = 6)	Time (n = 5) Equipment (n = 3)
	What others think (n = 4)	Care demands (n = 2) Appearance (n = 4)
Adaptation (n = 10)	I can do it now (n = 9)	It gets better (n = 9) Control (n = 4)
	What helps (n = 9)	Family (n = 3) Suitable support (n = 4) Ways of coping (n = 7)
	A change in understanding about PEG (n = 4)	-
Acceptance (n = 7)	That's how life is (n = 5)	-
	They need it (n = 6)	It allows them to be here (n = 3) Appearance (n = 6)

('n =' represents the number of transcripts for which that theme / construct was apparent)

Superordinate Theme 1: I'm no expert but it's down to me: Carers were asked to give a short description of their experiences of caring for their relative subsequent to PEG fitting. Although the opening question did not directly refer to discharge or transition from acute to home care, it was instrumental in the initiation of descriptions concerning the experiences of PEG. Encompassed within this main theme were two themes; 'tell me how to do it because I don't know how' and 'there's no one else who can do it'. These themes contributed to the meaning of the main theme.

Subordinate theme 1: Tell me how to do it because I don't know how

This theme denotes the sense of uncertainty surrounding the PEG process on returning home. It incorporates three constructs, 'Initial training', 'Information' and 'Worry'.

- Initial training

Training received prior to discharge was frequently discussed. Generally, training was not perceived to be sufficient to allow efficient independent coping at discharge. A quote that sums up this general consensus describes:

I used to get in a mess when I first started as they only showed me twice

(Sid: 4)

Some participants described complications which, in their opinion could have been prevented by thorough initial training:

*Once a week you were supposed to push in the tube, push it in slightly and turn it...
Now I wasn't told that*

(Jessie: 70-73)

Those individuals, who felt that they had received a comprehensive training package surrounding PEG management, reported that they felt prepared to cope independently from discharge:

I was taught very well there was one nurse particularly who took me through it step by step and I wrote it down in my note book err detail by detail... I wrote it in my own language how to do it step by step.

(Joy: 6-11)

- Information

Participants discussed which resources they believed would have made them feel more prepared for returning home. On reflection most carers believed more information would have been reassuring and would have allowed for better practical and emotional preparation:

I didn't have enough information about whether I was doing it right

(Harold: 19-20)

Others noted that additional information may have lessened the emotional impact of PEG:

I suppose if you had more information it might be less devastating

(Sid: 40-41)

The home environment was obviously different to that of the hospital and carers were unsure how the PEG process would change when incorporated into the home. Some carers felt that more information would have helped during initial discharge stages:

Do we have to be as firm at home with guidelines as they are in hospital?

(Becky: 65-66)

Carers wanted constructive management information as they felt inadequately trained to deal with situations where complications had occurred:

What my going to do if I can't get it right and can't feed him

(Jessie: 29- 30)

- Worry

Participants described their emotional reaction to the unfamiliar process of PEG. The carers reflected that they felt ill-equipped to complete the process which caused them to worry. A good example of this reaction is described by the quotes below:

You feel exposed when you're around it cause you don't know what to do

(Sid: 40)

I was very concerned erm because of it being unfamiliar to start with

(Erica: 8-9)

Subordinate theme 2: There is no one else who can do it so I have to

Despite perceptions of initial uncertainty, carers felt that the PEG was their responsibility. This theme captures carers' reflections of being exclusively responsible for the PEG. Encapsulated within this are four constructs, 'Services' 'being alone', 'overwhelmed' and 'worry'

- Services

Carers discussed service problems which negated the possibility of them having time out from the PEG or sharing the associated responsibilities. Many participants described a lack of provisions to support them with the PEG process:

There is a need for emotional support, physical support, informational support, practical support, financial support and none of it is there

(April: 88-89)

There aren't really the services, services aren't really in place to unblock it

(Libby: 9-10)

Carer's reflections suggest that service provisions surrounding PEG crisis care (e.g. tube blockage or tube dislodgement) are often inconvenient for both themselves and their relative:

I think to me if you have to keep going back to the hospital to change them (the button), they come out its more stress for, X's not very good at travelling anyway

(Erica: 30-32)

As well as difficulties related to services specifically designed for PEG care there were also problems surrounding general NHS and social care services. PEG was also perceived to result in a reduction of available support from social care:

There are no community carers that can manage X's PEG for the day

(Nancy: 136)

There's real problems getting respite to as soon as you mention they PEG they don't wanna know

(Sid: 31-32)

Some of the services still available to carers were felt to be inadequate once their relative had been fitted with a PEG. In some circumstances they did not meet the time intensive care demands that the process involves:

I didn't trust them with it (PEG) the first day I went about 1 o'clock time and said he hasn't had his 11 o'clock pill (administered via the PEG).

(Nancy: 123-124)

In other cases carers felt the inexperience and lack of knowledge health professionals had surrounding PEG caused the available services to be untenable:

often the professionals haven't even heard of it or er know how to do it or understand it. So if she was in they don't know and try to give her a drink if she's not well and that could kill her from choking. They've tried giving her medication in her mouth when she was in hospital so I can't have a break even er when she's in there and supposed, to be with people who know what they are supposed to be doing. I have to stay about, you know

(Sid: 46-51)

It was suggested that a mentor with personal experience of dealing with a PEG would have been the most suitable form of support and would have allowed individuals to feel less alone when dealing with the PEG.

I think they should have a system as well where people who go onto new tubes should have someone like a mentor, like people have mentors, to say to ring cause you can guarantee that if something goes wrong it's going to be in the middle of the night when no one is there anyway you know just to have somebody...Just for, for the first month or so just to... another family that's in the same situation they've probably being doing it along time but they can ring up and say I am having this problem what would you do.

(Erica: 203-212)

- Being Alone

Poor service provision and quality appeared to contribute to carer's sense of isolation where the PEG was concerned:

it makes you feel alone, frustrated, isolated and I don't know well awful really you are just, you are just, don't know where to turn cause your on your own and you have to find ways to fumble with it and deal with it by yourself.

(Libby: 120-123)

Those carers who felt they were alone with the PEG believed they had to correct any complications that arose and often seemed to blame themselves if a problem occurred:

you have to learn yourself and you have, I mean yes occasionally the machine did play up but you have to learn to do it

(Erica: 200-201)

Because the things kept leaking and I thought I'd been doing it so long why should they suddenly start leaking now? What am I suddenly doing wrong?

(Nancy: 45-47)

- Overwhelmed

The feeling of being alone with an unfamiliar device often overwhelmed carers. The magnitude of these feelings are reflected in the participant's quote displayed below:

It's a little bit awesome I suppose

(Harold: 39)

- Worry

Carers' worries about their relative appeared to be directly related to problems with available services, as described above. Their sense of being alone was often accompanied by worry. Dealing with problems alone was the most frequent source of worry within this context. Participants worried about potential problems that could occur:

You were worried about the tubes going to come out or the machines going to play up

(Erica: 103-104)

Their worry increased during problem solving situations as they felt they were self-reliant and the only help available was inadequate:

One night I couldn't get it to go at all as fast as it would start and before I could sort of give him a good night kiss and get out of the room it would bleep and I did panic and I was desperate. I kept stripping it all down and starting again

(Joy: 25-27)

Many of the carers were older adults. They had worried feelings about who would care for their relative when they were no longer able to:

I do worry about when, if I, you know, when I get older, if he's still here you know. Worry about other's taking over, will they have the special skills. When X had a peptic ulcer I knew how to slowly build his feeds back up and what to do.

(Nancy: 186-189)

Superordinate theme 2: My life has changed: socialising and eating

Despite the often challenging care requirements that carers faced before their relative's PEG, carers often found that their lifestyles changed post placement. The most frequently reported changes involved two areas of carers' lives; eating and socializing. It should be noted that the PEG is not responsible for individual's inability to eat. However prior to PEG fitting, carers were feeding their relatives orally (even though this process was difficult). It seemed that carers conceptualised the PEG as the 'end of oral nutrition', which is why this area of the carer's lives changed with the introduction of the PEG. This is despite some patients' continuing ability to maintain limited eating, as the ability to have a small amount of soft or normal food was not conceptualised as a meal, possibly because it was no longer needed to nourish the patient. This main theme encompasses three themes; 'don't like to do it because they can't', 'I have to be there for them' and 'What others think'. These themes highlight the carer's physical and emotional reactions to their relatives PEG.

Subordinate theme 3: I don't like to do it because they can't

Many of the carers' relatives (who had a PEG) were unable to communicate as a result of their illness. They were therefore unable to tell the carer whether they were satisfied with the PEG. However there still appeared to be a strong sense of carer congruency. That is to say that when carers perceived their relative to be unhappy with their

PEG related circumstances, they were more likely to feel uncomfortable about eating in front of their relative:

X as well was very nauseous for a long time when PEG was fitted so I was very aware of not making food smell... she'd be like urgh and start feeling sick so I would throw it away and I wouldn't eat either.

(April: 193-199)

Carers who felt their relatives were dissatisfied with the social limitations that PEG had caused for them, felt unhappy about going out without their relative. One participant explained that her husbands' social life had changed due to his inability to leave the house during an evening because of his feeding regime:

If there was something they could do for them to socialise....he got frustrated and I tended not to go out

(Becky: 47-48/ 75)

However the individuals who felt their relative was satisfied with the PEG were happier to continue life as usual.

His reaction of being kind of pleased with it affected us.

(Fran: 69-70)

Carers described several different reactions related to perceptions of their relative's tolerance. This subordinate theme has three constructs which encapsulate these reactions; 'Guilt', 'Avoidance' and 'Enjoyment'.

- **Guilt**

Carer's reactions to their perception that their relative was dissatisfied with PEG related circumstances included feelings of guilt. Carers' feelings of guilt often surrounded issues of eating and socializing. Below carers describe how their perceptions of their relative's desire to eat caused them to feel guilt about their ability to eat:

she used to get upset because she couldn't eat what she wanted to and, and she knew she couldn't and er I think that had a knock on effect we felt guilt because she couldn't eat

(Erica: 144-146)

I still eat out I just sometimes feel guilty that he doesn't eat. When X first came home from the hospital I did feel guilty that I was eating and he wasn't and I could see that he sometimes felt upset

(Nancy: 217-220)

- Avoidance

In some cases the relative's perceptions resulted in them avoiding situations that evoked difficult feelings. This reaction is described in relation to socializing by the carer below:

I'd be out, ok it's at work but to X that is out, so I'd be out all day at work and I'd want to go out again but X would find that difficult and because of that for a long time I didn't go out.

(April: 117-119)

- Enjoyment

Carers' perceptions of inequality often reduced their enjoyment of eating. This had a knock-on effect on the function:

I used to eat for pleasure now I eat for comfort

(Becky: 161)

Other carers found that since the PEG was fitted, they were more able to enjoy their food because meal times were no longer associated with the frustration of trying to feed their relative.

Subordinate theme 4: What others think

This theme illustrates carers' perceptions and experiences of the public's reactions to the PEG. The constructs 'Care demands' and 'Appearance' describe the ways in which the carers' social lives are affected by others' reactions to the PEG.

- Care demands

The reactions of others to the requirements of PEG can affect the carer's ability to socialise. One participant described how their friends' and families' reaction to the increased care demands associated with PEG, impacted on her ability to socialise with them:

'Well can't you start it later', 'well can't you do this'. Knocking X out of his own routine to satisfy them.... Of course that's had a knock on effect on me, definitely.
(Becky: 117-121)

- Appearance

Implicit within many patients' carer's descriptions was a sense that the way patients appeared when being fed would be intolerable to the public. This perception affected the carers ability to socialise. Carers felt unable to leave their relative, consequently they were restricted to the home during the feeding program which can take the majority of the day.

Subordinate theme 5: I have to be there for them

Carers' lives changed not only because of their perceptions of the relative's and the public's reaction but also because of the practical limitations (objective stressors) that using a PEG feed places on patients. These restrictions are highlighted in this theme. The constructs 'time' and 'equipment' illustrate the difficulties carers experience in relation to socialising and eating.

- Time

The time intensive demands that PEG care requires, impedes carers' ability to leave the house or prepare and eat a meal. The quote below describes what is involved in the process of administering medication:

It's a change because before I could do them quickly but now I find with crushing them up doing the PEG and finally flushing them through it takes a lot longer, you have to keep up with the washing up err if you don't at the time you find it really piles up you find you have lost almost half hour so you

(Harold: 90-93)

The combination of time it takes to administer medication using the PEG and the regularity at which these doses are required means that patients have little time to complete activities of daily living. This can often leave the carers' lives to be dictated by the PEG regime:

Meals have to be slotted in between her PEG you can't leave or do cooking, eating during, during a PEG sort of situation

(Harold: 167-168)

- **Equipment**

The equipment involved in the PEG process also affects carers' ability to leave the house. The quote below gives one carer's feelings about the restrictions that PEG related equipment can cause:

Getting everything packed up for the PEG makes you not want to go.

(Nancy: 205-206)

Superordinate theme 3: Adaptation

As predicted by the SRM model, carers found ways of coping with the PEG as time went by. This theme has a wide focus and captures the many forms of adaptation that appear to be related to PEG care including; changes in the familiarity of PEG, the ways carers think about the PEG and the things that the carers and others (including professionals) do in order to cope with PEG care. These elements are described within the subordinate themes 'I can do it now', 'What helps' and 'A change in understanding about PEG' which are encapsulated under this main theme.

Subordinate theme 6: I can do it now

Most carers that participated in this study had been using PEG with their relative for a significant amount of time. Many felt very competent in using the PEG and described that in retrospect, their experiences had improved. Within this theme the constructs 'It gets better' and 'Control' give insights into the changes.

- It gets better

This construct portrays the change in participants' perceptions surrounding the PEG process over time as they become more familiar with the PEG:

After a couple of weeks it was ok. Before that it was er a bit of a trauma

(Fran: 21)

as time went on and I got more confident with it I mean now I don't mind at all it's er it is a lot easier

(Jessie: 33-34)

- Control

It also incorporates the carer's reflections of a need for control over PEG management in order to feel secure:

I know how, how to do certain things you know if the tube goes wrong I know how to change that.

(Joy: 45-46)

Carers' reflections also seemed to indicate that they sought further control. Control appears to be sought in an attempt to relieve anxiety:

asked them if I could be trained how to do it to change them (the button) and I did get told by a nurse that no you can't do this and I at the time we were flying to America to Disneyland with her and I said look your telling me it has to be changed within an hour it has to be put back in within an hour or the hole will heal and I said what will happen if you are on a 10 hour flight we've got nobody up there that is going to be able to do it and I'm not going to be able to get the chance to do it so I think after a think they agreed to show me how to do it

(Erica: 21-27)

Carers also developed their own methods of dealing with the PEG. This also appeared to allow the carer to increased levels of control surrounding the PEG process:

when they've had a feed you swill it through as I call it but what I tend to do when I am pushing water through I squeeze the tube up and down to make sure all the residue of feed has gone

(Jessie: 115-117)

Subordinate theme 7: What helps

Whilst all carers had encountered different experiences related to PEG, most described at least one strategy or resources that they perceived had helped them to adapt. There were several common elements that contributed to this sub theme including; 'Family', 'Respite', 'Support from professionals' and 'coping strategies'

- Family

Some found that once they were more confident using the PEG, they were able to teach their family members how to administer feeds and medication which helped them to have time away:

a help really cause my grand daughter and grandson they are 16 and 17 and my own daughter well she's 30 odd but she, they all know how to do X's feed via the PEG and how to set it up and if anything goes wrong with it how, well more so grandchildren if any thing goes wrong with it erm, how to deal with

(Jessie: 202-205)

- Suitable support

When carers were able to attain suitable respite, they found that it had a significant effect on their well-being and ability to leave the house. One carer describes that:

Bringing the carers in to the home has had a big impact

(Libby: 57)

Those who received useful support from professionals also described improved sense of security surrounding PEG management:

We've been looked after well by the experts though...it makes you feel safe

(Sid: 58/60)

If I have any difficulty with PEG I can revert back to X (dietitian) at the hospital so I have a good support there, the other day I did report to Homeward because things kept leaking

(Nancy: 44-45)

- Coping strategies

Several techniques were described which were developed over time. Whilst not described by participants as coping strategies, it was apparent that these methods had helped them to adapt to their situation and appeased negative feelings.

All carers described the importance of routine. Many went on to describe difficulties associated with any disruptions:

I find if I can't stay in a routine during the day, I can just, I do get stressed

(Nancy: 25-26)

Most also gave their relatives a taste of the foods they were eating. This was especially true in cases where the carer's relative was unable to eat or drink anything orally. This strategy was sometimes suggested to carers by health professionals but often had been discovered through their own initiative:

I even get to the stage now where if I have a bit of steak it sounds awful I know but if I have a bit of steak or a bit of meat or even if I'm eating a sweet I say pop your tongue out then and I make sure it's clean and I wipe it over his tongue and he can taste the steak or a bit of fried onion you know. I mean he quite likes it.

(Jessie: 257-261)

Humour was another mode of coping. It appears that many carers used humour in order to appease their negative feelings that they are not orally feeding their relative.

We might have a bit of a joke on a nighttime I might say you know what would you like for your meal roast beef

(Harold: 185-186)

Subordinate theme 8: A change in understanding about PEG

Several carers were aware of a shift in their understanding of the PEG since discharge. Carers described being daunted by the PEG process when they were initially discharged. At this stage they explained that they understood the PEG process as a 'Medical procedure', which required accuracy and did not allow for flexibility. As time passed, carers commented that they were more relaxed with the procedure. This appeared to be related to their change in PEG conceptualisation, from a medical intervention to a method of feeding.

To me it was in my mind that it was like a medicine he had to have it exactly when it was supposed to go on otherwise it would be terrible. It was only once she (a carer) had laid it down to me in those terms, about it only being food that I was ok.

(Fran: 9-12)

Once able to relate the PEG process with a concept that they were familiar with, carers appeared to be more comfortable about the procedure and possible problems that may arise:

This was my one worry that I used to have that I was going to starve him which is a silly thing because if you go without food for a day you don't starve but it seemed that, that was his life line to me, the PEG was and erm and but now I don't really worry

(Joy: 49-52)

Superordinate theme four: Acceptance

When the researcher first greeted participants, they would often remark that the PEG caused no problem. Once specific areas were mentioned and carers were encouraged to express their experiences, several concerns and difficulties were raised. Adaptation did

not alleviate all of the carers concerns and problems relating to the PEG process. Many still described circumstances that were difficult. Despite this, carers frequently followed the description of a difficulty with a statement which indicated that PEG was 'not too bad'. Acceptance is contributed to by two constructs 'That's how life is' and 'They need it'.

Subordinate theme 9: That's how life is

Carers seemed to be resigned to the fact that their life would be different now their relative had a PEG. They did not appear to believe that their circumstances could alter and were resolute that they had to accept the situation and 'get on with it':

I still feel guilty, I feel guilt but that can't be helped I am always going to have that bit of guilt no matter what anyone says or does. I am always going to feel a little bit guilty

(Becky: 33-35)

I think when she started your committed it's not er a thing that you can erm start and then say I can't do it you've got to say I'm going to do it and carry on doing it erm there's no two ways about it

(Harold: 200-202)

Subordinate theme 10: They need it

In some cases carers appeared to have a sense of gratitude towards the PEG and the professionals involved with it. They understood that the PEG was a necessary aspect of their relatives' care. Constructs incorporated within this theme were 'It allows them to be here' and 'Appearance'.

- It allows them to be here

Many carers were acutely aware that without the PEG their relative would not be alive. The PEG was therefore conceptualized as the 'less of two evils':

You think they are there for a reason they are there for a purpose and they are saving his life

(Becky: 138-139)

I knew he couldn't do without it. I did ask if there was any alternative but they said not really

(Joy: 69-70)

- Appearance

Carers also acknowledged the physical benefit that the PEG (mainly surrounding the patient's skin and weight) had allowed, particularly in relation to their appearance:

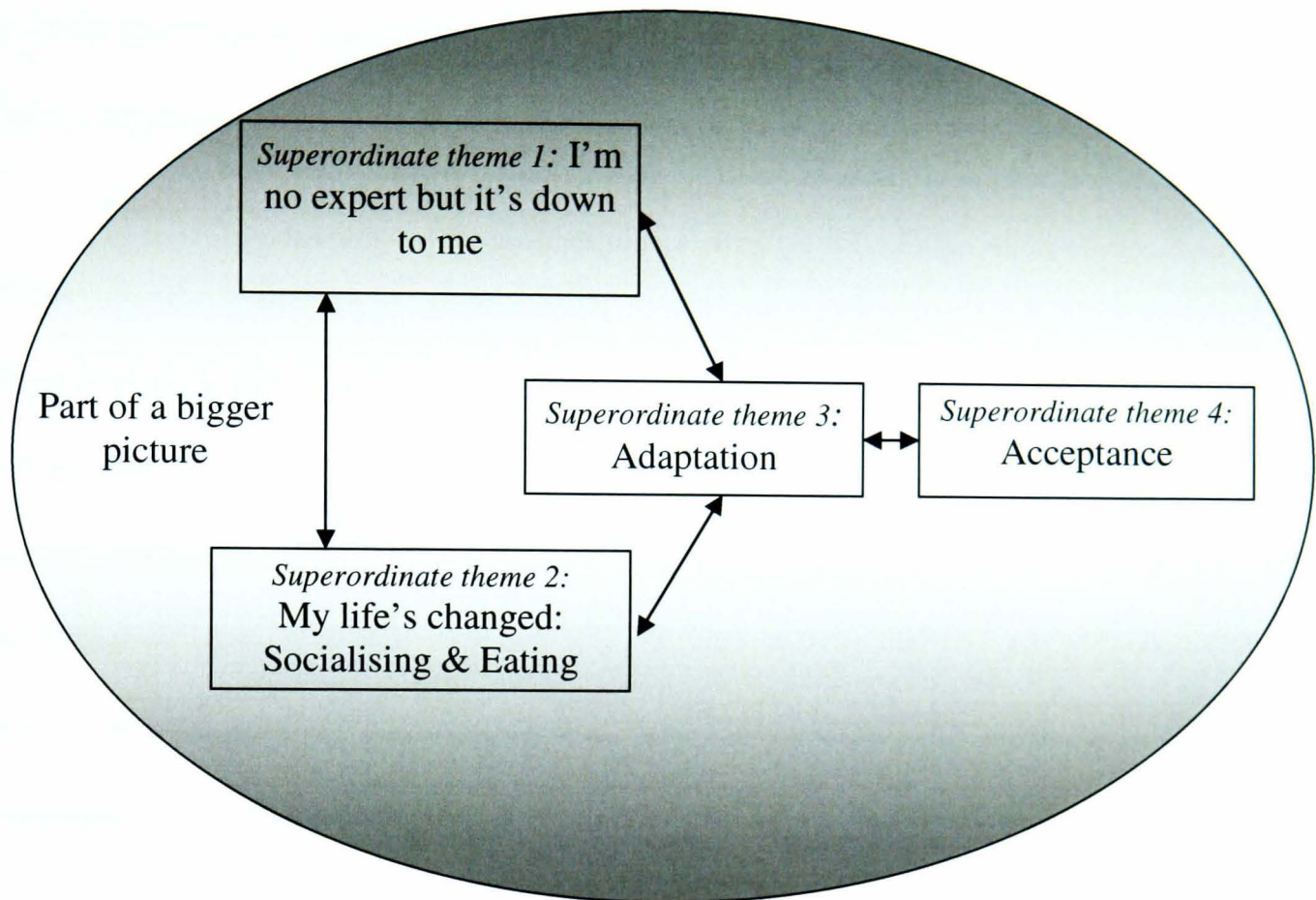
X was like a skeleton before she had her PEG I think she looks lovely I mean she's put on 2 and a half stone at least

(April: 160-161)

4.11.2 A Summary of Qualitative Results Using the Derived Model of PEG Carer Perception Process

Section 4.101 reviewed the emerging themes from exploratory analysis. This section progresses to take a more holistic view of the themes with the aim of understanding the PEG perception process. Figure 4.6 displays a model that has been derived from the emerging themes. This model creates a framework which shows the way in which the themes relate to each other. Joining the superordinate themes in this way provides a summary of the results from the thematic analysis and aims to allow a sense of carers' experiences and perceptions related to PEG.

Figure 4.6 A Model of PEG Carers' Perception Process



The majority of carers involved in exploratory analysis described feeling under prepared when their relative returned home with a PEG. Despite these feelings the perceived lack of suitable provision meant that they felt they needed to cope on their own. As made explicit in superordinate theme 1 'I'm no expert but it's down to me'. Carers' attempts to cope alone meant that their lives changed due to the practical demands of the PEG. In general, carers reported that they had less time to socialise and eat full meals. The equipment involved with the PEG also meant that they were less likely to leave the home.

Carer's reactions to perceptions of autonomous responsibility for the PEG also appeared to be related to life changes. The changes and the reasons behind changes are delineated in superordinate theme 2; 'My life's changed: Socialising & Eating'. Those who perceived that their relative was unhappy with the PEG were likely to have emotional

reactions to the PEG such as guilt and decreased enjoyment. They were therefore less likely to leave the home or eat meals in front of their relative. These carers were also affected by their perception of others' reactions to the PEG.

Initial stages of PEG management were described as more difficult than current circumstances as detailed in superordinate theme 3 'Adaptation'. Many carers described the ways in which they had adapted to cope with feelings of being independently responsible for the PEG and the areas of consequence they associated with PEG feeding. In some cases carers' adaptation was as a result of being more familiar with the PEG process or the provision of more suitable external support. However the majority of carers involved, described changes in their way of thinking about the PEG or dealing with areas of consequence they found difficult.

Once the carers had made some adaptations, to make living with the PEG more manageable, there appeared to be an 'acceptance' as is described in superordinate theme 4. This involved the understanding that they were the individual who would have to deal with the PEG and that their lives would be different. Their emotional reactions to the PEG were also accepted as carers were acutely aware that their relative needed this intervention. In general, acceptance appeared to be related to a sense of gratitude.

4.11.3 Results of Investigator and Theory Triangulation

A summary of emergent themes and the derived 'PEG carers' perception process model' were sent to a Clinical Psychologist, a Trainee Clinical Psychologist, a Dietitian and a participant who had agreed to review themes and make comments.

Clinical Psychologists: A Clinical Psychologist with experience in IPA and qualitative research methods and a Trainee Clinical Psychologist, both of whom were familiar with the transcripts, were involved in initial validation of analysis. They felt that some transcripts became complicated with other issues. Discussions facilitated the researchers thought processes which enabled the development of the PEG carers' perception process model within a bigger picture of care and illness. Subsequent to further analysis these colleagues confirmed the emergent themes and the links made within the model.

Dietitian: A dietitian who was involved in the recruitment process reviewed the anonymous transcriptions and gave her opinions about the emerging themes that had been identified. Some of the themes echo her own clinical experience. For example, her experience suggests that some carers who give their relatives on PEG a taste of food may not be acting in a safe manner. She has found that in some cases, despite warnings, carers will use tasting strategies. She feels that this clinical finding relates to the theme 'My life's changed: Socializing & Eating' as it emphasizes the value that carers place upon their relative's ability to have some oral enjoyment.

Participant: One carer who completed the review of themes remarked that they reflected her experiences. This participant acknowledged the different backgrounds and experiences of the carers and noted that the theme 'I am no expert but it's down to me' was more exaggerated in her case. In her e-mail response she noted that "*the initial frustration and lack of communication with our G.P's surgery by the hospital was downright dangerous*".

Summary: The above responses have been encouraging. They suggest that the credibility checks that were implemented have allowed the qualitative research findings to provide a 'true' reflection of the experiential descriptions of PEG carers' perceptions and experiences.

Chapter Five: Discussion

The aim of this study was to explore family carers' experiences and perceptions of PEG feeding. Using a psychological model (Leventhal et al's [1980, 1997] SRM) the study's main focus was to understand whether carers' perceptions of the PEG were related to their distress. These aims were generated from the findings of small qualitative studies, where carers' descriptions of PEG experiences involved feelings of distress (Brotherton et al, 2006; Liley, 2001). The rationale behind this study was the limited understanding of carers' reactions to the PEG and the lack of an objective measurement of distress in this population. A clearer understanding of these areas was hoped to allow the development of needs-led interventions.

Approximately half of this sample of PEG carers had a clinical level of distress, 43.6% had anxiety and 20.5% had depression. This is at the higher end of percentages that would be expected as Oyebode (2003) found that between a third and a half of informal carers were distressed. Compared with Rickman's (1998) sample of PEG caregivers, fewer carers were found to be anxious. However because of the design of Rickman's (1998) study, where there was a small sample of PEG carers and no standardized measures of distress, the comparison is not equitable. Findings also indicate that the proportion of carers suffering from depression was comparable to the percentage of PEG patients who suffer from this kind of distress (Roberge et al., 2000).

The GHQ-28 was used as a further measure of psychological distress. This tool differentiates between distinct types of distress. This measure found a lower level of clinical distress than the HADS. Only 13% of the sample were found to be clinically

distressed. It was found that PEG carers' suffered more from somatic symptoms than other types of distress.

5.1 Discussion of Research Questions

Question one: What are family carers' perceptions of their relatives' PEG?

Cognitive behavioural frameworks assume that thoughts are related to feelings. Thus, in order to understand the distress reactions to PEG, carers' perceptions of the PEG were investigated. It was hoped that a more in-depth knowledge of carers' perceptions would allow a clearer understanding of PEG related distress.

The average item scores on the adapted PPQ indicated that participants viewed their relatives' PEG as long term. Whilst averages on the majority of PPQ perception constructs were found to be neutral, it does not seem to that the dimensions are irrelevant to PEG carers. On closer examination of the items, there were skewed distributions of responses on many of the items relating to consequence, emotional representation, and control (see Appendix 8). Participants would either agree or disagree rather than responding neutrally. This suggests that the population is heterogeneous in their perception of the PEG.

The use of Methodological Triangulation also suggests that the five perceptions had relevance to PEG carers. There were differences in construct labels, yet the essences of the five perception constructs were apparent in the qualitative transcripts. The differences seemed to be a result of the dissimilarities between carers' language and the psychological terminology used in Leventhal et al's (1980, 1997) SRM.

The perception construct timeline was implied in open-ended response descriptions of worry about long term PEG related care. Reports about the problems and symptoms associated with PEG appear to link in with the description of the identity construct. Consequence areas were specifically addressed within the open-ended questionnaire. Changes in socializing and eating appeared to be involved in the PEG consequence perception. The perception construct control, was evident at two stages of the PEG perception process; at discharge, where carers described feeling unable to control the PEG and during adaptation, where carers seek to increase their ability in order to feel in control. Emotional representation constructs were also apparent in reports of the PEG process, where the carers talked about feelings of worry and being afraid.

Qualitative results also suggest that PEG carers' perceptions are not static over time. Whilst Timeline was not discussed in this manner, negativity associated with all other perception constructs appeared to be transient. Carers' retrospective statements suggest that negative perceptions diminished with time. The majority of carers within this sample had been supporting their relative with PEG at home for over 18 months. It is possible that the nature of the five perceptions constructs would be different if carers were less experienced with the PEG.

Question two: How do family carers' perceptions of PEG influence their psychological distress (anxiety, depression and guilt)?

To test the applicability of cognitive behavioural theory within this area of research, the SRM was used. This model was applied with the aim of ascertaining whether carers' perceptions of the PEG were related to their distress.

There were no significant relationships between the carers' perceptions of PEG and anxiety or depression. However carers' perceptions of the PEG were related more to anxiety than depression. The controlled variables, oral ability and decision making, were more strongly related to depression than were the five perceptions constructs.

There was a significant relationship between perceptions and guilt. The strongest relationship was between the Identity construct and guilt. The Identity perception measure on the PPQ asks respondents about the medical symptoms they associate with the PEG. The nature of this dimension's relationship with guilt indicates that the more symptoms perceived to be the result of PEG, the more guilt carers experience. Qualitative results suggest that carers feel it is their responsibility to solve problems when difficulties arise with the PEG. Therefore, it may be that Identity is related to guilt because carers felt responsible for preventing or dealing with the symptoms.

Another significant relationship was between Guilt and Emotional Representation. Whilst items measuring Emotional Representation asked carers about feelings of anxiety and depression when thinking about the PEG, this dimension was not found to relate to HADS anxiety or depression scores. This may suggest that the carers' subjective understanding of anxiety and depression (in relation to the PEG) reflect the societal shift in the everyday naming of feelings and emotions. Increasingly throughout the 20th Century, feelings of sadness or worry have been replaced by the terms depression and anxiety (Horwitz, 2005). Thus, whilst the carers relate to the psychiatric labels used in the Emotional Representation items, the emotions they are actually experiencing are milder stress reactions, which do not constitute clinical distress on psychometric measures.

There was also a notable relationship between Control perceptions and guilt, although this was not significant. There was a negative parameter estimate between control and guilt, given the marking scheme on the PPQ, which judged low levels of personal control as a negative perception. This suggests that carers' level of guilt is increased if they feel that they have more control over the PEG process.

Question 3: What is the phenomenological nature of family carers of PEG patient's perceptions and distress?

Qualitative data was used to gain a further understanding of carers' experiences and perceptions of consequence, particularly addressing the areas (eating, socialising, relationships with patient, relationship with others, appearance and sexual relationship) outlined in the literature review. This information also provided further insight into the nature of PEG carers' distress and allowed further understanding of the relationships between perceptions and distress.

Perceptions

- Control

Phenomenological data suggests that initially carers feel apprehensive and unsure of how to use the PEG effectively (they did not feel in control of the equipment or process). Carer descriptions relate this experience to feelings of worry. They also discussed how control was used to ease worry within the superordinate theme 'Adaptation'.

- Identity

Leventhal et al's (1980, 1997) SRM describes that the Identity dimension includes the concrete signs and symptoms that the individual perceives as being associated with the

illness (Scharloo et al. 1998). The average number of medical symptoms associated with the PEG was low. Given that PEG is not an illness, it is possible that the PEG's identity is broader than that of an illness. Phenomenological data suggests that the identity of PEG should include problems associated with the PEG, such as leaking, tube dislodgement, and pump malfunction.

Analysis of qualitative data also suggests that there are further elements of identity that should be considered. Subordinate theme 7: 'A changing in understanding about PEG' appears to indicate that there is a shift in carers' identity perception of the PEG. Some carers state that initially they perceived the PEG as an unfamiliar medical intervention. This was also found by Sleigh (2005), where parents described the PEG as 'unnatural', 'medical' and 'likely to inflict pain'. However participants in this study described a change in their thoughts about the PEG process, which allowed them to perceive the process as a method of feeding.

Carers linked the shift in their understanding of the PEG with their distress. This suggests that the nature of the above cognitive construct (alike identity) fits with the predictions of the SRM, where their perceptions and emotions are processed in parallel and relate to each other.

- Timeline

Carers appear to believe that PEG is either a long term or permanent intervention. Within quantitative analysis it was found that, despite carers' negative perceptions, there were no significant relationships between timeline and distress. Qualitative analysis also suggested that carers believed the PEG was a long term intervention. However, some accounts highlighted worries in relation to Timeline, describing fear over future care. This

may suggest that there is a relationship between carers' distress and timescale but that this was not detected by the quantitative measures used within this study.

- Consequence

Eating and socialising

Eating and socialising were the two areas which were perceived as the most negative consequence of PEG care in the additional items on the PPQ and the Likert, satisfaction sections of the experiences questionnaire. These results support the findings of smaller qualitative studies (Brotherton et al, 2006; Liley, 2001; Rickman, 1998).

These areas of consequence, identified in the introduction, were also apparent within the qualitative themes. Within open-ended questioning, socialising and eating were the two areas of consequence, where the majority of carers gave additional information about their thoughts, feelings and experiences.

In the review of the themes (see section 4. 10) Superordinate Theme Two describes the phenomenological nature of these two consequence areas. Analysis of this sample's transcripts highlighted the links between carers' thoughts, feelings and behaviours related to these areas of consequence. Whilst some research linked the carers' psychological reaction to the PEG with the consequence areas; eating and socialising (Brotherton et al, 2006; Liley, 2001; Rickman, 1998), these areas of consequence were found to relate to practical procedure-related restraints such as increased time demands and equipment issues, rather than the psychologically based restrictions (Pedersen et al, 2004; Rickman, 1998; Verhoef & Van Rosendaal, 2001). Some of the potential links made in section 1. 8, between practical and perceptual factors of eating and socializing, were apparent within findings. For example, carers did not want to leave the house because of their perception

that feeding in public would not be acceptable to others. The PEG carers' perception process model also shows a link between carers' perceptions of health professionals PEG capabilities and their ability to leave the patient in order to socialise.

Appearance

The additional items added to the PPQ on the consequence area 'Appearance' were congruent with qualitative findings. Carers either believed that their relative's appearance had remained the same or improved slightly ($M = 2.56$, $SD = 1.19$). The nature of improvements was mainly physical, involving changes in weight, skin and hair. The change in body image reported by PEG patients (Oley, 1997) with regards to the appearance of the stoma site and tubes did not appear to concern carers directly. Those who did remark on the appearance of PEG related equipment worried about how the patient might feel about people looking, suggesting a dyadic reaction to the PEG.

Relationship with the PEG patient

Unlike carers of parenteral patients, most carers do not appear to perceive that their relationship with the patient has changed since PEG introduction (Smith et al, 1991). This is apparent on the additional PPQ ($M = 2.59$, $SD = 1.33$) item and on the experiences questionnaire, where the majority of carers (64%) reported that there was no change in satisfaction in their relationship with the patient since the introduction of PEG ($M = 1.8/7$ on the Likert scale). The nature of this small degree of change appears to be related to an increase in time spent with patients, as described in some carers' responses to open-ended questions.

Relationships with others

Some carers (28%) perceive that their relationships with others are less satisfying since PEG introduction. However the strength of this perceived change does not seem to be as great in carers as it is in patient populations. Roberge et al's (2000) finding that 15% of PEG patients felt detached from their family, does not seem to reflect carers' perceptions of change. The results of the additional items on the PPQ suggest that the carer agreed that PEG care had an impact upon their relationships with others but that this was not a strong negative consequence for them. Likert scale results also suggest that carers do not perceive large amounts of change (2.5/7). Most carers who reported differences in this area (as a result of the PEG), described that they saw friends and family less and that their significant others had to come to them rather than meeting in alternative locations:

I can't go to them to see what they've been doing, I can't go along so they can describe things that they've been doing. I don't see people as much as I used to er people have to come to me, er not me to people.

(Harold; 132- 134)

Sexual Relationships

Many of the spouse carers in this sample felt that sexual issues were not a relevant aspect in their relationship with the PEG fed partner. Many reported that sexual contact with their partner had ceased prior to PEG placement. The participant who was a wife to a man who had his PEG placement in the earlier stages of his disease, stated that her sexual relationship had completely changed (7/7 on the Likert scale). This carer's descriptions agree with the PEG patients and carers' (from Ostomy populations) accounts of sex as a 'hidden issue'.

This carer discussed that similar practical issues, addressed by patients involved in Oley (1997) and Rickman's (1998) research, were the issues that had affected her and her partner. She did not feel she or her husband were less interested in a sexual relationship since PEG placement.

- Emotional representation

Carers describe being worried about the PEG when they are first discharged. The nature of this worry appears to change over time. Descriptions of worry become less globalised and appear to be more periodic when complications occurred. This worry is both prospective and concurrent to PEG related problem occurrence.

Descriptions also suggest that some carers felt upset by the PEG. This was linked with their relative's inability to eat. Whilst the PEG was not the cause of the patient's inability to eat, carers' descriptions suggest that it was a symbol of the time when oral nutrition ceased. Many also emphasized that the views (emotional representations) they might have held about the PEG, were not relevant to them because they believed the PEG was what was allowing their relative to stay alive. Such descriptions may relate to the quantitative findings that carers, who acknowledge high levels of negativity in their perceptions of consequence, have high levels of negativity in their perceptions of emotional representation.

Distress

Phenomenological carer responses provided additional information about the nature of psychological distress. Two main types of distress apparent within analysed transcripts were worry and guilt.

- Worry

Carers used many different names to describe feelings of PEG related worry. These included; anxious, frightened and daunted. Most of these descriptions related to carers' initial unfamiliarity with the PEG process. Prospective worry was also apparent. This mainly concerned problems that might arise as a result of the PEG and the future care of their relative.

Responses from open-ended questions also indicated that carers worried about hurting their relative's (with PEG) feelings. This worry appeared to relate to carers' guilt.

- **Guilt**

The nature of PEG carers' guilt appeared to be based on their worry about upsetting their relative. Carers' responses suggest that they imagine how they might feel if they were experiencing their relatives underlying condition and PEG placement. The introduction of the PEG appears to cause guilt because the carer fears upsetting their relatives by doing things that they can no longer do (since PEG placement). O'Connor, Berry, Weiss, Bush and Sampson (1997) suggest that this type of guilt reflects an exaggerated sense of responsibility and can be divided into several distinct but related types. The two forms of guilt that appear to be relevant to PEG carers are Survivor Guilt, Separation Guilt.

Modell's (1971) work looked at a subtle form of Survivor Guilt. The descriptions of an 'unconscious bookkeeping system' involved with this type of guilt appear to fit with some of the feelings and behaviours described by PEG carers. Participants described inhibiting their own lives (particularly eating, social eating and socialising) because of their perception that their relative was in a worse position compared to themselves. Weiss (1986) suggests that people act in this way because they feel they are enjoying themselves at the expense of others. This feeling was apparent within some of the descriptions given:

I don't like to go often unless it's a special occasion because I don't think it's fair on X eating in front of him, not just me but a crowd of people it's not too bad, one person or two persons eating in front of him but when it's a whole crowd I think its, plus you've got all that smell as well it must be a bit agonising

(Jessie: 182-185)

Separation guilt is described as an individual's belief that they are not entitled to their own life. Carers would be expected to feel that separation would result in their relative's death if they were suffering from this kind of guilt (Modell, 1965). Whilst this feeling was evident within some accounts, it is unclear whether these statements reflect guilt. As mentioned previously, these areas of guilt reflect an exaggerated sense of responsibility. Some carers' experiences of inadequate hospital, respite care and their inability to gain a qualified social carer to support their relative post PEG placement, meant that in some cases there could be a risk of harm to the patient if carers were separated from their relative.

5.2 Additional Exploratory Findings

5.2.1 Guilt as a Mediating Factor

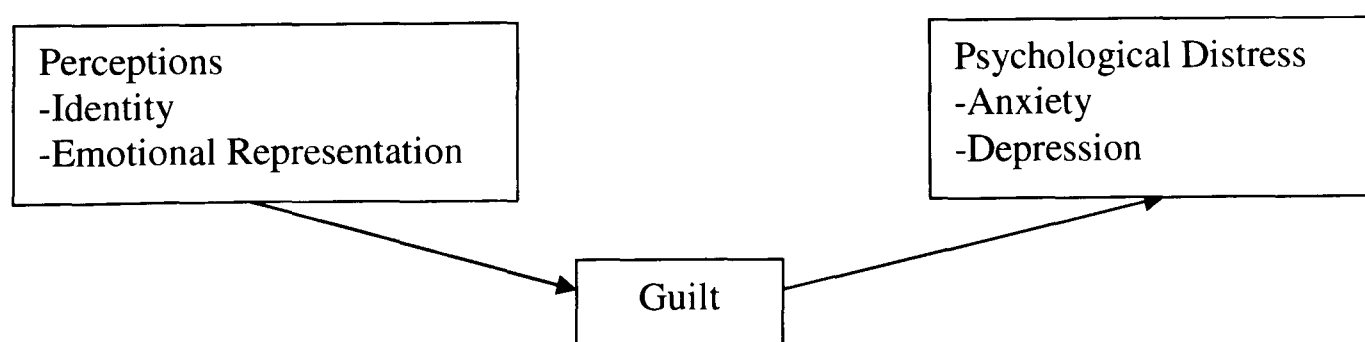
Guilt is known to serve an interpersonal function, which maintains bonds (Baumeister et al, 1994). Some researchers suggest that guilt can cause altruistic behaviour (Rawlings, 1968; Regan, 1971). Studies within couples have found that if the partner perceives their relative is suffering, they feel guilt which initiates their attempts to comfort (Lerner & Matthews, 1967). Findings of this study show that whilst the majority of participants report some level of guilt, only a small proportion scores highly. It is important that professionals do not assume that guilt is pathological. Professionals should keep in mind that a reasonable level of guilt is a natural response to changes that cause one of the

individuals in the relationship to feel that their circumstances are more advantageous. Guilt can motivate care-giving behaviour without negative effect on carers' well-being (O'Connor et al 1997). Also, the positive relationship between guilt and self efficacy (Baldwin, Baldwin & Ewald, 2006) suggests that a certain level of guilt associated with the PEG allows increased self-efficacy. Bandura's (1997) descriptions of self-efficacy may explain the finding that carers continue to seek control over the PEG and adapt relatively quickly.

However research suggests that guilt is a contributor to clinical distress (Freud, 1923; 1940; Klein, 1948; Modell, 1971). Findings suggest that the types of guilt associated with carers' perceptions of PEG (survivor and separation) are often perceived as pathogenic. Mental health becomes a concern when guilt is considered to be excessive or generalised (O'Connor et al, 1997).

This research project found significant relationships between identity, emotional representation and guilt rather than anxiety or depression. The HADS total was found to be positively correlated to the total guilt scale score. These research findings and the guilt literature described above appear to fit with Baron and Kenny's (1986) work on mediating variables. Figure 5.1 illustrates the potentially mediating effect of guilt between the perception constructs and distress.

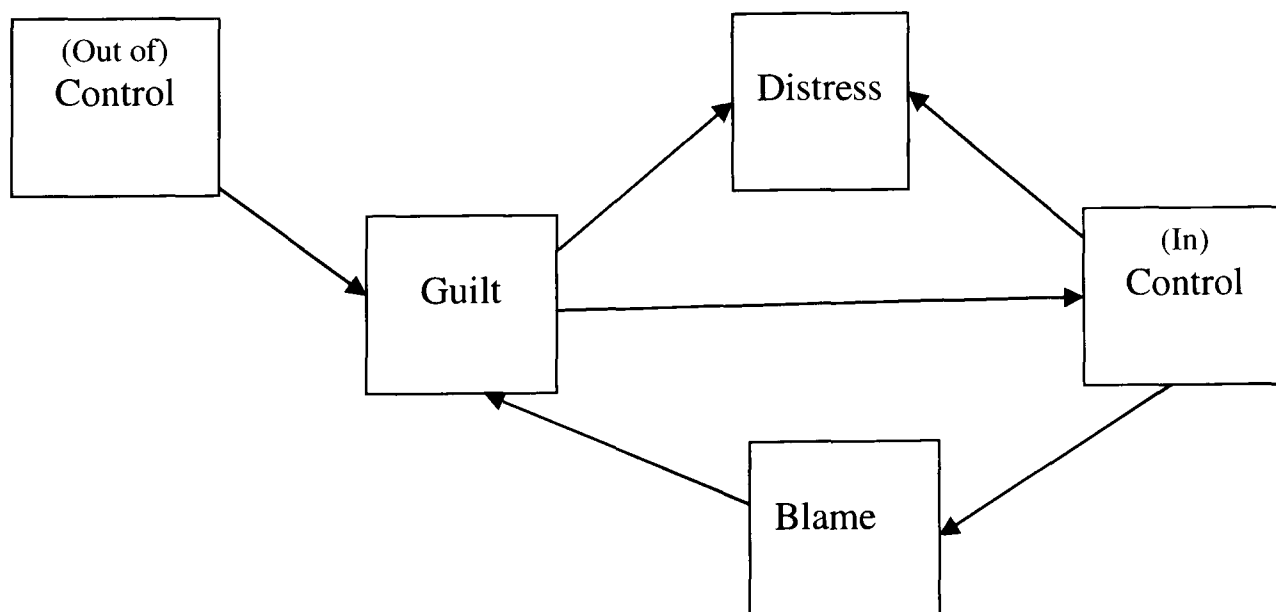
Figure 5.1. A Diagram of Guilt as a Mediating Variable



This model suggests that increased negativity in PEG identity and emotional representation perceptions would result in higher levels of guilt. High levels of guilt are pathological for PEG carers and would result in carer distress. The proposed model, where guilt acts as a mediating variable, is consistent with findings within other areas of interpersonal relationship research (Shilkret & Vecchiotti, 1997).

This model could be further developed for PEG personal control perceptions using both qualitative and quantitative findings. Whilst qualitative findings suggested that increased control over the PEG reduces distress, quantitative results suggest that high levels of personal control result in increased guilt. Using Methodological Triangulation, further interpretation of these findings suggest that whilst increased control perceptions relieved levels of distress, they can also reinforce carers' feelings of having sole responsibility for the PEG. Some carers' accounts suggest that during problem solving situations, they blame themselves for the difficulties that have arisen. This hypothetical model of the control perception is depicted in Figure 5.2.

Figure 5. 2. Hypothetical Model of the Control Perception in PEG Carers



This model proposes that with current preparation packages many carers feel out of control when their relative is first discharged with a PEG. This appears to cause feelings of guilt because the carer feels unable to use the PEG effectively to provide their relative with good quality care. Guilt becomes excessive as carers wonder how they will cope. This appears to result in distress. However guilt also appears to motivate control seeking. Having increased control, seems to initially reduce carers' distress. Yet, once the carer has had further training or has developed their own methods of controlling the PEG, they appear to feel that they are to blame if a problem occurs. This cycle of control, blame and guilt appears to continue until the carer has enough control to avoid situations that they cannot cope with, or once they have established a support network which allows them to feel they are not alone in the PEG process.

5.2.2 Coping Strategies and Hardiness

This study does not aim to understand the relationship between PEG carers' distress and coping or personality. However the additional exploratory information gained through open-ended questioning and the researcher's contact was felt to necessitate some discussion of these areas.

Coping Strategies

Silver, Wellman, Galindo-Ciocon and Johnson (2004) found that PEG care fits with unidirectional, dependent and stressful care as described by Pearlin et al's (1990) care giving model. Pearlin et al's (1990) model was adapted for technology-dependent patients (Smith, 1994). In Silver et al's (2004) research, this model was applied to care givers who supported older adults using HETF. Smith et al (2004) found that preparedness and competence was a mediating variable which affected the maintenance of the caregivers'

health. However it does not seem that PEG carers' coping strategies have been studied in this way. This study's findings suggest that the coping strategies carers use, may affect the relationship between their perceptions of the PEG and distress. Several types of coping mechanism that appeared to be relevant to PEG carers well-being are briefly discussed below; dyadic coping, avoidance, self-affirmation, and gratitude.

A psychological element that was not highlighted within other research was the dyadic response to the PEG, between the patients and the carers. The carer's emotional reactions and contentment with the PEG was found to be affected by the feelings of their relative. Responses of this nature were found to affect carers' consequence perceptions of eating and socialising. Some carers, who felt guilty about leaving the home or eating, linked their feelings with their perceptions that their relative was dissatisfied with the PEG. These research findings appear to reflect Bodemann's (1997) 'systemic-processual' view of stress and coping in interpersonal relationships.

Dyadic Coping is a process where both partners attempt to help each other cope with a stressor. This type of coping has been found to have a positive effect on the emotional well-being of each partner (Bodenmann, 1997). However for many patients, PEG is introduced within the latter phases of the illness (Dennehy, 2006). This often negates the use of Dyadic Coping. PEG carers may require further support if they perceive that their relative has a negative reaction to the PEG as they are less able to use adaptive coping mechanisms such as Dyadic Coping. Without such support it seems that strategies which fit in with avoidance definitions (eating alone or in secret) may develop. This type of strategy has been associated with the maintenance of distress levels (Maner & Schmidt, 2006).

Acceptance was felt to develop, in part, because of the carers' understanding of the PEG as an intervention, which was sustaining their relative's life. Self-affirmation (Steele, 1988) and Gratitude appeared to be two areas which were relevant to acceptance of PEG care requirements. Self-Affirmation is described as a process where the individual affirms their values, highlighting those that they hold as important (Tesser, 2001). This process helps them to cope with potentially stressful situations. It seemed that the carers valued their relative's continued existence over their own difficulties or perceptions associated to the PEG. Self-Affirmation appears to lead carers to have a sense of Gratitude surrounding the PEG.

People are expected to feel Gratitude if they have been given something that is understood as a benefit (Emmons & McCullough, 2003). PEG carers were reluctant to discuss negative aspects of PEG and often appeared to minimize difficult experiences. The researcher's experience suggested that this trend was a result of a sense of gratitude where carers felt that PEG was ultimately beneficial as it had allowed physical improvements for their relative. Gratitude has been found to result in benefits with regards to emotional well-being (Emmons & McCullough, 2003).

Hardiness

Anecdotal evidence from this study suggested that there were some internal qualities which had an impact upon carers' perceptions of the PEG and their distress. There has been some case study work on personality within PEG patient and carer dyads which suggest that there's a relationship between carers' personality and their response to the demands involved in PEG care (Grindel et al, 1996; Peteet et al, 1981). However an aspect of personality which has been found to be a buffer against the effects of stress, known as

'Hardiness', has not been explored within this population (Kobosa, 1979). Individuals, who are considered to have high Hardiness, perceive adverse life changes as a challenge. Some individuals with high levels of this internal quality, have even been found to experience psychological benefits when faced with adversity (Clark & Hartman, 1996) and carers have been found to be less vulnerable to distress (Clark, 2002).

Although this construct has not been explored by this study, early indications suggest that Hardiness acts as a moderating factor. Whilst all carers were able to describe some negativity in their perception constructs of PEG, some carers appeared to struggle with PEG responsibilities, whilst others looked upon their role as a challenge and were committed to providing their relative with the best quality of care possible. Qualitative data suggests that 'Hardiness' affects the strength of the relationship between carers' perceptions and distress.

5.3 Critique of Research

5.3.1 Conceptual Issues

Designing a research project, which aims to understand the impacts of PEG feeding for family carers, is fraught with difficulties. This is due to the numerous extraneous variables related to the heterogeneous background experiences that carers have encountered and because of the wider context that the PEG exists within.

The difficulties outlined below are acknowledged in hindsight of data collection and analysis. Many of these difficulties would have been difficult to predict due to the explorative nature of this study. Despite these difficulties, this piece of research has involved a group of carers who have received minimal regard within past research.

To the researchers' knowledge, this is the first piece of research to examine family carers' perceptions of PEG feeding. It has also been the first attempt to objectively measure carers' distress using standardised clinical measures. More specifically, it has allowed for a greater understanding of the nature of PEG caregivers' guilt, which has been subjectively reported within purely qualitative studies.

5.3.2 Design

A cross-sectional design was implemented because of the relatively small population size and time restrictions associated with this piece of research. However, the single data collection point associated with this type of design meant that it was not possible to compare how participants' perceptions had developed and how levels of distress had changed over time.

The reliance on sample averages is a disadvantage of this type of methodology (King, 2001). This difficulty may be particularly pertinent to this piece of work, as there was often a large range within average scores. It may have been more useful to assess intra-individual change through the adaptation process using a longitudinal design.

Participants often reflected on events that had occurred in the past, which contributed to their current perceptions of their relative's PEG. A retrospective account relies on carers' ability to recall events that happened in the past (King, 2001). Whilst there are difficulties associated with this type of account, it does not seem that this factor was of major importance within this study as this research aims to understand the carers' perceptions of PEG rather than accurate details of associated events.

A mixed method design, which adopted quantitative and qualitative methods, was implemented within this piece of research. This integrative approach was used with the aim of triangulating the two different types of data. Methodological triangulation aimed to gain a more thorough understanding of carers' perceptions. It was felt that this approach would be useful given the lack of research in this area. Quantitative methods aimed to allow the research to be generalisable, whilst the qualitative element aimed to allow rich descriptions which give context to the quantitative results.

However there are some researchers who believe there are major methodological flaws associated with mixed methods research (Sale, Lohfeld & Brazil, 2002). When considering the paradigms of the two approaches, the concerns associated with mixed methods design become more apparent. Quantitative methods maintain the underlying assumption of a single reality, which is not affected by a person's viewpoint or values. Therefore the researcher does not influence the phenomenon that is being studied (Guba & Lincoln, 1994). Qualitative methods assume a different ontological position where there is no 'one' reality, rather there are multiple realities based on one's own construction. The researchers and the phenomena are assumed to be integrated, with findings being jointly created (Sale et al, 2002).

Mixed methods have been found to result in the cross-pollination of methodologies. This has been the case within this piece of research where the use of frequency counts for responses to open-ended questions, have been used. This does not fit with the theoretical underpinnings of qualitative methods.

Some researchers argue that it is important the two methods be kept distinct. Whilst the same phenomena appear to be researched by both qualitative and quantitative

methodology, the interpretation of what the phenomena is changes according to the methodology that has been adopted. This would suggest that the methodological triangulation of results, which occurred in this piece of research, would be inadvisable, as the two parts of the research project are examining different aspects of the phenomena. Sale et al (2002) suggests that mixed methods are most useful if they are used in a complementary manner.

Other researchers argue that qualitative and quantitative methods should be integrated as they are 'tools' for research which have mutual purpose and rigor (Carey, 1993; Reichardt & Rallis, 1994). Researchers with this view point, note that arguments about qualitative and quantitative methods have been rife since the 1970s and whilst they are interesting, they do not produce research articles (Miles & Huberman, 1984)

The environment, within which the research was carried out, may also have impacted upon the findings of this study. With the aims of ensuring convenience for participants, the researcher often carried out the verbal administration of questionnaires within the participant's home. At the time participants were interviewed, the carer was often involved with the care demands of their relative. The presence of their relative may have caused them to understate their distress and perceptions of the PEG.

5.3.3 Sample

Carers were recruited from a charitable organisation and several different Trusts. It was hoped that the diversity of recruitment origins would allow for a more representative sample, permitting some generalisation across the British population of PEG carers.

To the researchers' knowledge, this study recruited the largest group of family carers involved with the PEG process to date. This is an important achievement as this under-represented population, has been found to require further understanding in all relevant pieces of research to date (Brotherton et al, 2006; Liley, 2001; Rains, 1981; Rickman, 1998; Silver et al, 2004).

Recruitment seemed to allow for a sample which was representative of this population in respect of age. Often, due to the illnesses that necessitated PEG placement, it is older adults who require HETF. 75% of these individuals require related support from an informal carer (Silver, 2004). The Office for National Statistics found that 2.8 million people aged over 49 years provided regular informal care in the United Kingdom (ONS, 2001).

The sample was diverse in respect of their backgrounds in terms of the amount of time caring prior to PEG placement, severity of relative's illness and duration of their relative's illness. This may have accounted for the skewed distributions of perception and guilt responses. Whilst it would be useful to understand the effects of the extraneous variables, it is important to consider that many services provide support for all PEG patients and carers. Rather than segregating research to specific populations, it may be more useful to consider the effects of the extraneous variables on carers' perceptions and distress by using alternative research designs.

Statistical techniques were put in place which aimed to control for extraneous factors that may have affected carers' levels of distress. However there were several factors that were not allowed for within this piece of research. The underlying disease of the carer's relative could not be controlled for, given the varied diagnoses that necessitated

PEG placement. Given the previous findings that PEG patients' QoL were related to the severity of their underlying disease (Schneider et al, 2000) it would be useful to discern the effects of illness severity on the carers' perceptions and distress.

The demographic questionnaire did not request the participants to disclose their ethnic background this was not felt to be an important factor influencing carers perceptions or experiences of the PEG. This lack of data meant that no analysis could be done to assess the effect of culture on perceptions of the PEG. However, whilst the sample appeared to have been mainly white British, there were some interesting descriptions from one carer who talked about the differences in meaning and timings of food in her culture. This lady (who appeared to be of an Indian origin) described that food is often laid out in the home to be eaten throughout the day rather than food being present only at specific meal times. She felt that this had meant that the PEG had created much more of a disruption for her and her family than for a typical British family. Research shows that food is conceptualized differently as a result of their cultural upbringing (Kelleher & Hillier, 1996). People of different cultural origins have also been found to have different beliefs about the provision of informal care for relatives (Wallhagen & Yamamoto-Mitani, 2006). This appears to effect the way in which carers' deal with the PEG. In one study Mexican American carers were found to be more likely to carry out care tasks related to the PEG than were white informal carers (Silver et al, 2004). Including an item about carers' ethnic background may therefore produce some interesting results in samples where ethnicity is more varied.

In the majority of cases the reason for participant refusal was not known. However in some cases the carers told dietitians, they felt unable to participate because they had 'too much to do at home' or that things were 'too difficult at the moment'. In some cases this

may not have been in relation to the PEG issues. Yet it is possible the PEG was a factor and that the sample of carers in this study was less distressed than those carers who refused to take part.

All but one of the participants, who originally agreed to be interviewed, undertook the process. The majority of carers involved commented that they had enjoyed the verbal administration of questionnaires. There were no negative reports. One participant wrote to the researcher subsequent to the interview stating that she hoped that *“this has helped you as much as it has helped X and especially me.”*

Many carers described that they had valued the interview process as they had few opportunities to talk about PEG. Carers appeared to prefer open-ended questions where they had an opportunity to talk around their responses. Often the researcher felt that valuable information was lost as the carers talked around issues that could not be fully recorded when filling in the PPQ.

In the Trusts where the number of participants recruited was large enough to permit statistical analysis, there was no significant difference in distress. However Trust participation was voluntary. This may have affected the results (those dietitians who volunteered to be involved in the study may have been more confident in their service).

5.3.4 Measures

- Independent variable measure

Whilst this measure provided a good preliminary understanding of PEG carer perceptions, it is not thought to be suitable for use in future work unless further adaptation

is made. This is due to the number of limitations that have been identified post implementation.

The IPQ-R measure was not specifically designed for this population. This necessitated adaptations to be made. There were attempts made to validate this measure prior to its use. Face validation from two dietitians provided feedback, which suggested that the measure seemed quite negative. Given that PEG is not an illness but is a medical intervention, it is possible that the negative format of the IPQ-R was not appropriate for participants in this study. Further adaptations to the measure were therefore made. This was troublesome as it involved the reversal of marking schemes to allow for positively framed questions. At times it also seemed to cause questioning to appear repetitive. This was noted in reliability analysis with regards to the timeline subscale (questions one to five were found to be very closely correlated).

Despite attempts to amend the questionnaire's format to give a mixture of both positive and negative questions, feedback from participants suggested the questionnaire was too negative. In the face to face verbal administration process, it was possible to talk around these issues with carers. Postal administration methods did not allow for this.

It is possible this aforementioned issue may have caused some potential postal participants to withdraw from the study. Five of the carers who were sent the questionnaires, as a postal package did not respond. The perception of negative questioning in the PPQ may also have had an effect on participants' responses to open-ended questioning. As described in section 5.2, the superordinate theme 'Acceptance' reflects a sense of gratefulness. It is possible that rather than a clinical phenomenon this theme is a

reflection of the participants' attempts to counterbalance their descriptions of the PEG after perceiving the PPQ as having a negative bias.

The marking scheme for the Identity subscale was also found to be problematic for some carers. This was because many carers said they were not sure whether a listed symptom was related to the PEG or to their relative's underlying illness. Carers in these circumstances said they felt there should be the option of 'Don't know'. Past research has also noted that an extra 'Don't know' column would be useful for other populations (Land, 2006).

The marking schemes for areas of consequence on the experiences questionnaire were non-commensurate to scoring of the additional items of consequence within the PPQ questionnaire. It was therefore not possible to perform a statistical comparison of the results. However the researchers' accounts suggested some participants who talked about negative areas of consequence in the open-ended and less specific questions, would disagree with items referring to the same areas of consequence in the directive questions on the PPQ. This may explain the relationship between guilt scale scores and consequence items on the Likert scale responses, in the absence of a relationship between guilt and PPQ consequence. As discussed previously, this may suggest that whilst the five perceptions from the SRM are relevant to PEG carers, the PPQ tool is not an effective tool and could be improved in order to elicit carers' perceptions.

- **Dependent Variable Measures**

A general difficulty with these measures was that some carers reported feeling unsure about whether they were to respond in respect of their current situation in general or whether to be specific to the PEG. This suggests that the information given to carers about

how to answer questionnaires was not explicit enough, causing confusion about how to respond.

Given the size of the questionnaire package and the sample, the value of including the GHQ-28 is questionable. Breaking down the nature of the carer's distress into more specific areas may have been more useful with a larger sample size, as it would have allowed for a prevalence score for different types of distress.

5.3.5 Analysis

The GLM was used in quantitative analysis. This study's objectives; to understand the effects of PEG perception variables on the distress response, appeared to be consistent with the purpose of GLM analysis. However it is important to consider that the GLM is usually used in laboratory experiments where responses are more controlled corresponding to a smaller error variance. There is therefore the assumption that the sample is normally distributed and has homogenous variance (Khuri, Mukherjee, Sinha & Ghosh, 2006). This piece of research was undertaken in clinical settings and involved human responses, which were variable. This may have affected the usefulness of this analysis.

Within this study, the GLM assessed the linear function of the distress response variable involving the PEG perception variables. Prior to analysis there was no reason to presume that there would be more complicated relationships. Thus, curved distributions were not considered. Relationships which do not fit a linear distribution may therefore have been missed.

In addition to methodological triangulation, two other forms of triangulation were used in this piece of research: investigator triangulation and theory triangulation. These methods aimed to ensure the validity of the qualitative results (Guion, 2002).

Theory triangulation involves the inclusion of data analysis from several different professional perspectives (Guion, 2002). Ideally individuals from outside the researcher's field, examine the transcripts using the same form of analysis as the researcher. Findings are then compared to ensure validity. Unfortunately this was not possible within this piece of research, as the dietitian who was involved in the validity checks was not trained in IPA methods. However the dietitian reviewed the anonymous transcripts and the summary of themes and gave her comments on the interpretations made.

To bolster the validity of findings, a participant was also approached and asked to critique qualitative results. This participant reviewed the transcripts and a summary of the themes and made comments based on her reading and her own experience of caring for an individual with a PEG.

5.4 Clinical Implications

The results of this study suggest that improving carers' perceptions of PEG identity decreases levels of carer guilt. As the identity subscale measures the number of symptoms that carers attribute to the PEG, it would seem appropriate to consider the impact of the physiological mechanistic improvements in PEG nutrition. It seems the continued medical advances, which allow for decreasing numbers of PEG associated symptoms, will contribute to a reduction in carers' level of guilt.

However, it does not seem that carers' distress is solely related to the physiological responses of their relative. As, despite findings which suggest pump-fed patients suffer less PEG related symptoms than bolus-fed patients (Shang, Geiger, Sturm & Post, 2003), it was found that carers using pump feeds were significantly more anxious and depressed than those using bolus feeds. This suggests the carers' perceptions of PEG cannot be fully understood in terms of patients' measured physiological response. Such a finding advocates further research into the carers' cognitive understandings and emotional responses to the PEG.

Negative Emotional Representation perceptions of the PEG were also found to increase carers' guilt. An intervention, which aims to reduce the likelihood of negative emotional representation perceptions developing, could minimise guilt feelings. Methodological Triangulation suggests that there are psychological aspects involved in the development of negative emotional representation perceptions of PEG. Carers describe feeling more afraid about the PEG when they are unfamiliar, alone or perceive the process as a rigid medical intervention. One intervention may be the provision of education, which allows carers to conceptualise the PEG as a feeding process, prior to discharge. This education maybe useful because once carers can conceptualise the PEG as a method of feeding the principles behind the procedure appear to become more familiar to them. This appears to allow the carer to impart information they already understand regarding nourishment (i.e. that their relative will not starve if there is difficulties which delay the feeding process). Thus the administration can be perceived as less pressurised and therefore anxiety provoking. Education to aide this transition in thinking may involve imparting PEG

carers with information about how PEG nourishes patients, highlighting the level of flexibility surrounding some of the timings and rates of feeds in problematic situations.

As previously noted, Lipman's (2003) work highlights the disparity between oral nutrition and artificial feeding. These differences are purported to necessitate differential terminology that separates the processes. It is argued that artificial forms of feeding should be referred to in a manner that emphasises them as medical intervention processes. Lipman (2003) argues that this would prevent misunderstandings about the nature of the process and could therefore reduce negative reactions to the PEG.

The findings of this study are incongruent with Lipman's (2003) suggestions. Carers' reflections suggest that worry associated with the PEG, was lessened by a shift in understanding, from PEG as a medical intervention to PEG as a method of feeding. This finding implies that a change from the current terminology to more medical naming could have a detrimental effect on carers. Medical naming may negate the process of adaptation increasing the duration of heightened PEG related distress.

The correlation between emotional representation and consequence suggests that interventions which improve the carers' emotional representation perceptions, would also allow for a reduction in perceptions of negative consequence associated with the PEG. As eating was found to be a major area of consequence it is possible the intervention described above, which helps carers to associate PEG with natural forms of feeding, may reduce perceptions of consequence, particularly those related to their own eating.

Qualitative findings also suggest that control over the PEG allows carers to feel less guilt. Carers who feel they have a lack of control surrounding the PEG describe negative feelings surrounding the thoughts that they cannot provide independent efficient care for

their relative. If there is further research in this area, the long-term implications may involve increasing carers' sense of control over the PEG prior to discharge. The findings of this study suggest that increased control could be allowed through adequate initial training of PEG requirements and processes with further information to support applications in home settings. However the quantitative findings, which suggest increased levels of control, are related to heightened guilt, suggesting that carers need to feel that they are supported. Descriptions of general and PEG specific services suggest some carers felt that the current provisions did not meet their needs, leading them to feel alone with the responsibility. Thus, an intervention which aims to improve carers' perceptions of the PEG, should consider not only carers' feelings of PEG control but also their sense of being supported.

The above finding also suggests carers' emotional needs should be considered when the decision is made about whether to use bolus or pump methods with patients. Those carers who have negative emotional representations of the PEG and feel they have limited control may be more suited to bolus methods, where less technological control is required and the process may be more readily conceptualised as a feeding method due to the length and timing of feeds.

The majority of carers perceive that their relative has been provided with PEG as a long-term life sustaining intervention. They are therefore unlikely to ask for extra PEG related provisions, after they have made initial adaptations. This seems to be due to a sense of gratitude. However this does not seem to indicate that the carer is satisfied with the support they are receiving. Regular reviews, where carers are given adequate opportunities to talk about PEG related issues, may be useful to ascertain whether further support is

needed. As PEG is part of a bigger picture of care, and given the limitations of screening measures, a semi-structured interview approach would be the most useful tool for conducting reviews. Findings suggest that a useful interview should address perception constructs, including eating and socialising consequences.

NICE guidelines (2006) recognise there is minimal nutritional training for general healthcare professionals. Guidelines highlight the 'essential' need to determine whether further education of healthcare professionals would have an impact on patient care, including the effect on the frequency of visits to the GP. These research findings suggest that further healthcare staff education would have an impact on carers and patients' psychological wellbeing. It seems that carers believed they were 'alone' in the PEG process, as they do not feel the front line health professionals can assist them. Carers also felt that there were minimal suitable respite or support provisions due to a lack of staff training. Such perceptions appear to cause worry about their ability to cope independently. There was also a belief that the PEG experience would be less distressing for their relative if complications such as tube blockages could be dealt with by community healthcare professionals rather than necessitating a hospital admission (resulting in delayed feeding and medications). This finding also advocates further training for healthcare staff.

5.5 Summary and Conclusions

In accordance with methodological assumptions, it seemed carers were able to distinguish between their relative's illness and issues related to the PEG.

The essence of the five perception constructs (timeline, consequence, control, emotional representation, and identity) of the SRM appeared to be relevant to PEG carers.

The areas of consequence discussed in section 1.8 were all found to be relevant to carers to differing degrees. The heterogeneous nature of the sample meant that some perception constructs and areas of consequence were more relevant to some carers than others. This appears to be due to several moderating and mediating variables, which require further investigation. Given that PEG is an intervention rather than illness, it is not surprising that phenomenological findings suggested PEG perception constructs were made up of different elements, compared to the perception constructs of illness. Whilst the conceptual elements of illness perceptions may be relevant to this population, further adaptation of the IPQ-R may be required in order to measure these dimensions.

Despite the findings that roughly half of the sample were experiencing, what would be considered as a clinical level of anxiety, there were no significant relationships between perceptions and this form of distress. This suggests perception constructs do not fit neatly within Leventhal et al's (1980, 1997) SRM model. However there were significant relationships between guilt and the identity and emotional representation constructs. Given the positive correlation between guilt and distress, it is possible guilt is a mediating variable between PEG perceptions and distress.

Phenomenological information generated from this study suggested the cognitive behavioural mechanisms, which are apparent within Leventhal et al's (1980, 1997) SRM and Williams' (2001) Five Areas Model of distress, are applicable to PEG carers. Carers' descriptions linked their perceptions about the PEG to feelings of distress. This finding implicates several clinical interventions which tackle, or prevent the development of negative thought patterns associated with the PEG.

The 'PEG carers' perception process model' (based on the analysis of carers responses to open-ended questions) also appeared to be similar to stages two and three of the SRM framework. This also relates to Williams' (2001) Five-area model of distress as the carers' perceptions of PEG, affects their emotions, physical feelings and behaviour. However further research would be required to clarify these suppositions. Coping was not specifically explored within this research and these early findings cannot profess to have a clear understanding of coping mechanisms involved in PEG care.

Whilst the clinical implication sections aim to provide an insight into future practice, readers should consider the exploratory nature of this investigation. These are early research findings, which require further research to determine whether such proposals would provide useful needs-led interventions.

5.6 Future Research

Based on the findings of this study there are other valuable research projects that could enable a better understanding of the experiences, perceptions and psychological well-being of PEG carers.

The qualitative part of this study indicates that preparedness has an important role to play in carers' initial perceptions of the PEG process and their distress. A useful future study could use quantitative methods to understand the relationships between carers' beliefs about how prepared they are to cope with the PEG, their perceptions of the PEG and their level of distress. As a result of the heterogeneous nature of PEG carer populations, a longitudinal design would be most suitable. Research on groups of carers using similar technical medical interventions to PEG, suggest adaptation occurs within the first three

months of placement (Smith, Moushey, Ross & Gieffer, 1993). PEG carers within this study suggest that the adaptation process is much more rapid. Data collection points, which were within one week of discharge, 3 months of discharge and 6 months after discharge, may allow an understanding of the intra individual changes and adaptations to supporting a relative with a PEG.

Silver et al (2004) developed a questionnaire about PEG caregivers' beliefs about their ability; the Home Enteral Nutrition Caregiver Task checklist. This was developed for an American population, but with adaptation, would be suitable for UK carers. This would perhaps provide a useful tool for the type of study noted above. The PPQ would require further adaptation in order to understand the perceptions of this group of carers. The information that has been generated within this piece of research could allow for the development of this more accurate quantitative tool.

One of the clinical implications of this study is the suggestion that further initial support may prevent the development of negative perceptions of PEG, reducing the likelihood of pathological guilt. A study, which examines the effect of support on distress, would be useful. There is currently no information about the most efficient mode of support. However several carers suggested the use of mentorship may be useful. Carers discussed the possibility of families, who are experienced in the PEG process, being given the option to volunteer into a mentorship scheme. They suggested that having a link to an experienced family who they knew they could contact in times of need would have been of great benefit within the early stages of discharge. Given the dietitians feedback regarding carers' tendency to give their relatives a taste of foods even when they have been told that it is unsafe, the draw back to such a scheme is that mentors may give advice which would not

be deemed to be medically safe. To overcome such a problem those carers who volunteer into a mentoring program should be offered further training and supervision involving PEG specific issues and boundary setting. Such a scheme could be piloted within a study which could compare the distress levels of PEG carers in contact with mentors with those who are not linked with the provision.

There are several possible extraneous variables which were not controlled for within this study. To gain a further understanding about carers PEG related distress, a study which uses matched groups (with regards to the carer, patient dyads) could be used to compare distress levels between informal carers whose ill relative has a PEG and those who do not. This type of research has been carried out within child research (Pedersen et al, 2004) but has not been conducted within carers of adults with a PEG.

This study explored carers' perceptions of the PEG rather than the objective context of the care provision (objective stressors). However the constructs that contributed to many of the themes, discussed many practical and service issues. Nolan, Grant and Ellis (1990) found that subjective stressors, akin to those described by Pearlin et al's (1990) model, were more influential on levels of care-giver burden than objective stressors. The nature of this study did not allow for such a comparison between the two distinct types of stressors. This would be an interesting area for future research.

A study involving the exploration of carers' coping would be a useful addition to the literature and may allow the development of the model derived from this study. An understanding of coping surrounding PEG would also be functional within clinical work and discharge preparation.

Finally, given the significant relationship between PEG perceptions and guilt, an important avenue of research would include further investigation on the nature of PEG carers' guilt.

The low average group score and the range of scores, suggest the guilt scale tool does not access the aspects of guilt associated with PEG care. The Guilt Scale used in this study was developed for family carers of individuals with dementia. It seems that guilt associated to PEG care is characteristically different to that of carers of dementia patients. Given the lack of understanding about the nature of PEG carers' guilt it would not have been possible to have foreseen this difficulty prior to analysis. The qualitative findings of this study suggest the Interpersonal Guilt Questionnaire – 45 (IGQ-45), (O'Connor et al, 1997) may be more useful in future studies. This measure contains subscales that assess survivor guilt and separation guilt.

A further study of PEG carer perception and distress using a more appropriate guilt tool would be useful. Such research may allow exploration of the potential mediating role of guilt in the relationship between PEG perception and distress.

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Appendix 1.1: The Demographics Questionnaire

The Demographics Questionnaire

Demographics questionnaire

Please indicate your response by circling the statement that you feel is most applicable to you or writing in the area made available for your response.

Gender

Male
Female

Age

18 – 44 years old
45 – 64 years old
64 – 84 years old
85 years or older

What is your relation to the individual who is receiving nutrition via PEG

.....

What condition has necessitated your relative to require PEG?

.....

.....

What was the duration of your relative's illness prior to the PEG PLACEMENT?

3 – 6 Months
7 - 9 Months
More than 10 months
No illness prior to PEG procedure (Emergency procedure)

How was the decision surrounding PEG made?

My relative and I were not involved in decision making the decision, medical professionals took the decision (emergency procedure)
Elected, my relative was involved in making the decision about PEG
Elected, my relative and I were involved in decision making

Which of these methods is used to give the tube feed?

Bolus (i.e. using a syringe)
Continuous (i.e. using a pump 24 hours a day)
Continuous Intermittent (i.e. using a pump for part of the day/ night)
Other
Please specify
.....

What nutrition is your relative able to take by the mouth?

Fluid and normal food
Fluids and liquidized/ soft food
Fluids only
Nothing

How long has the feeding tube been in place?

Less than 3 months
About 3 – 6 months
7 – 9 months
More than 10 months

How long has your relative been tube feeding from home?

Less than 3 months
About 3- 6 months
7 – 9 months
10 - 18 months
More than 18 months

How many hours of care do you provide for your relative per week?

Less than 5 hours
About 5 – 10 hours per week
10 – 15 hours per week
15 – 20 hours per week
More than 20 hours

Do you currently receive regular visits (at least once per month) from health/ social care professionals (community dieticians, district nurses etc)?

Yes
No

Appendix 1.2: The PPQ Questionnaire

The PPQ Questionnaire

Your views about Percutaneous Endoscopic Gastrostomy (PEG) in your relative

Listed below are a number of symptoms that your relative may or may not have experienced since their PEG placement. Please indicate by circling *Yes* or *No*, whether you believe your relative has experienced any of these symptoms since their PEG placement, and whether you believe these symptoms are related to your relative's PEG placement.

	My relative has experienced this symptom since their PEG was fitted.			This symptom is related to my relative's PEG fitting.		
	Yes	No	Yes	No	
Fullness	Yes	No	Yes	No	
Regurgitation	Yes	No	Yes	No	
Nausea	Yes	No	Yes	No	
Vomiting	Yes	No	Yes	No	
Diarrhoea	Yes	No	Yes	No	
Constipation	Yes	No	Yes	No	
Flatulence	Yes	No	Yes	No	
Irritation of the stoma site (e.g. leakage of fluid, infection, granulation tissue)	Yes	No	Yes	No	
Sleep disturbance (If partner feeds over night)	Yes	No	Yes	No	

I am interested in your own personal views of how you see your relative's PEG placement.

Please indicate how much you agree or disagree with the following statements about your partner's PEG placement by ticking the appropriate box.

	VIEWS ABOUT YOUR RELATIVE'S PEG	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
PP1	My relative's PEG will remain in place for a short time					
PP2	My relative's PEG is likely to be permanent rather than temporary					
PP3	My relative's PEG will remain for a long time					
PP4	The need for my relative to use a PEG will pass quickly					
PP5	I expect my relative to have their PEG for the rest of their life					
PP7	My relative's PEG has major consequences on my life					
PP8	My relative's PEG placement does not have much effect on my life					
PP9	The fact that other people know about my relative's PEG strongly affects the way they see me.					
PP10	My relative's PEG has serious financial consequences					
PP11	My relative's PEG has caused difficulties for those who are close to me					
A	The introduction of my relative's PEG has changed my relationship with them					

B	My relative's PEG has interfered with the relationship I have with my family and friends					
<p><i>If your relative is your partner please complete letters C and D. If not please skip these items and begin at letter E:</i></p>						
	VIEWS ABOUT YOUR RELATIVE'S PEG	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C	My sexual relationship with my partner has changed since they had their PEG placement					
D	My partner is less interested in a sexual relationship with me since their PEG placement					
E	PEG use has improved my relative's appearance					
F	PEG use has caused my relative's appearance to deteriorate					
G	Since the fitting of my relative's PEG, my mealtime habits have changed					
H	My enjoyment of mealtimes has decreased since the fitting of my relative's PEG					
I	My enjoyment of mealtimes has increased since the fitting of my relative's PEG					
J	The frequency with which I eat socially with family and friends has decreased since the fitting of my relative's PEG					
K	The frequency with which I eat socially with family and friends has increased since the fitting of my relative's PEG					
L	Since my relative began PEG feeding at home the frequency with which I complete social activities has changed					
M	My employment status has changed since the introduction of home PEG feeding in my relative					
PP12	There is a lot I can do to control my relative's PEG related symptoms					
PP13	What I do can determine whether the PEG helps my relative or not.					
PP14	The useful effect of PEG depends on me					
PP15	Nothing I do will affect whether the PEG is useful or not					
PP16	I have the power to influence how PEG helps my relative					
PP18	My experience related to my relative's PEG will improve in time					
PP33	I get depressed when I think about my relative's PEG					
PP34	When I think about my relative's PEG I get upset					

PP35	My relative's PEG makes me feel angry					
PP36	My relative's PEG does not worry me					
PP37	My relative's PEG makes me feel anxious					
PP38	My relative's PEG makes me feel afraid					

Appendix 1.3: The Guilt Scale Questionnaire

The Guilt Scale Questionnaire

GUILT SCALE

This questionnaire is about guilt that people may feel when looking after someone who is fed via Percutaneous Endoscopic Gastrostomy (PEG). Please indicate the response that best fits with your experience.

4. Always 3. Very Often 2. Often 1. Sometimes 0. Never

- 1) Do you worry that you might unintentionally hurt your relative's feelings?
- 2) Do you feel that you let your relative down in some way?
- 3) Do you find yourself wishing you could make amends for anything you have done or said to your relative?
- 4) Do you feel trapped by the responsibility you feel you have for your relative?
- 5) Do you worry about not meeting the obligations you feel you have towards your relative?
- 6) Do you accuse yourself of neglecting other people (e.g. Spouse, children, good friend's etc.) because of the time you spend with your relative?
- 7) Do you ever worry that you take your frustration out on other people?
- 8) Do you blame yourself when your relative has had a 'bad day'?
- 9) Do you worry about not treating your relative as well as you could?
- 10) Do you worry that you are sometimes cruel to your relative?

Appendix 1.4: The Open-Ended, 'Experience of PEG for the Family Carer' Questionnaire'

2) Please circle the extent to which the following statement applies to you.

The relationship that I have with my relative has changed since they were fitted with PEG

Not at all
1 2 3 4 5 6 Completely
7

Please tick the appropriate statement:

I am more satisfied with my relationship with my relative since they were fitted with PEG

I am less satisfied with my relationship with my relative since they were fitted with PEG

There is no change in my satisfaction with my relationship with my relative since they were fitted with PEG

Is there anything else you would like to add about the effects of PEG on your relationship with your relative?

3) Please circle the extent to which the following statement applies to you.

My relationships with others have changed since my relative was fitted with PEG

Not at all
1 2 3 4 5 6 Completely
7

Please tick the appropriate statement:

I am more satisfied with my relationships with other people since my relative was fitted with PEG

I am less satisfied with my relationships with others since my relative was fitted with PEG

There is no change in my satisfaction with my relationships with others since my relative was fitted with PEG

Is there anything else you would like to add about the effects of PEG on your relationships with others?

4) Please circle the extent to which the following statement applies to you.

My relative's appearance has changed since they were fitted with PEG.

Not at all
1 2 3 4 5 6 Completely
7

Please tick the appropriate statement:

I am more satisfied with my relative's appearance since they were fitted with PEG

I am less satisfied with my relative's appearance since they were fitted with PEG

There is no change in my satisfaction with my relative's appearance since they were fitted with PEG

Is there anything else you would like to add about the effects of PEG on your relative's appearance?

5) Please circle the extent to which the following statement applies to you.

My eating habits have changed since my relative was fitted with PEG.

Not at all
1 2 3 4 5 6 Completely
7

Please tick the appropriate statement:

I am more satisfied with my own eating habits since my relative was fitted with PEG

I am less satisfied with my own eating habits since my relative was fitted with PEG

There is no change in my satisfaction with my own eating habits since my relative was fitted with PEG

Is there anything else you would like to add about the effects of PEG on your own eating habits?

IF YOUR RELATIVE IS YOUR PARTNER, PLEASE COMPLETE QUESTION 6. IF NOT, PLEASE SKIP THESE FINAL ITEMS.

Appendix 2.1:Hull and East Riding Research Committee Approval Letter

Hull and East Riding Local Research Ethics Committee

Room SC39
Coniston House (Trust Headquarters)
Willerby Hill Business Park
Willerby
HULL
HU10 6ED

Telephone: 01482 389246
Facsimile: 01482 303908

19 June 2006

Miss Alexandra Legge
Trainee Clinical Psychologist
The University of Hull
The Department of Clinical Psychology,
The Hertford building, The University of Hull
Cottingham Road, Hull
HU6 7RX

Dear Miss Legge

Full title of study: **What is the influence of family carer perception about the use of Percutaneous Endoscopic Gastrostomy (PEG) on their mood?**

REC reference number: **06/Q1104/69**

Thank you for your letter of 15 June 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by the Chair acting under delegated authority

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	1	20 April 2006
Investigator CV	Alexandra Legge	01 April 2006
Protocol	1	01 April 2006
Questionnaire: Demographic Questionnaire	Non-validated	01 April 2006
Questionnaire: Revised Experiences Questionnaire	2	01 June 2006
Questionnaire: Revised perceptions questionnaire	2	01 June 2006
Questionnaire: Guilt Scale		01 April 2006
Questionnaire: GHQ-28		01 April 2006
Questionnaire: HADS		01 April 2006
Advertisement	2	01 June 2006
Participant Information Sheet: Revised Information Sheet	2 Patient	01 June 2006
Participant Information Sheet: Revised Information Sheet	2 Participant	01 June 2006
Participant Consent Form: Revised Consent form	2	01 June 2006
Response to Request for Further Information	Letter addressing all issues raised by the committee	15 June 2006
Protocol Flow Diagram	1	01 April 2006
CV Supervisor	Prof Esme Moniz-Cook	20 April 2006

Research governance approval

You should arrange for the R&D department at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final research governance approval before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/Q1104/69

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely


Mr. Graeme Duthie
Chair

Email: louise.hunn@humber.nhs.uk

Enclosures: Standard approval conditions

Copy to: Humber Mental Health trust
The Research and Development Department,
Humber Mental Health Trust Headquarters,
Willerby Hill, Beverley Road, Willerby.

R&D Department HEYH NHS Trust

Appendix 2.2: Hull and East Riding Research and Development Approval Letter

Our Ref: SW-12/06/06-Alex Legge.doc

12 June 2006

Alexandra Legge
Trainee Clinical Psychologist
The University Of Hull
The Department of Clinical Psychology
The Hertford Building
Cottingham Road
Hull, HU6 7RX

Dear Alexandra Legge

Re: What is the influence of family carer perception about the use of Percutaneous Endoscopic Gastronomy (PEG) on their mood?

I am please to notify you formally that this study has been approved by the Trust and may now proceed.

Humber Mental Health Teaching NHS Trust conducts all research in accordance with the requirements of the Research Governance Framework, and the NHS Intellectual Property Guidance. In undertaking this study you agree to comply with all reporting requirements, systems and duties of action put in place by the trust to deliver research governance, and you must comply with the Trust information management and data protection policies. In addition, you agree to accept the responsibilities associated with your role that are outlined within the Research Governance Framework as follows:

- The study follows the agreed protocol
- Participants should receive appropriate care while involved in the study
- The integrity and confidentiality of clinical, other records and data generated by the study will be maintained
- All adverse events must be reported to the Trust and other authorities specified in the protocol
- Any suspected misconduct by anyone involved in the study must be reported

The Trust is required to return information on the progress of studies to the National Research Register, and to report research findings. We will, therefore, ask you every 6 months for such updates. This includes full reference of any publications arising from the project.

I would like to wish you every success with this project

Yours sincerely



Duncan Courtney
Senior Projects Officer

cc. Amanda Barton, R&D Manager, WHPCT, 44 Portland Street, Hull, HU2 8JX

Appendix 3: Email Sent to the Heads of Nutrition and Dietetics Departments Across Britain

Email Sent to the Heads of Nutrition and Dietetics Departments Across Britain

Department of Nutrition and Dietetics xxxxxxxx

Date xxxxxxxx

Dear xxxxxx,

I am writing with the hope of your support in a piece of research that I am undertaking with family carers of PEG consumers.

As PEG feeding at home is becoming a more common treatment option for a multitude of different patients and consequently patient numbers in the community are ever increasing, it seems to be appropriate that we are able to understand the psychosocial as well as the medical issues that arise. Recent studies and discussions with community health practitioners have suggested that people experience unexpected social and psychological consequences of either receiving or living with a family member who receives PEG feeds. These individuals are often supported by health practitioners who feel that they would like further training to support the psychological and social needs of the family.

Whilst there is some information about the needs of a person with PEG, less is known on how their families are affected. The present study aims to understand the psychosocial experience of the family in order that we can develop methods of meeting their needs.

I am a Trainee Clinical Psychologist conducting a study for my doctoral research to be completed in June 2007. I am interested in gaining contact with all family carers aged 18 years and over who undertake an active role in the PEG process for an adult relative

The Hull and East Riding NHS research ethics committee has reviewed this study and it is being supervised by Professor Esme Moniz-Cook.

I am hoping to recruit participants from around the country between now and March 2007 and would be delighted if you felt that your service could be involved in this research.

- **This would not require any extra workload/ time on your part** other than to pass on an information sheet (which I will provide) to potential participants.

- Participants can be involved through postal questionnaires or face-to-face interviews (these are designed to be brief) with myself. Early indicators show that participants value the opportunity to discuss their experiences
- All departments involved in the study would receive information about the final findings and conclusions.

If you would like more information, I would be happy to come and meet with the professionals in your service (to discuss the research and methodology) before you make a decision (I have also attached a full proposal for further information).

I would also be grateful for any help you could provide (e.g. placing an advert for the study in your department), which may help me recruit in your locality and/or any further advice you could offer me.

If you feel there is any way in which you could help me I would be pleased if you could contact me using this e-mail address; **research_a.legge@hotmail.co.uk**. or on telephone number; **0775 794 6525**.

Thank you for your time and support.

Miss Alexandra Legge (BSc)

(Trainee Clinical Psychologist)

Appendix 4.1: Information Sheet for Participants

Information Sheet for Participants

Humber Mental Health 
Teaching NHS Trust

Participant Information Sheet

What do families think about the administration and use of Percutaneous Endoscopic Gastrostomy (PEG)?

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

- Part 1 tells you the purpose of this study and what will happen if you take part.
- Part 2 gives you more detailed information about the research.

Please ask if there is anything that is not clear or if you would like more information.

Part 1.

What is the purpose of the study?

- PEG feeding in the home has become more common since more patients are being discharged as early as possible from hospital.
- The government has recognised that people who care for a family member may in their own right require a variety of types of support.
- There is not very much information about the experiences of individuals who care for a person with a PEG, but what little is known seems to suggest that the extra responsibilities involved with a PEG may present difficulties and thus affect the day-to-day lives of families.
- Psychologists often find that the way that we think about a situation can have an effect on how we feel about it. This study hopes to understand how you, as a family member caring for your relative, think about the PEG and whether this has any impact on how you feel (i.e. the quality of your life).
- This study aims to improve health care professionals' understanding of your current situation and needs in order to make recommendations on how health services can help those who support their relative with PEG at home, in the future.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and you will be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time or a decision not to take part will not affect the standard of care that you or your relative receives.

What will happen if I take part?

If you agree to take part in this study, the researcher will be given your home telephone number and address and will call you within the next couple of weeks to confirm you are interested in the study and answer any questions that you may have. At this time, the researcher will ask whether you would like to complete the questionnaires via post or within a face-to-face interview. If you opt for the researcher to be present an arrangement will be made to see you at a time suitable to you, at your own home or at an alternative venue. This study will involve you filling in six brief questionnaires on mood and what you think about the PEG. These should not take more than thirty minutes to complete but the researcher will be happy to spend more time talking with you about your experiences if you wish. Questionnaires can also be posted to you with a stamped addressed envelope for return to the researcher.

Will my taking part in the study be kept confidential?

Yes. All information about your participation in the study will be kept anonymous and confidential. If the researcher feels concerned about your health on the completion of the questionnaires she may discuss the possibility of referring you to another health professional. Further details are included in part 2 of the information sheet.

Contact details

If you have any further questions at this time, please do not hesitate to contact the researcher (Miss Alexandra Legge) on 0775 794 6525 or email research_a.legge@hotmail.co.uk.

If the information in Part 1 has interested you and you are considering participation, please continue to read the additional information in part 2 before making any decision.

Part 2.**What will happen to the results of the research study?**

The data will be written up as part of professional postgraduate training at the University of Hull and will be submitted for publication in an appropriate professional journal. It is hoped that the information will be used to create an information sheet to help support carers and consumers. A seminar will also be held where health professionals will be informed of relevant issues highlighted by the research.

What will happen if I don't want to carry on with the study?

If you withdraw from the study, all identifiable materials will be destroyed, but we will need to use the data collected up to your withdrawal.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do her best to answer your questions 0775 794 6525.

Will my taking part in the study be kept confidential?

All information, which is collected, about you during the course of the research will be kept strictly confidential. All information will be stored in a locked filing cabinet and will have your name and address removed so that you cannot be recognised from it.

Who has reviewed the study?

This study has been reviewed by the Hull and East Riding NHS local research ethics committee (LREC).

Thank you for your time.

Appendix 4.2: Information Sheet for Participant's Relative with a PEG Placement

Information Sheet for Participants Relative with a PEG Placement



What do families think about the use of Percutaneous Endoscopic Gastrostomy (PEG)?

Why has my relative been asked to participate in this study?

Over the past few years PEG feeding at home has become more common. Health professionals have begun to understand some of the issues that you may experience as a result of your tube feeding. However as yet we have less understanding how tube feeding at home affects your relative. If we can understand what support your relative might think is important, then we can ensure that we provide them with this, which will in turn, we hope, help them to give you the best support that you need with your PEG.

What will it involve?

Whilst this research is interested in tube feeding it will not actively involve you. If your relative agrees to take part in this study the researcher will contact them and ask them how (by post/ with researcher) and when would be most convenient for them to complete 6 brief questionnaires on mood and thoughts about the PEG process. The overall conclusions of this study will however be available to both yourself and your relative on completion and it is hoped that this information can inform and improve future services for you and your relative.

If you would like any further information or have any questions please do not hesitate to contact the researcher on 0775 794 6525 or email research_a.legge@hotmail.co.uk.

Thank you for your time.

(Your relative's decision about whether to participate in this study will not have any affect on your current care provisions.)



Appendix 5: The Advert used in the PINNT Newsletter to Recruit Charitable Sample

The Advert used in the PINNT Newsletter to Recruit Charitable Sample

- **Does your family member receive nutrition via PEG?**
- **Are you interested in NHS service development for families like you?**
- **If you answered yes, we would love to hear from you...**

PEG feeding in the home has become a common way of supporting people with medical conditions. Therefore the numbers of families involved in the caring for relatives with a PEG has also increased. Health professionals are aware of the extra responsibility that PEG feeding can cause individuals and their families.

Whilst the government wants to support family members who care for their relative we do not have a full understanding of how using a PEG in the home actually affects family life. We hope to gain a greater understanding of this in order to inform and improve future services for families who support a relative using a PEG.

I would be interested in hearing from any family member aged over 18 years and who are involved in their relatives PEG procedure. I would like to take up about 30 minutes of your valuable time (more if you wish to chat to me) to complete some brief questionnaires on what you think and feel about the PEG. You can opt to have the questionnaires posted and a stamped addressed envelope will be included for return. However I would be pleased to call on you and complete these questionnaires with you.

If you are interested in being involved I would be grateful if you would contact me on **0775 794 6525** or email; **research_a.legge@hotmail.co.uk**.

Thank you for your time and support.

Appendix 6: Participant consent form

Appendix 7: Kolmogorov – Smirnov Tests for Normality

Kolmogorov – Smirnov Tests for Normality

Method of feeding and anxiety score

Oral Category	Statistic	Df	P=
Relative using PEG able to eat or drink	.156	18	.200
Relative using PEG unable to eat or drink something	.143	21	.200

Method of feeding and depression score

Oral Category	Statistic	Df	P=
Relative using PEG able to eat or drink	.204	18	.046
Relative using PEG unable to eat or drink something	.251	21	.001

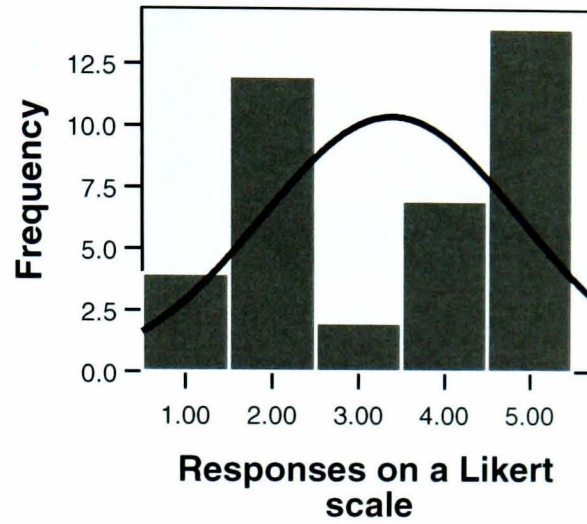
Method of feeding and guilt score

Oral Category	Statistic	Df	P=
Relative using PEG able to eat or drink	.163	18	.200
Relative using PEG unable to eat or drink something	.143	21	.200

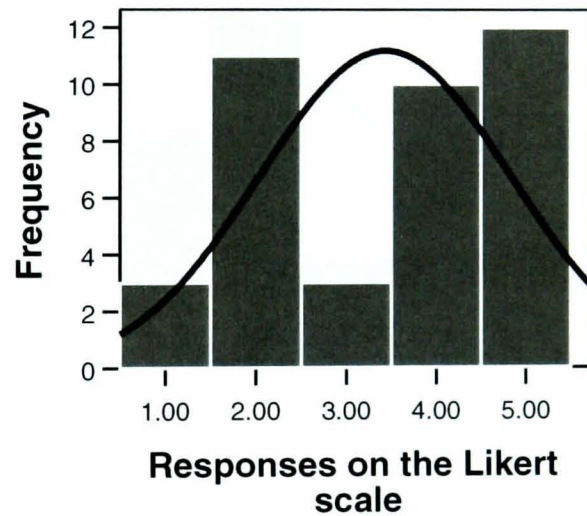
Appendix 8: Histograms Displaying Score Ranges on the PPQ

Histograms Displaying Score Ranges on the PPQ

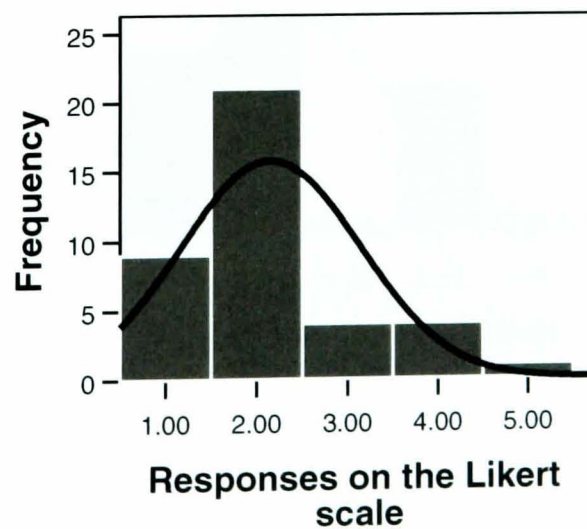
Consequence item one: My relatives PEG has major consequences on my life



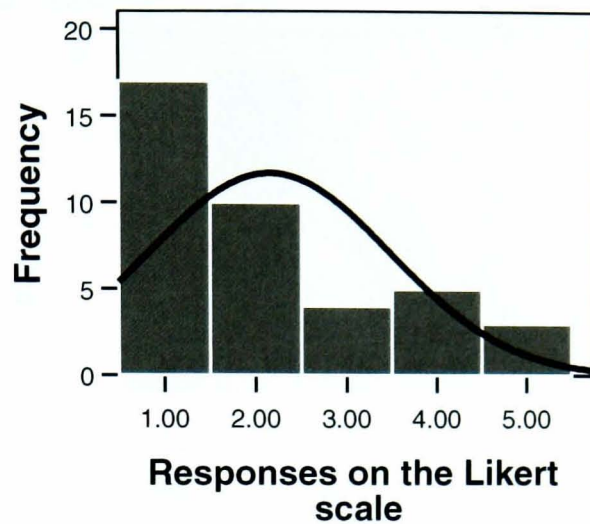
Consequence item two: My relatives PEG placement does not have much affect on my life



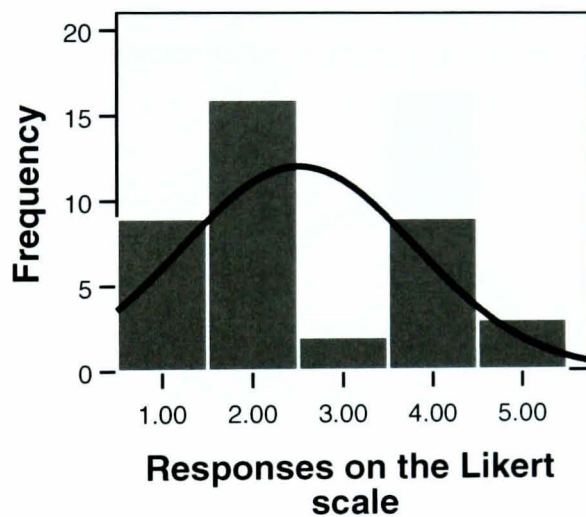
Consequence item three: The fact that other people know about my relatives PEG strongly affects the way they see me.



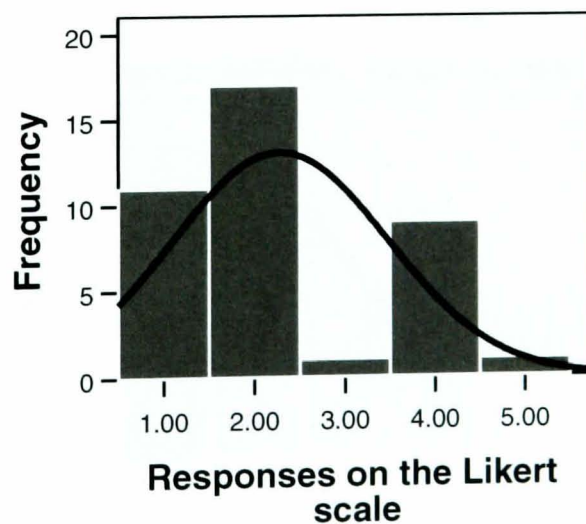
Consequence Item four: My relatives PEG has serious financial consequences



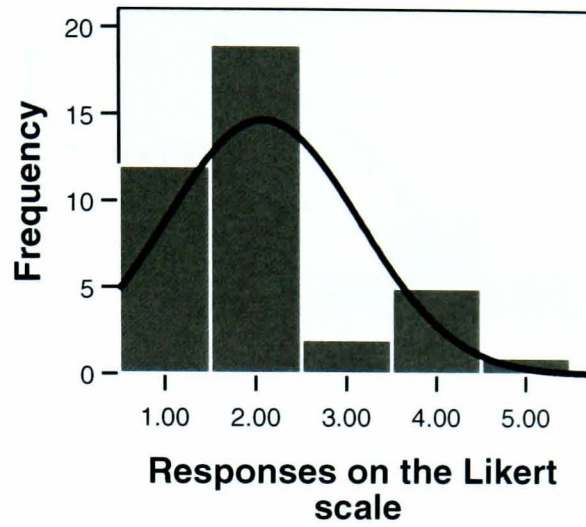
Consequence Item five: My relatives PEG has caused difficulties for those who are close to me



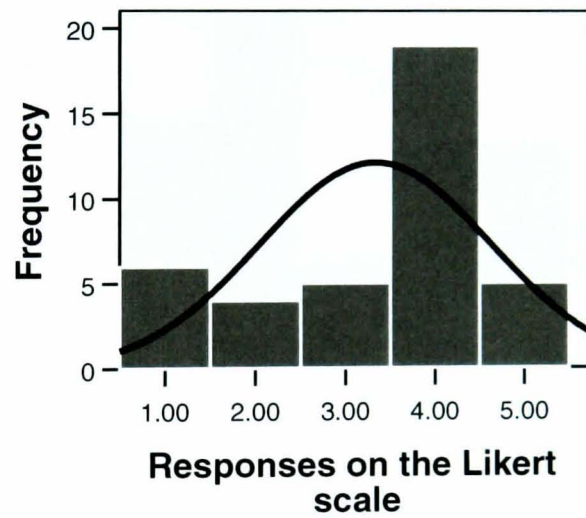
Control item one: There is a lot I can do to control my relatives PEG related symptoms



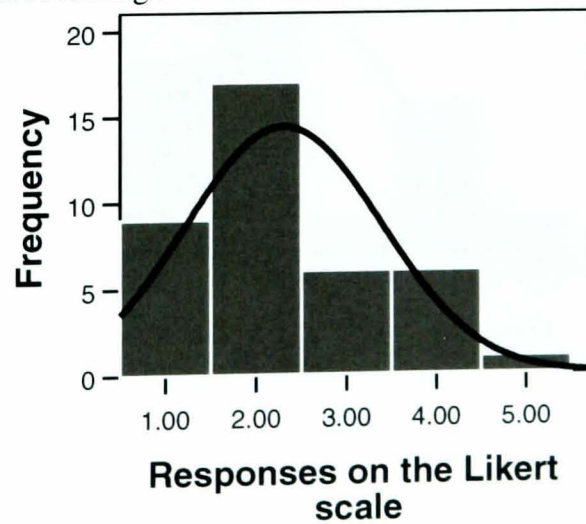
Control item two: What I do can determine whether the PEG helps my relative or not.



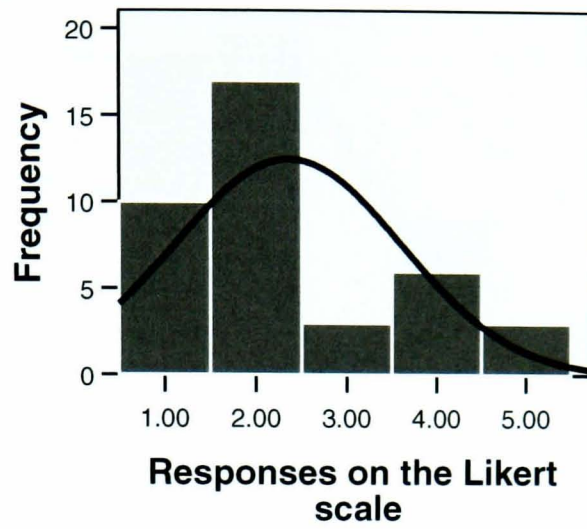
Control item three: The useful effect of PEG depends on me



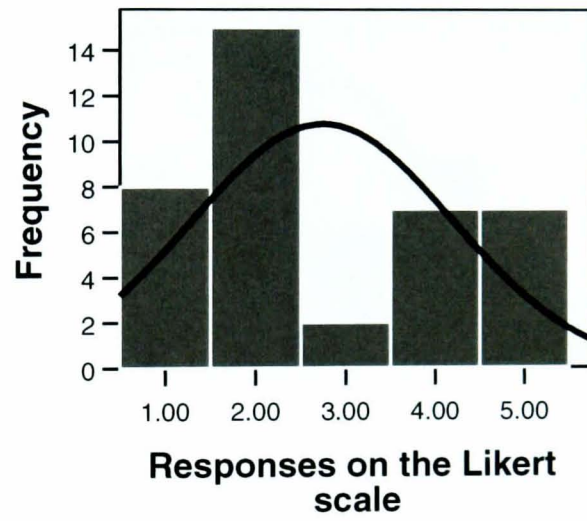
Control item four: Nothing I do will affect whether the PEG is useful or not



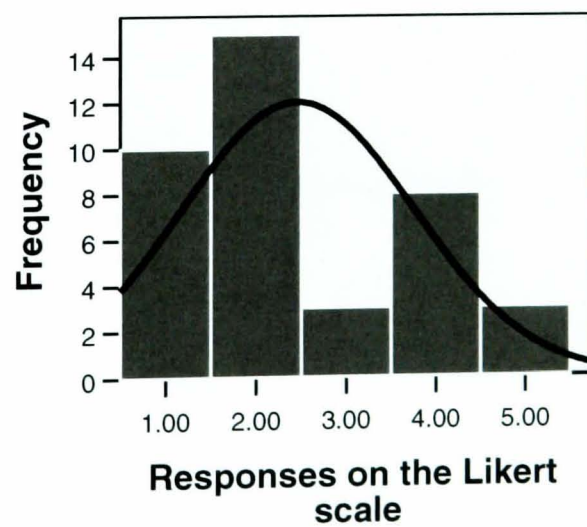
Control item five: I have the power to influence how PEG helps my relative



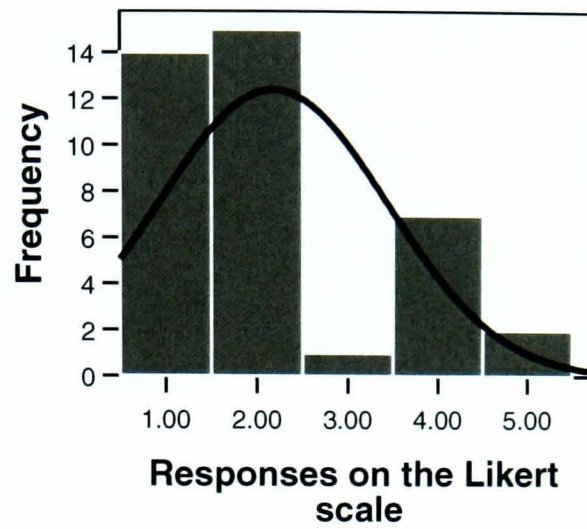
Emotional Representation item one: I get depressed when I think about my relatives PEG



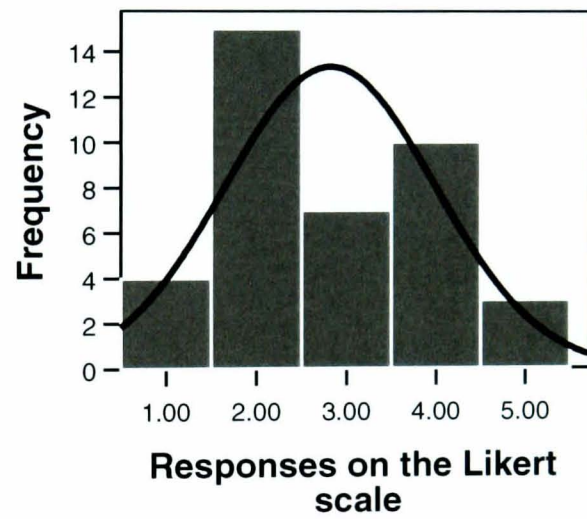
Emotional Representation item two: When I think about my relatives PEG I get upset



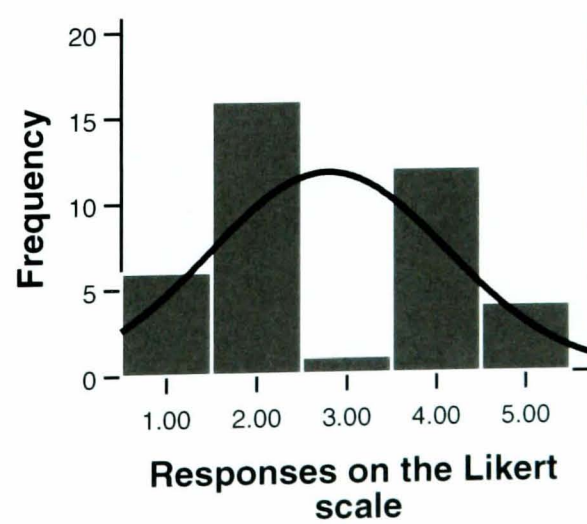
Emotional Representation three: My relatives PEG makes me feel angry



Emotional Representation item four: My relatives PEG does not worry me



Emotional Representation item five: My relatives PEG makes me feel anxious



Emotional Representation item six: My relatives PEG makes me feel afraid

