An exploratory study of the views and experiences of food and weight loss in patients with operable pancreatic cancer, before and after surgical intervention.

A thesis submitted to the University of Manchester for the degree of
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ABSTRACT OF THESIS submitted by Christine Ann Cooper
For the degree of Master of Philosophy and entitled 'An exploratory study of the views and experiences of food and weight loss in patients with operable pancreatic cancer, before and after surgical intervention'

Month and Year of Submission Submitted May 2013.

Background: Malnutrition and cachexia are common in patients with pancreatic cancer and can affect up to 85% of patients. Cancer and its treatments place significant demands on the nutritional status of patients, which can be exacerbated by admission to hospital. Cancer of the pancreas also has a major impact on the nutritional status of patients after surgery, due to the resection of the gastrointestinal and biliary tract as well as the pancreas. Patients with cancer may have additional protein energy depletion due to cachexia, because of an imbalance between the nutritional needs of the patients and demands of the tumour. Nutrition can play an important role in the management of surgical cancer patients, but intervention needs to be implemented early to prevent malnutrition and weight loss becoming the dominant feature of the disease trajectory.

Aim: In this study, the aim was to investigate the perceptions and experience of patients about food, weight loss and nutritional interventions before, during and after surgical treatment of pancreatic cancer.

Methods: An exploratory study underpinned by hermeneutic phenomenological philosophy was conducted in 2011. Thirteen post surgery patients with pancreatic cancer were recruited from an NHS Trust in the north of England. Sampling was purposive and data were collected using semi-structured, in-depth, open-ended interviews, which were digitally recorded and transcribed verbatim. The interpretation of the data was guided by phenomenological and hermeneutic methodology.

Findings: Each of the participants interviewed told a unique story of their experiences and the findings convey the commonalities found in the participants' perceptions of their experiences. Six themes emerged from the data: recovery from cachexia, adaptation and surgical effects on oral intake, experiences of nutritional support interventions, dietary information, dietary counselling and the road to recovery post surgery.

Conclusion: This study revealed how patients with pancreatic cancer experienced physical and psychosocial difficulties, with weight loss and adaption to changed physiology after surgery, to maintain their nutritional status. Nutritional support interventions need to be targeted to aid in the rehabilitation of this group of patients, with the goal of providing individual dietary counselling and information to prevent disease recurrence. The most important finding in this study is that patients with operable pancreatic cancer after surgical intervention require a lot more nutritional input, from healthcare professionals, including dietitians.

Relevance to clinical practice: These findings highlight the importance of dietitians, in particular those working as part of a multi disciplinary team. They are in a key position to have a positive therapeutic influence on the nutritional status of patients with pancreatic cancer and could enable clear guidelines for the nutritional management of this group of patients to be developed. A specialist dietitian dedicated to this group of patients could facilitate more dietetic involvement and regular contact with patients. This would enable the promotion of individualised dietary counselling and help to improve nutritional intake and quality of life in this group of patients.

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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Abbreviations

BAPEN- British Artificial Parenteral and Enteral Nutrition
BMI – Body Mass Index
CASP - Critical Appraisal Skills Programme
CAQDAS – Computer Assisted Qualitative Data Analysis Software
CC – Christine Cooper (Researcher)
CINAHL - Cumulative Index to Nursing and Allied Health Literature
GP – General Practitioner
HPN - Home Parenteral Nutrition
IPA - Interpretive Phenomenological Analysis
Kcals -Kilocalories
Kg- Kilograms
MAU - Medical Assessment Unit
MeSH - Medical index subject headings
NHS- National Health Service
PALS - Patient Advice and Liaison Service
QOL- Quality of Life
SB – Sorrel Burden (Research Supervisor)

The Author

After completing my degree in Dietetics, I started working as a dietitian in the National Health Service in 2005. I had the opportunity to conduct research whilst completing my degree and my interest in gaining more experience in research has continued during my working career.

Whilst being involved in research over the last seven years, I have worked in various dietetic roles in West Yorkshire and Greater Manchester, which included working at Manchester Royal Infirmary as a Specialist Gastrointestinal Surgical Dietitian.

My research interests have focused on the assessment of integrating nutritional management into care pathways for gastrointestinal cancer patients. Other research interests have included nutritional assessment in clinical practice, liver disease, irritable bowel syndrome and coeliac disease.

Chapter 1: Introduction and background

Chapter 1: Introduction and background

Cancer is a major cause of morbidity and mortality throughout the world (Cancer Research UK, 2012). It is the second most frequent cause of death in Europe and is becoming the leading cause of death in old age (Von Meyenfeldt, 2005). Pancreatic cancer is one of the most fatal and aggressive human cancers and even at the start of the 21st century it continues to be a major incurable health problem (Hawes et al., 2000). Pancreatic cancer has a poor overall prognosis and only 3% survive for longer than 5 years after diagnosis (Travis, 2005) despite advances in surgery and chemotherapy (Lee et al., 2012). This is due to difficulty in diagnosis and at the point of identification most tumours are not suitable to be surgically removed (Krech and Walsh, 1991).

1.1 Prevalence of pancreatic cancer

Statistics from 2008 verify that 8,085 people in the UK were newly diagnosed with pancreatic cancer and it is the eleventh commonest type of cancer in the UK (Cancer Research UK, 2012). The incidence is increasing in Europe, with around 70,000 people in the European Union in 2008 being diagnosed with pancreatic cancer (Cancer Research UK, 2012). It should be noted however, that the increase does not appear to be due to an improvement in diagnosis rates (Travis, 2005), but due to the increasing accuracy of imaging and the improved knowledge in critical care (Phillips et al., 2009). Thus the number of patients having surgery for pancreatic cancer, for both benign and malignant tumours is increasing, although it is still only 10-20% of patients (Uomo et al., 2006), as many patients have advanced disease or distant metastases at the time of presentation.

1.2 Causes of pancreatic cancer

The causes of pancreatic cancer remain unknown, however there are several risk factors which have been identified in the development of pancreatic cancer, based on cohort and case-control studies (Hidalgo, 2010). Cigarette smoking is thought to account for 30% of pancreatic cancer cases (Hassan et al., 2007) and high alcohol consumption has been identified in several studies (Hassan et al., 2007, Silverman, 2001). There is also evidence, although less conclusive, that a high dietary fat intake is associated with an increased incidence (Silverman et al., 1998). Other causes include predisposing medical conditions such as a history of diabetes mellitus, chronic pancreatitis or gallbladder disease (Hidalgo, 2010).

Age is another risk factor for pancreatic cancer and 80% of cases are in people over 60 and it is still relatively uncommon in people under 40, but the total number of cases for men and women are similar (Cancer Research UK, 2012, Howe and Burch, 1996).

1.3 Symptoms of pancreatic cancer

The majority of patients do not present to their General Practitioner (GP) until their disease is advanced, due to the presenting symptoms of pain, dyspepsia and weight loss, having an insidious onset which can easily be mistaken for other gastrointestinal disorders or illnesses (Krech and Walsh, 1991). These symptoms can be ambiguous and non-specific, with the amount and extent of symptoms depending on stage and site of the disease (Krech and Walsh, 1991). Patients usually visit their GP with painless jaundice as the main presenting symptom. Jaundice is clinically detectable when serum bilirubin is 50 mmol/L (reference range 3-18 mmol/L), this will give an abnormal yellowish discolouration to the sclera of the eyes, skin and mucous membranes (Travis, 2005). Pruritus, dark urine and pale coloured stools are other presenting symptoms (Uomo et al., 2006).

1.4 Physical symptoms of pancreatic cancer

Malnutrition and cachexia are common in patients with pancreatic cancer (Fearon et al., 2006, Fearon et al., 1999) and can affect up to 85% of patients with this disease (Argilés, 2005). Malnutrition occurs when nutrient availability fails to meet the body's nutritional requirements (Mattox, 2005). However, cancer-associated malnutrition is multifactorial and differs from simple starvation (Uomo et al., 2006). Malnutrition can progress to cachexia, a specific form of malnutrition which compromises skeletal muscle metabolism, alters skeletal muscle function, reduces cardiac mass, the ability of cardiac muscles to contract, impairs immune response and can lead to oedema (Sic) (Argilés, 2005, Baracos, 2000, Baracos, 2006). The amount of depletion of skeletal-muscle mass is critical to overall survival of patients and can prolong recovery to normal function and decreases quality of life (Baracos, 2006). The mechanisms of cachexia are complex and in patients with this form of cancer are associated with a sustained pro-inflammatory cytokine response, poor dietary intake and the catabolic effects of sepsis (Braga et al., 2002). Other symptoms, which affect oral intake in pancreatic cancer patients, are jaundice, pruritus and pain (Travis, 2005).

The incidence of malnutrition is also affected by anticancer therapies (Bachmann et al., 2008) as well as the demands of the disease, subsequent treatments, and admission to hospital. However, inadequate intake of energy and nutrients alone is unable to account for the substantial changes in nutritional status seen in patients with advanced cancer (Baracos, 2006, Von Meyenfeldt, 2005).

Cancer cachexia is a syndrome associated with many illnesses, but as there has been no universally accepted definition of cachexia, it has often not been indentified or diagnosed and is frequently left untreated (Evans et al., 2008). An international consensus has now defined cancer cachexia as

"a multifactorial syndrome, which is characterised by an ongoing loss of skeletal muscle mass. This can be with or without loss of fat, but it cannot be fully reversed by conventional nutritional support, thus leading to progressive functional impairment. The pathophysiology is characterised by a negative protein and energy balance driven by a variable combination of reduced food intake and abnormal metabolism"
(Fearon et al., 2011, p.490).

The figure below represents the 3 stages of cancer cachexia, as defined by the definition from the international consensus however not all patients will progress through each stage (Fearon et al., 2011).

Precachexia	Cachexia	Refractory cachexia
Involuntary weight loss <5% Metabolic signs, such as anorexia and impaired glucose tolerance	Weight loss >5% of stable body weight in the past 6 months, or a body mass index (BMI) less than 20kg/m^2 and an ongoing weight loss of more than 2%, or sarcopenia and ongoing weight loss of more than 2%	Very advanced disease, or rapidly progressive cancer that is unresponsive to anticancer therapy. Active management of weight-loss no longer possible or appropriate. Not expected to survive longer than 3 months

Figure 1: Stages of cancer cachexia

Weight loss is a dominant predictor of mortality in patients with cancer, and the highest prevalence of weight loss is found with patients with solid tumours, of which pancreatic cancer is an example (Dewys et al., 1980). Fearon et al (2006) found that in patients with pancreatic cancer, 80% of patients have lost at least 10% of their total body weight at the time of diagnosis, with the cachexia syndrome present in 20-25% of patients. Since patients with pancreatic cancer tend to present late, they are more likely to have lost weight by the time they have been diagnosed and nutritional decline leading to cachexia may start before the clinical signs are apparent (Argilés, 2005). This fact is clinically significant as weight-losing patients have higher operative mortality and morbidity rates, than those who have not lost weight prior to surgery (Fearon et al., 1999).

Cachexia is a significant cause of morbidity and mortality it effects up to two thirds of cancer patients (Stephens et al., 2008) and 20% of cancer-related deaths are as a result of cachexia (Tisdale, 2001). Weight loss in patients with cancer is seen as a poor prognostic indicator, due to increased morbidity, a poorer quality of life, a reduced level of activity and increased mortality (Stephens et al., 2008). The early detection of nutritional decline and identifying patients at risk of developing malnutrition is a critical role that nurses can participate in, using nutritional screening (Davies, 2005). Thus enabling early nutritional interventions to be implemented (Davies, 2005), which can improve response to treatment, quality of life and reduce morbidity and mortality (Stephens et al., 2008) in patients with cancer.

Clinically cachexia is characterised by anorexia, changes in taste perception, early satiety, weakness and weight loss (Sic) (Baracos, 2006, Fearon, 1992). This pattern of weight loss differs from simple starvation, which can be seen in anorexia nervosa patients, where the most significant factor is loss of body fat and where skeletal muscle is retained (Stephens et al., 2008).

As previously discussed patients with pancreatic cancer often develop a large number of physical symptoms, however, these symptoms are not only physical in nature, but can also play heavily on the emotional well-being of patients (Lee et al., 2012). Thus, attempting to provide the best care for patients with pancreatic cancer, quality of life should be of prime concern, when deciding which course of action to follow, especially for those where survival is limited. A holistic approach needs to be considered not only the biological threats of the disease, but the repercussions on the patient's emotional, social and spiritual well-being need to be taken into account as well (Fitzsimmons et al., 1999).

1.5 Treatment of pancreatic cancer

Pancreatic cancer and its treatments place significant demands on the nutritional status of patients, which can be exacerbated by admission to hospital, because of the psychosocial and environmental difficulties of being in hospital (Warnock et al., 2005). The incidence of malnutrition in all hospitalised patients is widespread and the ground-breaking work of McWhirter (1994) found an overall incidence of malnutrition of 40%, with moderate or severe malnutrition in 27% of patients. The 2008 Nutrition Screening Survey conducted by British Artificial Parenteral and Enteral Nutrition (BAPEN) revealed a 42% prevalence of malnutrition in hospitalised cancer patients (Russell and Elia, 2009). Malnutrition in cancer patients who are otherwise suitable for major surgery is a considerable risk factor leading to poorer outcomes, as they have a higher risk of morbidity and mortality (McLeod et al., 1995). Cancer patients may have additional protein energy depletion due to cachexia (Braga et al., 2002).

Cancer of the pancreas has a major impact on the nutritional status of patients with this disease because treatment may include major resection of the gastrointestinal and biliary tract as well as the pancreas. Gastrointestinal dysfunction after surgery can occur with symptoms of delayed gastric emptying, early satiety, reflux and malabsorption due to pancreatic exocrine and endocrine deficiency (McLeod et al., 1995). This complex surgery increases metabolic demands and further compounds any pre-existing nutritional disorders (Gupta and Ihmaidat, 2003). A recognised risk factor postoperatively is protein energy malnutrition and the use of artificial nutritional support has helped to improve the clinical outcomes for patients in relation to post-operative complications (Braga et al., 2002, Gianotti et al., 2000). Artificial nutritional support post-operatively, such as enteral or parenteral feeding aims to ensure the patient has sufficient energy and nutrients to maintain or improve nutritional status and immune function, minimise gastrointestinal symptoms and improve quality of life (Argilés, 2005).

Evidence of the efficacy of artificial nutritional support for the maintenance of nutritional status and outcomes of acute hospitalised patients is now a recognised practice (Gianotti et al., 2000). This has been proposed as an essential part of perioperative care for patients, who are malnourished, undergoing surgery for a malignant tumour (Braga et al., 2002) and patients are no longer kept ‘nil by mouth’ for prolonged periods after surgery (Barlow et al., 2008). However, Goonetilleke and Siriwardena (2006) state that “the optimal timing of delivery of feed is unclear: should nutritional supplementation be given after surgery or should support cover the entire perioperative period” p.6. In a systematic review of studies on perioperative nutritional support in patients undergoing pancreatic duodenectomy for suspected malignancy the mean weight loss pre-operatively was between 3.9-7.1kg (Goonetilleke and Siriwardena, 2006). The studies in the review did not discuss weight loss post-operatively. The review found a wide variation in the trial protocols for the style of nutritional intervention and time period administered. This included, enteral nutrition using standard and immune-enhancing formulas and parenteral nutrition. Therefore a formal meta-analysis of pooled data was unfeasible and likely to be misleading given the wide disparity in the study protocols. The outcome measures associated with these studies included complications, length of stay and physiological markers. Although, the selection of end-points varied, the review showed that the studies reduced infective complications with enteral feeding. However, there seemed to be little evidence for routine parental feeding in the post-operative period. The main theme to emerge from the review was the lack of detailed baseline data on patients’ nutritional status during the perioperative period (Goonetilleke and Siriwardena, 2006).

Weight loss has been considered the main indicator for poor nutritional status in surgical patients (Bozzetti et al., 2007) and perioperative nutritional support has been found to positively improve the clinical outcomes for patients in relation to post-operative complications (Bozzetti et al., 2007, Brennan et al., 1994, Gianotti et al., 2000). A prospective trial of early enteral feeding versus ‘nil by mouth’ by Barlow et al (2011) of gastrointestinal surgical patients, which included 29 pancreatic duodenectomy patients found that early enteral nutrition delivered within 12 hours of leaving the operating theatre was not only feasible, but safe and associated with better clinical outcomes. This reinforces the argument to abandon traditional ‘nil by mouth’ strategies and contemporary enhanced recovery after surgery programmes, no longer prescribe periods of post-operative starvation (Barlow et al., 2011). It is noteworthy that Bozzetti (2007) reported nutritional support is in fact the only variable that can be easily modified by the surgeon to prevent postoperative complications. Preventing complications after pancreatic duodenectomy is important to hasten post-operative recovery, minimise mortality and reduce length of stay in hospital (Barlow et al., 2011). In a recent trial, wound infections, anastomotic leaks and length of stay were all reduced in patients receiving early postoperative enteral nutrition and in a cost minimisation exercise this was found to result in a cost saving to the National Health Service (NHS) (Barlow et al., 2008).

When the nutritional status of patients with pancreatic cancer has been investigated throughout the patients’ journey a significant decrease in anthropometric measurements including body mass index, upper arm anthropometry and hand grip strength after surgery has been demonstrated (Goonetilleke et al., 2008). However, these indices remained stable from the time of admission to hospital until the time of operation and therefore providing patients with pre-operative nutritional support does not appear to improve a patients’ nutritional status. These changes post-operatively have been sustained at three months after discharge (Goonetilleke et al., 2008). This important finding indicates that patients potentially require nutritional supplementation for up to three months post surgery, to improve their nutritional status.

The research to date has focused on clinical outcomes post-operatively and lacks information on patients’ views and experiences, thus influencing the design of the proposed study. The proposed study aims to seek the lived experiences of personal meanings of food, nutrition and weight loss for each of the research participants before and after surgical intervention for operable pancreatic cancer.

The following chapter presents further background to this proposed study in the form of a critical review of the literature. This search has been conducted to identify gaps in the literature of experiences, from patients with cancer, their relatives or professionals caring for cancer patients concerning their views towards nutrition and weight loss.

Chapter 2: Critical review of the literature

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2.1 Background

In the previous chapter pancreatic cancer was discussed in relation to its effect on the nutritional status of individual patients. The potential effects of malnutrition and cachexia on the perioperative outcomes were documented, thus highlighting the link between poor nutritional status and clinical outcomes, such as post-operative complications. The previous studies have been biomedical in nature and have not focused on the clinical outcomes and the effect this has on the individual, by seeking their perceptions and experiences.

2.2 Title of the critical review: Exploration of nutrition in weight losing cancer patients; a critical review of qualitative literature

The following critical review of the literature aims to provide a narrative description of qualitative research written on the experiences of nutritional issues in weight losing cancer patients. Although studies have examined the physical and biological effects of cancer cachexia and highlighted the detrimental impact of weight loss in patients with cancer (Poole and Froggatt, 2002), these studies do not take into account the patients' experience of these symptoms. Therefore the purpose of this critical review was to identify any gaps in the current literature and to summarise existing qualitative research on the experiences of weight loss in patients with cancer and ascertain what implications this has for dietetic practice and the proposed study. The literature review will be conducted in the form of a critical review of the literature to critique the body of evidence on experiences of weight loss in patients with cancer published over the last 20 years.

2.2.1 Introduction

Nutrition can play an important role in the management of the cancer patient (Rock, 2005), but intervention needs to be implemented early to prevent cachexia and weight loss from becoming the dominant feature of the disease trajectory (Baracos, 2006). A better understanding of cachexia and strategies on how to approach it could improve the experience for patients and their carers (Churm et al., 2009).

The results of a study by Churm et al (2009) highlighted that healthcare professionals were aware of the common features of anorexia-cachexia syndrome, including weight loss and a change in appetite, which are typical features of the syndrome. But the understanding of the syndrome varied amongst doctors and nurses and therefore it would seem reasonable that the basic management of key symptoms were addressed. These were dry mouth, early satiety and poor appetite, which are all common complaints of patients with cancer. The management strategy for poor appetite was referral to a dietitian, which was reported by 61% of respondents. Nutritional supplements and dietary advice were given by 40% and 32% respectively (Churm et al., 2009). Dry mouth was treated appropriately with basic advice given on mouth care and artificial saliva preparations. However, almost a third (29%) of respondents did not know how to treat or recognise early satiety. This study was conducted because of the general opinion that cancer cachexia is poorly managed and patients are left with symptoms, which may be treatable. The results seem to concur with that opinion, however it is possible that healthcare professionals feel a sense of hopelessness when dealing with cancer cachexia, because of disease progression or a lack of effective resources to guide management of the syndrome (Churm et al., 2009).

Patients undergoing cancer treatment such as chemotherapy, surgery or radiation will need wide-ranging nutritional care, which should involve the collaboration of all members of the multidisciplinary team. Each of the team members should be able to recognise nutritional issues and suggest strategies leading to positive patient outcomes (Baracos, 2006). Many people with cancer and their carers feel that nutrition is an area, in which they can actively seek information and play an active role. Therefore it is essential that patients' nutritional needs and concerns can be indentified and dealt with as they arise (Robotin et al., 2010).

Dietitians need to understand the course of malignant disease and its treatment, this can be informed by close collaboration with the multidisciplinary team (Baracos, 2006). Maintaining good nutritional status whilst undergoing treatment for cancer, may possibly lead to an improved quality of life (Rock, 2005). A randomised controlled trial by Ravasco et al (2005) involved patients with colorectal cancer undergoing radiation therapy, reported the benefits of nutritional counselling. Patients were seen by a dietitian and prescribed a therapeutic diet using regular foods, with further modification for individual requirements. The results of this study (Ravasco et al., 2005) suggest that individualised dietary counselling even with the detrimental effects of radiation therapy is more beneficial when compared to non prescriptive approaches that do not take into account personal preferences (Rock, 2005). Most notably the beneficial effects were still maintained 3 months after radiation therapy (Ravasco et al., 2005).

Healthcare providers need to be aware how family members view the significance of weight loss and decreased appetite and anticipate that nutrition can be a considerable source of anxiety for relatives and carers (Hopkinson and Corner, 2006, Strasser et al., 2007). Also family conflict can occur as a result of this and a lack of intervention with nutritional support may, be interpreted by the family as neglect of the patient (McClement, 2005).

Qualitative research has developed out of a wide set of disciplines and traditions, for example anthropology and sociology, with a wide range of underpinning philosophies and no single approach or definition (Mason, 2002). While the underpinning philosophy may differ, qualitative research does have some common characteristics (Popay et al., 1995). Qualitative research aims to generate in-depth accounts from individuals or groups, by interviewing them or observing their behaviour. Qualitative research focuses on answering questions of “why’ and ‘how’, by the generation of rich data and the exploration of real life behaviour, thus enabling the patients and carers to voice their experiences (Kuper et al., 2008b). However, qualitative research has historically, been positioned low in the hierarchy of evidence, but it is increasing and provides further methodological tools for health researchers (Kuper et al., 2008b), to explore and explain how patients experience certain aspects of the healthcare system. There is a growing consensus, that qualitative research should guide the decision making process used, in the development of health policy and practice (Swift and Tischler, 2010). By focussing on patients’ feelings, meanings and experiences, the healthcare professional is able to understand how patients perceive health services (Bowling, 2009), thus enabling a more comprehensive understanding of the healthcare system (Kuper et al., 2008b).

By reviewing qualitative research that has investigated loss of appetite and weight in patients with cancer, this review seeks to elicit whether, the reported problems of loss of appetite and weight loss, are primary concerns for patients, their carers or healthcare professionals. Although both symptoms are common in patients with cancer, especially advanced cancer, it is not clear how many patients perceive these symptoms as distressing, as little is know about the patients’ experience.

2.2.2 Research design for the critical review

Using a systematic approach, a critical review of primary qualitative published research in peer-reviewed journals on experiences of weight loss in cancer patients published over the last 20 years, which included a pre-defined inclusion and exclusion criteria, was conducted.

2.2.3 Formulation of the research question

In order to search for qualitative studies on patients with cancer experiences of cachexia and weight loss, the researcher formulated a research question. This was clear and focused (Ritchie and Lewis, 2003), but not a narrowly defined research question, as the goal of the critical review was to give an overview of published qualitative research in this field. The question, which guided the structured search for relevant literature was, “what are the experiences of weight loss in patients with cancer?”

2.2.4 Inclusion criteria and exclusion criteria

Inclusion criteria for this review were that a report must use a qualitative methodology, for example interviews, focus groups, or observations consistent with the valid aims of qualitative research. The original report needed to be written in English, describing the experiences of people with cancer or those of their carers or health care professionals about their views towards nutrition and weight loss. All studies only included adults (>18 years old).

Reports were excluded that fulfilled one or more of the following conditions: (a) the use of mixed methods, where qualitative findings could not be separated from quantitative findings (b) non-English sources, (c) grey literature such as editorials or other reports that lacked original research results and (d) studies that discussed eating habits for cancer prevention or weight gain and issues predominantly about body image.

2.2.5 Search strategy

Table 1 highlights the databases searched for this critical review of the literature and justifies why the researcher chose the specified databases.

Table 1: Electronic databases searched

Databases	Justification
Cochrane Database (2005 to January 2011)	This database was searched for any previous systematic reviews, focussing on qualitative studies on weight losing cancer patients
Cumulative Index to Nursing and Allied Health Literature (CINAHL)	This database was chosen for its recognised focus on issues related to health and healthcare and nursing and allied healthcare professionals' roles could be argued to fit more appropriately with qualitative methodological approaches compared to medical research.
Embase (1980 to 2011 Week 06)	This database was chosen for its recognised focus on issues related to health and healthcare and propensity to list more qualitative research.
Ovid Medline® Daily Update)	This database was chosen for its recognised focus on issues related to health and healthcare.
PsychINFO (1806 to February Week 2 2011)	This database was chosen for its recognised focus on issues related to health and healthcare.

Key words were entered in various combinations to electronic databases and these were qualitative, cancer, cachexia, weight loss, appetite, nutrition, food and eating and drinking. Medical index subject headings (MeSH) and textword searches were carried out with the appropriate combination of the terms using Boolean operators “OR” and “And”. The combination of these terms yielded 47 hits (see appendix 1).

The search also included all philosophical and non-philosophical approaches, interpretative, theory generating and descriptive qualitative methodology, to include as many relevant primary qualitative studies, in the critical review.

Finally, manual reference checks were performed to supplement the above electronic searches. This search strategy was done iteratively, until no new qualitative studies were found on review of the reference lists of retrieved articles.

2.2.6 Review strategy

The review proceeded in four stages with the inclusion and exclusion criteria applied at each stage. Two people looked at the titles and abstracts and undertook data extraction to minimise selection bias in the procedure. The review was conducted by the researcher (CC) and by one of the researcher's supervisors (SB).

2.2.7 Stage 1: Inclusion of abstracts

Abstracts from the searches were imported and organised using EndNote X3, a software programme for bibliographic management and examined to determine inclusion using the criteria discussed earlier. If the abstract did not provide this information then the article was excluded.

2.2.8 Stage 2: Retrieval of articles

Full articles were retrieved, if the abstract had not been rejected in stage 1. Papers reporting primary research published in peer-reviewed journals, written in the English Language and available locally or by inter-library loan were retrieved. The articles were reviewed in-depth and independently evaluated by each of the reviewers (CC & SB).

2.2.9 Stage 3: Data extraction

A data extraction form (see appendix 2) was designed by (CC) and data abstracted from each article included by both (CC) and (SB):

1. Publication details
2. Patient population, number of patients, sampling and health characteristics
3. Research design and data collection methods

In total 47 abstracts were identified from the initial search, however duplicate abstracts, studies that discussed eating habits for cancer prevention or weight gain and issues predominantly about body image and studies that were not qualitative on closer scrutiny were excluded. Thus 25 studies were excluded and both reviewers agreed on the exclusion of these studies. Full articles for the remaining 22 studies were retrieved, however after the data extraction criteria had been applied, four did not meet the full inclusion criteria and were subsequently excluded from the critical review, by mutual agreement of both reviewers. The reasons for exclusion included; a study by Hopkinson et al (2006) was a cross sectional study and therefore did not meet the inclusion criteria. A mixed methods approach used by Orrevall et al (2009) was excluded because it was not possible to separate the quantitative data from the qualitative data. Although the mixed methods study by Strasser el al (2007) was included because it predominately used grounded theory methodology. The final two studies (Olsson et al., 2002, Reedy et al., 2005) although they both used qualitative methodologies were excluded as one discussed convalescence after gastrointestinal cancer surgery, but did not discuss food and nutrition issues and the other discussed the quality of food patients were eating and therefore did not meet the inclusion criteria. Thus, 18 studies were included in the critical review of the literature (See Table 2).

Table 2: Description of the studies included in the critical review

Author & Date	Research focus	Design	Sample and setting	Themes
Holden (1991) USA	To explore the emotional ramifications of anorexia in the terminally ill cancer patient.	Semi-structured interviews.	14 patients and their respective primary caregivers selected from a hospice programme.	A difference of opinion between carers' views and patients' views on eating and terminal illness. Patients would prefer their family members to take a less assertive approach to their eating difficulties.
Wilson et al. (1991) USA	To explore eating problems identified from the patient's perspective during and after treatment for head and neck cancer and strategies used to improve food intake during treatment.	Open Ended Interviews.	11 head and neck patients cancer with after radiotherapy, identified from two metropolitan radiation therapy departments.	Outlines eating strategies and interventions that will assist patients with head and neck cancer to maintain nutrition.
McGrath (2002) Australia	Reflects on 2 previous studies where nutritional issues were not the main focus, but were expressed as a concern.	Phenomenological philosophy using Open Ended Interviews.	22 patients having treatment at a major metropolitan hospital with haematologic malignancies and 10 of their respective carers	Food and eating seem to be of great significance, both to patients and caregivers for people with haematologic malignancies. The significance of food is not seen just in terms of its nutritional value, but as an important quality of life issue.

Author & Date	Research focus	Design	Sample and setting	Themes
McClement et al. (2003) Canada	To develop a conceptual model of family caregivers beliefs and behaviour in relation to nutritional issues.	Grounded theory philosophy using Interviews and participant observation.	47 participants from 4 groups were included in this study: 13 hospitalised palliative patients with cancer (including bowel, larynx, lung, brain, breast, renal and stomach cancers), 13 family members of hospitalised palliative patients with cancer, 11 healthcare providers and 10 bereaved family members who had previously experienced the death of a relative on a palliative care unit.	This study puts nutritional aspects of palliative care into context from the ward environment patients, family and caregivers.
Orrevall et al. (2004) Sweden	An investigation into the nutritional situation prior to the introduction of Home Parenteral Nutrition (HPN) from the perspective of patients and family members.	Semi-structured interviews using the constant comparative method for data analysis.	13 palliative care patients with cancer (including pancreas, oesophagus, gastric, rectal, breast, lung and ovarian cancers) and 11 of their family members. Patients were selected if the were receiving the minimum of 900/Kcal at least three times per week via HPN.	Patients and family members saw the possibility of receiving HPN as a relief and a possible alternative to constantly having an inadequate intake. Hospital routines, meal preparation, meal delivery systems all contributed to patients' malnourishment.
Orrevall et al. (2005) Sweden	Exploratory study to investigate the views and experience of HPN in a group of advanced cancer patients.	Semi-structured interviews, analysed inductively using constant comparisons.	13 palliative care patients with cancer (including pancreas, oesophagus, gastric, rectal, breast, lung and ovarian cancers) and 11 of their family members. Patients were selected if the were receiving the minimum of 900/Kcal at least three times per week via HPN.	Patients with advanced cancer and their family members experience physical, social and psychological benefits from HPN. However, HPN is only a partial solution to existing food problems.

Author & Date	Research focus	Design	Sample and setting	Themes
Warnock et al. (2005) UK	To identify factors that are barriers and facilitators to cancer patients eating in hospital.	Non-participant observation.	2 wards with 30 beds each in a cancer centre with cancer patients of mixed diagnosis. 5 x 3 hours observations relating to the physical and social environment on the wards by two researchers, one on each ward.	Nutrition was influenced by a complex interaction of factors. Themes relating to the physical environmental were: disease related factors, dependence on others for support with nutrition, preparation for meals, and the organisation of food delivery. The social environment described interactions between patients, staff and visitors that related to nutrition.
Hopkinson et al. (2006) UK	To explore the experience and concern about weight loss in people with advanced cancer, their caregivers and specialist nurses.	Hermeneutic phenomenology using semi- structured interviews.	30 patients with advanced cancer (including breast, lung, prostate, head and neck and gastrointestinal cancers) under the care of 2 community homecare services, 23 caregivers and 14 nurse specialists.	Weight loss is a source of concern for patients with advanced cancer, especially when it becomes visible, as this could be perceived as a proximity to death and symbolised a loss of control over the disease.
Hopkinson & Corner (2006) UK	To develop an understanding why eating can be troublesome in patients with advanced cancer and examine helping people with changes in eating habits.	Hermeneutic phenomenology using in-depth Interviews.	30 patients under the care of 2 community teams with advanced cancer, (including breast, lung, prostate, head and neck and gastrointestinal cancers), reporting a change in eating habits, and no longer receiving treatment. 14 nurse specialists and 23 caregivers.	Patients who are living with eating related concerns have different preferences ranging from acceptance to engaging in self-action.

Author & Date	Research focus	Design	Sample and setting	Themes
Dewey & Dean (2007) UK	To explore the nutritional management of patients with advanced cancer and weight loss.	Principles of grounded theory using semi-structured interviews.	14 District, Community or Specialist Macmillan nurses caring for patients with incurable cancer.	7 themes emerged which were; Nurses Roles, Assessment of nutritional status, Impact of weight loss and eating-related disorders, Acknowledging weight loss Training for nurses, Management strategies and Expectation of interventions.
Strasser et al. (2007) Switzerland	To discover and describe eating-related distress on male patients with advanced cancer and their female partners.	Grounded theory philosophy using interviews & Focus groups	19 cancer patients with > 5% weight loss and problems with appetite and their partners with whom they spent 50% of their mealtimes (including upper gastrointestinal tract, pancreas, colorectal, lung, head and neck, prostate and haematological cancers) attending a General Hospital	Eating-related distress is a complicated issue for men with advanced cancer and their partners affecting their daily habits and relationships.
Shragge et al. (2007) Canada	To investigate the process that explains how patients with advanced cancer compensate for anorexia and mange the emotional and social consequences of a decreased intake.	Glaserian grounded theory philosophy using Interviews.	9 patients with advanced cancer (defined as recurrent, metastatic or refractory with mixed cancers) undergoing chemotherapy or palliative radiation and other supportive therapies were included, through a palliative homecare service or outpatient department of a General Hospital.	Patients often accept their reduced intake and caregivers need to be encouraged by the development of interventions on how to support the efforts of the patient. These interventions may help resolve conflict that often arises in relation to eating between the patient and family members.

Author & Date	Research focus	Design	Sample and setting	Themes
Wainwright et al. (2007) UK	To gain an in-depth understanding of patients experience of appetite loss and how this affected Quality of Life (QOL).	In-depth Interviews using Thematic analysis.	11 oesophagectomy patients 3 months after surgery. Sampled from a large teaching hospital.	The psychosocial aspects of eating and the stigma and embarrassment this causes. Weight loss after treatment can take on a sinister outcome and thus body weight is something that needs to be closely monitored. How the body remaps itself and adapts after surgery.
Dewey & Dean (2008) UK	To explore the management of patients with advanced cancer and weight loss cared for by nurses both in primary and secondary care.	Grounded theory philosophy using semi- structured interviews.	14 District and Community or Specialist MacMillan nurses who had nursed a minimum of 5 patients with incurable cancer.	Nurses play an important role in the delivery of high quality cancer care in the UK. However, there is a huge amount of variability in delivery of services and practice.
McClement & Harlos (2008) Canada	To examine the nutritional care experiences in advanced cancer from the perspectives of patients, families and healthcare providers.	Grounded theory philosophy using Interviews and participant observation.	13 palliative inpatients on a palliative care unit) including bowel, larynx and lung cancers), 13 family members, 11 healthcare workers working on the unit and 10 bereaved family members whose relatives had previously been inpatients on the palliative care unit.	This study gave a voice to patients of families and grounds our understanding of families regarding perceptions and behaviours regarding the nutritional care of a terminally ill relative.

Author & Date	Research focus	Design	Sample and setting	Themes
Reid et al. (2009) UK	To explore the lived experience of cachexia for patients with advanced cancer and their family members.	Heideggerian Phenomenological philosophy using interviews underpinned the study.	15 patients with a diagnosis of incurable cancer (including lung, haematological, osteosarcoma, prostate, mesothelioma, bile duct and adenocarcinomas cancers) and 12 family members., sampled from both inpatients and outpatients in a regional cancer centre.	Defines the experience of cachexia for patients with advanced cancer and their relatives and confirms the huge challenge it presents within the clinical setting.
Reid et al. (2009) UK	To investigate tension over food that exists between patients and family.	Heideggerian Phenomenological philosophy using Unstructured Interviews.	8 patients with a confirmed diagnosis of advanced, incurable cancer (including lung, prostate, acute myeloid leukaemia, bile duct, cystadenocarcinoma and mesothelioma cancers) weight loss of >10% and living at home. Each patient was asked to nominate a family member to be involved in the study.	Highlighted the anxiety that surrounds eating and the distress it causes to families.
Reid et al. (2010) UK	To focus on the experience of patients and their family members with regard to care provided by healthcare professionals.	Interpretive Phenomenological Analysis (IPA) using unstructured interviews.	15 patients with incurable cancer (including lung, haematological, osteosarcoma, prostate, mesothelioma, bile duct and adenocarcinomas cancers) and 12 family members sampled from both inpatients and outpatients in a regional cancer centre.	3 themes emerged from the study; a lack of acknowledgement from healthcare providers about patients' reported weight loss, a lack of information about their cachexia from healthcare professionals and a lack of appropriate supportive intervention.

2.2.10 Stage 4: Quality assessment

Qualitative research incorporates a vast range of methods with differing philosophical underpinnings, it is not easy to produce a set of criteria, which can be used as a quality check list and generally applied (Mays and Pope, 2000, Pilnick and Swift, 2010). It needs to be interpreted by informed reflective thought and not just the application of a simple scoring system such as those that have been designed to assess quantitative studies (Kuper et al., 2008a).

Despite the increasing recognition of the importance of qualitative methods in health research, there have been limited attempts to define quality standards for assessing the results (Popay et al., 1998). Critical Appraisal Skills Programme (CASP) (Critical Appraisal Skills Programme, 2006) are tool-based approach for quality of qualitative research with clearly defined questions. The researcher used CASP to assess the quality of the articles to enable the researcher and the researcher’s supervisor to have clearly defined questions, thus allowing agreement on the quality of the articles. CC and SB, using the rating scales based on CASP, assessed each article for quality. These require the demonstration of:

1. A clear statement of aims of the research with consideration of qualitative methodology as the most appropriate approach;
2. an appropriate sampling strategy (e.g. details regarding how and where participants were selected; details provided on non-participants; and consideration of data saturation in relation to sampling size, i.e. ensuring that no additional data are gained by further data collection);
3. rigorous data analysis (e.g. in-depth description of the analysis process and how the categories/themes were derived for the data; sufficient data to support the findings; attempts to ensure the reliability of data by methods, such as feeding back to participants and repetition of analysis by more than one researcher);
4. accurate interpretation of data (provision of illustrative quotes to support theme development); and
5. transferability of results (i.e. relevance of study to the wider population beyond the study sample, which allows the reader to relate to similar characteristics).

The quality of the studies were assessed by each of the reviewers by reading the full article to ascertain if the researchers had clearly described the aims of the research, provided a clear description of the method and the participant characteristics and that there was coherence and consistency in their methodological approach. Holloway (1997) suggests that the reader should be able to replicate the study, if it is well presented this view is also supported by Mays and Pope (1995). They advocate that fellow researchers, reading the study, should potentially be able to follow the method, analyse the data and primarily reach the same conclusions. Table 3 demonstrates how the articles were assessed for quality by applying the CASP questions. Although some of the studies did not meet all the quality criteria, both CC and SB felt that sufficient information had been provided to include them all in the narrative review.

Table 3: Quality assessment of each of the articles

Author /Date	Clear aims	Sampling	Data collection methods	Reflexivity	Ethical Issues	Accurate interpretation of the data	Strengths and weakness of the approach using the quality criteria
Holden (1991)	Yes	Limited	Limited	No	No	No	This paper did not discuss many of the quality criteria, however this was the first paper highlighting the experience of cancer cachexia from the patient perspective
Wilson et al. (1991)	Yes	Yes	Yes	No	Yes	Yes	This was a good quality paper and added valuable information to the current body of knowledge concerning the complex relationships between nutrition and patients with cancer
McGrath (2002)	Yes	Yes	Yes	No	Yes	Yes	This was a good quality paper and highlights the significant nutritional problems associated with aggressive treatments for haematologic malignancies
McClement et al. (2003)	Yes	Yes	Yes	No	No	Yes	This paper did not meet all the quality criteria, however it highlighted a way in which family members of palliative patients with cancer can manage their nutritional needs
Orrevall et al. (2004)	Yes	Yes	Yes	No	Limited	Yes	This paper did not meet all the quality criteria, however it highlighted that patients should be given the opportunity to have HPN at the end of life, but if healthcare professionals offered a more structured approach to cachexia and weight loss. Then this would reduce the need for HPN in palliative cancer patients

Author /Date	Clear aims	Sampling	Data collection methods	Reflexivity	Ethical Issues	Accurate interpretation of the data	Strengths and weakness of the approach using the quality criteria
Warnock et al. (2005)	Yes	Yes	Yes	No	Limited	Limited	This paper did not discuss many of the quality criteria, however this was a good pilot study, and highlighted the social and physical environmental issues surrounding nutrition whilst in hospital
Orrevall et al. (2005)	Yes	Yes	Yes	No	Limited	Yes	This paper did not meet all the quality criteria, however it highlighted that patients should be given the opportunity to have HPN at the end of life, but if healthcare professionals offered a more structured approach to cachexia and weight loss then this would reduce the need for HPN in palliative cancer patients
Hopkinson et al. (2006)	Yes	Yes	Yes	No	Yes	Yes	This was a good quality paper and highlights the importance of addresses concerns about alleviating psychosocial suffering of weight loss in patients by breaking the weight loss taboo
Hopkinson & Corner (2006)	Yes	Yes	Yes	Yes	Yes	Yes	This was a good quality paper and highlighted that addressing patients concerns with weight loss and changes in eating habits may need to include education on optimising nutritional intake for patients with advanced cancer
Strasser et al. (2007)	Yes	Yes	Yes	Yes	Limited	Yes	This was a good quality paper and highlighted that eating related distress is complicated in men with advanced cancer and their partners, which affects their daily habits and potentially their relationship

Author /Date	Clear aims	Sampling	Data collection methods	Reflexivity	Ethical Issues	Accurate interpretation of the data	Strengths and weakness of the approach using the quality criteria
Dewey & Dean (2007)	Yes	Yes	Yes	Yes	Yes	Yes	This was a good quality paper and provided valuable information regarding nurses nutritional assessment of patients with advanced cancer and acknowledgement of weight loss
Wainwright et al. (2007)	Yes	Yes	Yes	No	Yes	Yes	This was a good quality paper and contributed to the body of evidence and acknowledged that Oesophagectomy patients require a lot more help with learning to eat again than a brief consultant with a dietitian post surgery
Shragge et al. (2007)	Yes	Yes	Yes	No	Yes	Yes	This was a good quality paper and highlighted that proactive control of symptoms, such as nausea, individual nutritional interventions and healthcare professionals discussing appetite and weight loss with patients should not be avoided
Dewey & Dean (2008)	Yes	Yes	Yes	No	Limited	Yes	This was a good quality paper and contributed to the body of evidence and acknowledged that the voice of the patient and their family members has not been heard
McClement & Harlos (2008)	Yes	Yes	Yes	Limited	Yes	Limited	This paper did not meet all the quality criteria, however it highlighted the need for future research to ensure that the knowledge base of patients and family members experiences, given the complex interplay between physiological and psychosocial dimensions of cancer cachexia

Author /Date	Clear aims	Sampling	Data collection methods	Reflexivity	Ethical Issues	Accurate interpretation of the data	Strengths and weakness of the approach using the quality criteria
Reid et al. (2009)	Yes	Yes	Yes	No	Yes	Yes	A good quality study and very valuable at highlighting the multi-dimensional ramifications of cancer cachexia for patients with advanced cancer and their family members and confirms the huge challenge it presents within the clinical setting
Reid et al. (2009)	Yes	Yes	Yes	No	Limited	Yes	This was a good quality study and highlighted the tension that exists between patients and their families, regarding the amount of food eaten by patients with cachexia, due to a lack of understanding about the role food, in cancer cachexia management
Reid et al. (2010)	Yes	Yes	Yes	No	Yes	Yes	This was a good quality study and highlighted the need for future supportive informational interventions for patients and their families to understand weight loss and cachexia

2.2.11 Results and structure of the critical review

The studies in the critical review (see Table 2) identified key themes, which will be presented under the following headings:

- Loss of appetite as a source of anxiety.
- Conflict felt between patients and family.
- Conflict between healthcare providers and family members regarding the nutritional care of the patient.
- Significance of weight loss for patients.
- Struggling to maintain oral intake without an appetite.
- Healthcare assessment and management of patients' weight loss.
- Patient experiences of alterations in body image.
- Improving practice and nutrition in hospitals.

These themes have been identified by the researcher as being potentially significant to answering the question, which guided the structured search for the relevant literature. It should be noted that the studies had other findings and themes as discussed in table 2, however only the themes highlighted above will be further discussed in this critical review.

2.2.12 Overview of the articles

Eighteen qualitative articles were identified and included in the review. Table 2 summarises some of the key methodological features of the articles. The largest percentage of studies focus on cancer patients with advanced disease and poor prognosis (n=15). Two studies focus on patients after treatment for cancer and one study focuses on an acute cancer unit population.

Table 4: Types of participants included in the studies

Types of participants	Patients only	Patients and family or caregiver	Patients, bereaved and current caregivers or family	Patients, family members or caregivers and healthcare professionals	Healthcare professionals only
No of studies	3	8	2	3	2

Sampling is a general feature, when designing a qualitative study and ideally samples are selected purposively, this means that they are selected for a purpose. For example, to provide thick detailed descriptions about a particular phenomenon, table 4 highlights the types of participants involved in the studies. Eight studies used this method of sampling, (Dewey and Dean, 2007, Dewey and Dean, 2008, Hopkinson and Corner, 2006, Hopkinson et al., 2006a, Reid et al., 2009a, Reid et al., 2009b, Reid et al., 2010, Shragge et al., 2007). Three of the studies used convenience samples (Strasser et al., 2007, Warnock et al., 2005, Wilson et al., 1991), although non-random samples are appropriate for qualitative research, as the results would not be aiming for statistical generalisation to a population. However, two studies (Holden, 1991, Wainwright et al., 2007) used random selection, this approach is more commonly used in quantitative research where the aim is to produce a statistically representative sample. Although, Holden (1991) used random selection, the participants were selected with the purpose of answering the research question, by providing a thick description of the phenomenon under study. However, it could be argued that this is a limitation to the study as there is no discussion about other potential patients that might have been eligible for inclusion in the study. Wainwright et al (2007) also stated that participants were randomly selected for interview. However, these were a subsample of a larger questionnaire study and they did use a sampling frame with exclusion criteria, to select the most appropriate patients for interview.

Five studies did not discuss sampling (McClement and Harlos, 2008, McClement et al., 2003, McGrath, 2002, Orrevall et al., 2005, Orrevall et al., 2004), but giving a clear indication of sampling strategies may further enhance credibility (Fade, 2003) and limitations to the sample should be clearly justified (Kuper et al., 2008a), in order to capture the many aspects of the phenomenon. However, the characteristics of participants involved in the studies are important and how they were approached to take part in the study. Each of these studies did provide the reader with a description of who was involved in the study and how they were approached.

Often, very little analytic detail has been provided in methodological descriptions, regarding the philosophical and pragmatic underpinnings of the study (Table 2). However, qualitative data in the articles reviewed typically were analysed using thematic or content analyses or drawn from grounded theory methodology (constant comparison, theoretical coding). Six studies used either descriptive or interpretive phenomenological philosophy to underpin the studies (Hopkinson and Corner, 2006, Hopkinson et al., 2006a, McGrath, 2002, Reid et al., 2009a, Reid et al., 2009b, Reid et al., 2010), where the interpretive aim was stated as entering the life world of the participant and clarifying the personal meaning of cancer cachexia for each of the participants. The appropriateness of the selected method, needs to be justified and explained in a clear and systematic manner (Kuper et al., 2008a). As detailed in Table 1, the only article in this review that did not carefully describe the methods used to collect data was Holden (1991).

Qualitative researchers need to be reflexive during the research process, by recognising their role in the research process and the influence that the researcher brings to the research process with their pre- knowledge and views (Draper and Swift, 2011). This is essential to qualitative research, as researchers try and create a trust through a personal relationship, during the interview, as a means to try and obtain a disclosure of the interviewee’s world (Kvale, 2006). However, only three studies in this review discussed reflexivity (Table 3). The researchers involved in the studies were mainly healthcare professionals either still working in practice or who had previously worked in practice. The potential power relationship of researcher versus healthcare professional should be addressed, by clearly discussing how reflexivity was achieved.

Ethical issues should also be taken into consideration and a thorough explanation of how ethical standards have been met needs to be provided to the reader, for example, issues around informed consent and confidentiality, as qualitative researchers are collecting participants’ personal experiences and participants need to be informed how the results will be disseminated to the public (Kuper et al., 2008a). Table 3 shows that two studies in this review did not mention ethical issues in the articles and a further six studies provided limited information. The issue of confidentiality and anonymity is important to minimise harm and protect participants from possible concern due to sharing their personal experiences (Kuper et al., 2008a).

2.2.13 Influence on practice and future research

Healthcare research is conducted with the aim of informing or influencing practice and in order to do this the researchers need to show that their findings can be applied not only to that one specific group of participants (Pilnick and Swift, 2010). The findings of a qualitative study are not intended to be generalisable in the same way as quantitative studies (Kuper et al., 2008b), as they provide thick descriptions of participants. However, the results maybe transferable to other contexts and researchers can assess if they apply to their own setting, by considering sampling strategies and good theoretical reasons why the sample was selected at the design stage of the study (Draper and Swift, 2011). But, generalisability is difficult in different types of patients and different healthcare contexts from that of the UK.

Table 5: Results- what these studies add to practice and key research for the future

Author / Date	What these studies add to practice and key research for the future
Holden (1991)	Need to be aware of the complex emotional issues surrounding food in hospices
McGrath (2002)	Effective strategies should be routinely integrated into the hospital care of patients undergoing chemotherapy. These include access to a dietitian especially when patients are undergoing chemotherapy, eating patterns need to be assessed, adequate cooking facilities need to be provided in the hospital setting, and finally well-written and informative information to reduce distress caused by eating problems
McClement et al. (2003)	This study gives insight into contrasting opinion
Orrevall et al. (2004)	Looks at how care is provided to anorexia/cachectic patients
Orrevall et al. (2005)	The need to develop guidelines for giving HPN not just in terms of nutritional aspects but also optimising Quality of Life for both patient and family members
Hopkinson & Corner (2006)	Development of a conceptual Model of the Patient Experience of Living with Eating Changes and Advanced Cancer
Hopkinson et al. (2006)	Highlights the issue of weight loss taboo
Dewey & Dean (2007)	This study shows the need for further views of other healthcare professionals. Also highlighted that patients' and relatives' views should be sought to find out what information and services they would like to receive
Wainwright et al. (2007)	Adds to the implication of the need for support and rehabilitation in oesophageal cancer patients post surgery
Shragge et al. (2007)	Development of an intervention, which could be useful in guiding clinicians
McClement & Harlos (2008)	Suggests a need for psychosocial interventions for healthcare providers of patients, families and healthcare providers regarding the nutritional care of cancer patients in terminal illness
Dewey & Dean (2008)	Nurses play an important role in the delivery of high-quality cancer care in the UK. Therefore they need to welcome the change and expansion from 'nurse-led' to multidisciplinary working. Leading to team structure with clear systems and criteria
Reid et al. (2009)	This study illuminated the impact of cachexia and it is therefore important for nurses to understand the multidimensional impact of cachexia to inform future care delivery
Reid et al. (2009)	Provides an insight into the tensions that exist over food between patients and their families
Reid et al. (2010)	Patients and families need information, but they also need support as well to cope with fears and anxieties in relation to cancer cachexia

Table 5 highlights what the studies in the review add to practice and future research. Table 5 shows that the studies by Hopkinson et al (2006) (Hopkinson and Corner, 2006, Hopkinson et al., 2006a) and both studies by McClement (McClement and Harlos, 2008, McClement et al., 2003) generated a conceptual model. It has been suggested that using interpretive work to generate a conceptual model or theoretical model can be relevant to informing practice, especially if an explanation is given from the authors of how this can be applied beyond the study sample (Hopkinson et al., 2011). Shragge (2007) theorises that weight-losing cancer patients, using the development intervention of ‘shifting to conscious control’ to compensate for anorexia, could guide clinicians in providing appropriate interventions for anorexia. These studies have added to the evidence that patients and family members consider food to be important in how nutritional care is delivered to weight-losing cancer patients (Hopkinson et al., 2011). They have also highlighted the need for further research to establish the challenging circumstances regarding the declining appetite and weight loss of advanced cancer patients.

2.2.14 Loss of appetite as a source of anxiety

Holden (1991) was one of the first to explore the experience of cancer cachexia from the patient perspective, finding some evidence to suggest that sufferers are less troubled than family members about lack of nutritional intake. This study included 14 patients, nine male and five female who were randomly selected from hospice programs in the USA and their respective primary caregivers who were mostly married couples. Using semi-structured interviews with different open-ended questions for patients and caregivers, which were based on hospice clinical experience. Primary caregivers frequently reported anorexia to be of greater concern than other problems. Patients felt they would like their family members to take a less assertive approach in attempting to cope with a problem to which they were quite prepared to accept. However, Holden’s (1991) results are not solely patient focused, and results describing family perceptions are incorporated in preference to the patient voice. Caregivers described grieving over their loss at being less able to continue in their role of food preparation. They also, expressed feelings of anger and frustration when trying to get the patient to eat (Holden, 1991).

A study conducted by Strasser et al (2007) focussing on the psychosocial consequences of eating-related distress between men with advanced cancer, who had weight loss, of >5% in the previous six months or problems with their appetite and their female partners, with whom they spent >50% of their meals. 18 couples took part in the study, with three or four couples in each focus group to encourage participation from spouses. The findings reported that some patients still had some appetite, which they rapidly lost when the meal was served or felt ‘disgust’ after a few bites, especially if a large meal had been served. The appearance and smell of food caused an aversion for some patients and being limited to certain consistencies because of swallowing difficulties were also cited as troublesome.

Weight loss was initially welcomed by patients, but was later seen to be unpredictable and impossible to control. Therefore, eating was a way to gain energy in order to stay alive, so patients forced themselves to eat, to try and prevent further weight loss, in a struggle for survival. Partners found that daily cooking routines changed, because what was a habit became a challenge for the partners in knowing what to prepare and how much and felt their lives were made up of calories, fat and protein. Patients found it frustrating when a partner had cooked something they had previously enjoyed and had to say ‘I can’t eat any more’ (Strasser et al., 2007, p.134).

The experience of couples found by Strasser et al (2007) suggested that even the most well meant attempts to strike a balance in these circumstances are likely to be met with repeated disappointment and eventually a pervasive and mutual sense of anguish. Patients feel greater pressure from their partners to eat and the cessation of oral intake needs to be respected as a sign of a patient’s autonomy and dignity. Professionals may contribute to helping a couple by giving advice and explaining that cachexia at an advanced disease state is irreversible and how to avoid futile attempts at unrealistic nutritional goals to avoid further distress to the couple (Strasser et al., 2007).

Other qualitative work included in this critical review has described the experience of patients and family members in the period leading up to the introduction of home parenteral nutrition (HPN) (Orrevall et al., 2005, Orrevall et al., 2004). Orrevall et al (2004) and Orrevall (2005) interviewed 13 patients (five males, eight females) with advanced cancer and 11 of their family members (five wives, four husbands and two daughters) who were contacted via advanced home care teams. Patients needed to be receiving HPN at least three times per week, with a minimum of 900kcal/time. A dietitian with extensive experience of cancer care interviewed all patients and family members in their own homes. The study reported that the general importance of an adequate intake of food was well recognised by patients, but due to a variety of factors such as nausea, loss of appetite, swallowing difficulties and taste changes they were unable to eat (Orrevall et al., 2004). All patients experienced weight loss and as previously found this was welcomed at first, prior to a diagnosis of cancer.

Patients reported that before commencing HPN mealtimes were always a source of worry and often despair that affected the interpersonal relationship of the family and mealtimes were no longer enjoyable. Family members reported feeling totally responsible for the nutritional needs of the patient and felt that if they didn't provide a meal then nothing would be consumed. Patients were grateful for the help even though they could not eat the food provided stating, "I knew I had to eat and get my strength back, but it didn't work, I just couldn't do it" (Orrevall et al., 2004, p.1284).

Some patients and family members felt that hospitalisation prior to commencing HPN also contributed to their malnutrition, because of the way meals were prepared and the delivery system, although a few patients described the meals as well-prepared, they were not able to eat them (Orrevall et al., 2004).

All the patients in this study were commenced on nutritional supplement drinks, but described limited success with taking them, due to their smell and taste. Some patients were referred to a dietitian, but felt the advice was common sense and not helpful to the current situation they were in (Orrevall et al., 2004).

Both studies (Orrevall et al., 2005, Orrevall et al., 2004) found HPN gave a sense of relief because nutritional needs were being met and felt this had a positive effect on Quality of Life. Both families and patients did not feel pressured into accepting HPN and although they had little knowledge of parenteral feeding, they only had concerns regarding the technical equipment for HPN. It is often a concern for healthcare professionals that a patient will stop eating orally while receiving HPN, but this was not found to be the case. In fact patients reported trying to eat as much as they could manage and rarely related their eating problems to HPN (Orrevall et al., 2005). In contrast to Holden (1991), Orrevall (2004) found that patients who were not in the final stages of disease expressed fear that an inadequate food intake could lead to death by starvation and both family members and patients found the possibility of receiving HPN a relief and positive alternative (Orrevall et al., 2004).

The findings from Orrevall (2005) found that for some patients HPN increased their appetite and others reported little change. However, patients felt they had more strength and energy with HPN, again this differed between patients, for some it meant feeling fitter, food tasting better and for others it was the relief of not being dependent on family members (Orrevall et al., 2005). Some patients were also able to tolerate nutritional supplements, whilst receiving HPN.

Although the benefits of HPN experienced by some patients has been discussed, it was also described by family members as only a partial solution to eating problems, as the joy of eating and the role that food plays at mealtimes was missed by patients (Orrevall et al., 2005).

The findings from the studies by Holden (1991), Strasser et al (2007) and Orrevall (2004 & 2005) have recognised that loss of appetite is a source of anxiety for patients with cancer, however this has not been expressed solely from the patients point of view.

2.2.15 Conflict felt between patients and family

McClement (2003) emphasised that the patient experience of anorexia and cachexia had not been comprehensively described and therefore the purpose of the study was to develop substantive theory regarding the social processes inherent in family interactions with patients and health care providers around nutritional issues on a palliative care unit. The study consisted of 13 terminally ill cancer patients, mainly females receiving care on a palliative care unit, 13 of their family members, 10 family members whose relative had died on the unit in the past year and eleven health care workers who regularly worked on the unit. The study resulted in the formation of a concept model to describe ways in which family members balanced patient needs while meeting their own needs, in relation to provision of nutritional care. The coping strategies of “fighting back” (p.745) by family members, by trying to get more calories into the patient had the consequences of upsetting the patient. The study also reported patients’ feelings of anger by these actions. In contrast to “fighting back” other family members were “letting nature take its course” (p.745). This was the action taken by family members of not focussing on feeding the patient, but demonstrating their care in other nurturing activities. While some family members who were unsure how to deal with the declining food intake of their dying relative “waffled” between “fighting back” and “letting nature take it’s course” and acted inconsistently to both the patient and healthcare providers regarding nutritional care (McClement et al., 2003).

The findings resulted in the generation of a preliminary model of how subjectively family members cope and make sense of palliative cancer patients declining nutritional intake at the end of life. The results of this study were used in a further study by McClement & Harlos (2008) to describe in further detail one of the sub-processes of the model regarding “letting nature take it’s course”. Patients of these family members reported that they appreciated not being constantly nagged to eat and made to feel like nutritional ‘under-achievers’ (McClement and Harlos, 2008, p.186) and having mealtimes feel like a battleground.

Both of the studies conducted by McClement (McClement and Harlos, 2008, McClement et al., 2003) reported that declining appetite was of little importance to the patients themselves, but caregivers found it to be very upsetting. Thus, caregivers admitted to coaxing, nagging, pushing and begging patients to eat, leading to family conflict, as they did not view decreased nutritional intake as an expected element of disease progression and the dying process. Critically, many interviewees were unaware that intake cessation might be considered ‘normal’ for patients who are terminally ill and did not seek assistance or information with managing cachexia (McClement and Harlos, 2008). However, the focus remained on describing the feelings of family and caregivers, with the patient experience not distinctly described (McClement and Harlos, 2008, McClement et al., 2003).

Shragge (2007) conducted a study to try and reduce the conflict between patients and caregivers, by the development of interventions such as counselling and education to understand the strategies used by patients to cope with cachexia. Twelve patients who were mostly male with advanced cancer were recruited to this study, through a palliative homecare service and outpatient department of a general hospital. The participants were interviewed between one and three times and to give context to their experiences with appetite, eating and weight changes they were asked to describe the course of their disease trajectory. The findings reported that anorexia and other symptoms meant their spontaneous desire for food was severely diminished. However, so that they could continue to eat, the participants used an adaptive process. This was termed “shifting to conscious control” (Shragge et al., 2007, p.228), which was the conflict between the decision to eat and the struggle required to maintain some dietary intake, even without an appetite. Although the participants had a loss of appetite other symptoms such as nausea and delayed gastric emptying were controlled, which may have a positive impact on the intake of food (Orrevall et al., 2004). If continuing to eat without an appetite did imply a cognitively generated motivation, then caregivers need to be counselled and educated that pressuring patients to eat when they have “hit a wall” (Shragge et al., 2007, p.232), will not change eating habits. The statement made by patients “I can’t eat” (Shragge et al., 2007, p.232) is not a rational choice, but a representation of reality. These interventions may help resolve the conflict between patients and family members relating to eating as previously discussed (Shragge et al., 2007).

An exploratory study underpinned by Heideggerian phenomenology was conducted by Reid et al (2009) to understand the lived experience of cachexia for cancer patients and their family members. The study included 15 patients (eight males, seven females) with advanced and incurable cancer and > 10% weight loss in the previous six months and 12 family members who were recruited from a large teaching hospital. The weight loss had to be progressive and involuntary and perceived as problematic. The findings were organised into themes, which confirmed a cyclical pattern of physical, psychological and the social impact of living with cachexia (Reid et al., 2009b). Patients reported that a continual focus on their appearance was seen as off-putting and embarrassing and led them to make the connection between continued weight loss and impending death. However, family members although well aware of patients’ terminal diagnosis, did not make this connection. Patients acknowledged the importance of maintaining a good oral intake in order to prevent further weight loss, but reported trying to force themselves to eat. The impact on family and social roles is complex. Patients and families of dying patients believe that a person’s strength is under his or her own control and not eating can be interpreted as not trying hard enough to get well (Reid et al., 2009a).

The findings from Reid et al (2009) also reported that reduced dietary intake by patients was a source of conflict between themselves and family members. Patients felt they were living in an environment where food was the sole focus that they could not escape. Changes in eating habits and preferences also created conflict and for patients it became a chore trying to eat, especially when continued pressure by family members solely focussed on food. Patients also described eating to please their family members, as a way to avoid conflict over food: “I eat something to shut them up, I’m not really hungry but it’s just a way to please them” (Reid et al., 2009a, p.442).

Social isolation and lying were other tactics patients (Reid et al., 2009a) used to avoid conflict over eating, these findings mirror previous work by McClement et al (2004). The findings from Reid et al (2009) confirm those of Holden (1991) where a lack of information regarding cancer cachexia and a continual focus on food often lead to conflict with the patients’ family and distress for the patient (Reid et al., 2009a, Reid et al., 2009b, Reid et al., 2010).

Although previous research by Holden (1991) suggested that conflict can arise between patients and their family members over food. The results in the study by Reid et al (2009) have outlined the negative implications of conflict, because family members have stated that patients were only eating to avoid further conflict and satisfy their family members. However, food is seen as symbolic by family members to show their love and affection and due to a lack of understanding of cancer cachexia, they felt guilty when they could not convince their loved one of the need to eat (Reid et al., 2009a).

As previously found in a study by Strasser et al (2007), female family members described feelings of frustration and rejection when food offered to their loved one was refused, in an attempt to provide support through nourishment (Reid et al., 2009a).

In summary, family members of patients with advanced cancer find it very difficult not to focus solely on their loved one’s oral intake, which causes conflict amongst families.

2.2.16 Conflict between healthcare providers and family members regarding the nutritional care of the patient

Cancer cachexia has been found difficult to deal with by healthcare professionals and presents a very challenging clinical scenario in practice. Patients and their family members reported that cancer cachexia was not acknowledged even when reported in the clinical setting (Reid et al., 2010).

The major theme from the results of Reid et al (2009) which utilises the data from a larger study (Reid et al., 2009b) was the ‘lack of response from healthcare professionals’. This major theme was further divided into sub themes of lack of acknowledgement, lack of information and lack of intervention. Family members in this study (Reid et al., 2009b) also sought the help of healthcare professionals, because of their concerns about continued involuntary weight loss, but felt that their concerns were not appropriately dealt with. This led to feelings of anger, frustration and despair when it was visibly noticeable and reported to healthcare professionals that patients had lost weight.

The findings by Reid (2009) also suggested the perceived lack of appropriate intervention by healthcare professionals regarding patients’ weight loss suggested this was beyond the scope of the healthcare professionals’ therapeutic remit. This undermined their faith in the professional’s knowledge about cancer cachexia and the causes of the ongoing weight loss (Reid et al., 2010).

This finding mirrors previous work, which suggested that healthcare professionals were reluctant to instigate discussions about weight loss with cancer patients (Dewey and Dean, 2007). However, the results from Reid et al (2009) found that by not acknowledging the issue, providing information or delivering supportive healthcare interventions meant that both patients and their families experienced distress and felt unsupported (Reid et al., 2010). Providing correct information and timely explanations may help patients be proactive in their own management (Hopkinson and Corner, 2006), and not thought of as ‘the weight loss taboo’, as described by Hopkinson et al (2006) when weight loss is not discussed between patients, their family members and healthcare professionals.

It was also as suggested by McGrath (2002) and Hopkinson et al. (2006) that there was a ‘silence’ when discussing weight loss with healthcare professionals. However, Reid (2009) suggests that ongoing patient focused communication between patient, family member and healthcare professional could provide a basis for this much needed information exchange.

Useful and supportive information for family members, would help them understand that food should be a source of enjoyment for patients with advanced cancer and will not stop the progression of cachexia. Furthermore, information needs to explain why feeding a patient with cancer cachexia may be futile and explain the difference between starving a patient and cancer cachexia (Reid et al., 2009a). These interventions may help to reduce the conflict felt by families and shift their focus away from food.

Patients and relatives interviewed by Orrevall et al (2004) stated that physicians did not ask about weight loss and some did not respond when being informed about a patients weight loss or give any advice on how to deal with eating problems. Orrevall et al (2004) suggested that more interaction between family members, the physician and/or dietitian might help decrease the stress felt by family members, that the sole burden of the patients’ nutritional needs falls on their shoulders. It could also help in trying to solve nutritional issues, such as not being able to eat due to nausea and pain, by actively offering treatment before if becomes a major concern.

These studies have shown that family members of patients with advanced cancer require help and supportive information to help them deal with cancer cachexia, however the voice of the patient has not been heard.

2.2.17 Significance of weight loss for patients

Recognising that caregivers have been used to give views through their eyes instead of patients in describing cancer cachexia associated distress motivated Hopkinson et al (2006), to qualitatively examine the prevalence of concern about weight loss in advanced cancer sufferers. The findings of a purposive sample of 30 patients under the care of two community palliative care teams, 23 caregivers and 14 specialist nurses using in-depth interviews, informed by hermeneutic phenomenology and analysed using framework analysis, were used for two articles (Hopkinson and Corner, 2006, Hopkinson et al., 2006a). The nurses’ experience ranged from 1 to 23 years working with palliative care patients. The participants were 16 men and 14 women, who were asked to nominate a caregiver. Of the 23 caregivers in the study, 15 were spouses, four were children and four were friends/other relations. The findings reported seven themes representing components of experiences of weight loss, these were; ‘visible weight loss’; ‘measuring proximity to death’; ‘personal responsibility for weight’; ‘physical weakness’; ‘emotional weakness’; ‘helplessness’ and ‘the weight loss taboo’ (Hopkinson and Corner, 2006, Hopkinson et al., 2006a).

These themes were used to form the basis of a concept model of the experience of living with weight loss and advanced cancer. The model shows that the relationship between time and the experience of weight loss is important. Particularly how weight is perceived to being of concern, during the course of advanced disease. Weight will usually decline during the cancer journey and when the individual appears physically wasted, this is seen as undesirable a progression of disease and approaching death (Hopkinson et al., 2006a).

Hopkinson et al (2006) reported that patients experienced visible weight loss as undermining, because it was seen as physical and emotional weakness, which they perceived as a loss of control over their disease and a loss in the battle to avert death (Hopkinson et al., 2006a). Only two patients reported discussions with their palliative care nurse about weight loss, which was initiated by the patient, nurses believed there was little that could be done to help the patient. Patients experienced this lack of support as feeling abandoned and that nobody cared, leading to a sense of ‘helplessness’ (pp.308). Nurses also experienced ‘helplessness’ as discussing weight loss was seen as ‘taboo’, because they felt ‘nothing could be done’ (Hopkinson et al., 2006a, p.310).

Patients often do not feel comfortable if they perceive that their symptoms are severe enough, but a proactive approach to the management of nutritional problems can help patients and family discuss nutritional decline and treatment options (Hopkinson et al., 2006a).

The second article (Hopkinson and Corner, 2006) reported the findings of how patients with advanced cancer experienced eating compared to when they had last thought of themselves as healthy. Patients reported changes in eating habits, which included early satiety, a loss of appetite and enjoyment of food, these were reported by 14 of the 30 participants and food aversions by 22. As previously found in other studies in this review (Shragge et al., 2007, Strasser et al., 2007), some participants managed two or three mouthfuls before the physical desire for food diminished.

Some patients reported concerns with their eating habits, especially if they were unable to eat fruit and vegetables in the belief that maintaining a healthy diet were linked to a sense of well-being. Patients described feelings of being frustrated, worrying they were abusing their body, not looking after themselves and were responsible for their illness. Whereas patients who had never found healthy eating particularly important did not hold themselves accountable for the types of food they were they were eating (Hopkinson and Corner, 2006).

The specialist nurses in the study all voiced concerns about ways to help patients with eating difficulties and had low expectations of being able to change patients eating habits. Some found it difficult to move patients towards eating for joy or comfort and suggested this was something they could do little about. Nurses reported feeling this was a difficult hurdle to help patients across and used terms like “transition” or “coming to terms with” (Hopkinson and Corner, 2006). However nurses who did help patients with their eating had concerns whether this type of intervention was appropriate, and also reported the difficulty of accessing dietitians.

The findings demonstrate that even patients with advanced cancer and impending death, wanted to engage in self-help and health promotional activities, to help themselves live with their eating-related concerns. However, these patients were disappointed with the lack of support they received from health professionals, in response to trying to optimise their health by dietary manipulation (Hopkinson and Corner, 2006).

The significance of weight loss for patients with advanced cancer and the distress caused by cancer cachexia has been discussed. However as these studies have included patients, caregivers and healthcare professionals, it is not clear how weight loss is perceived to be of concern solely from the patients’ point of view.

2.2.18 Struggling to maintain oral intake without an appetite

McGrath (2002) conducted a phenomenological study of the lived experience of treatment in haematology patients three months after stem cell transplantation and the retrospective insights from caregivers on end of life care for patients with haematological malignancies. The study included 22 patients (13 males, 9 females) who were interviewed during their outpatient visit to the hospital where they were undergoing chemotherapy and ten principle caregivers mainly women. The study found that the importance of food when patients are undergoing intensive treatment such as chemotherapy, particularly for therapeutic reasons, was seen to be significant during treatment. However, many reported losing their taste buds and felt it was difficult to build up an appetite knowing that food may taste metallic or bland and tasteless.

Patients also reported what they thought of as unacceptable hospital food, which added to the distress of nutritional challenges felt by caregivers and many families brought in food from home. However, this was not successful for all patients and some could still only take one bite and eat no more (McGrath, 2002). This was found to be a negative and frustrating experience for caregivers as reported in (Hopkinson and Corner, 2006, Reid et al., 2009a, Strasser et al., 2007) studies previously discussed.

The study also found that dietitians were seen as potentially playing a significant role in regard to eating distress, with some making suggestions of what to eat, assisting in food preparation and providing drinks. However, some dietitians were criticised for their practices of being authoritarian, by trying to force patients to eat, which was seen as counterproductive and distressing to the patients. The physicians were also seen to play an important role in providing therapeutic measures to assist the appetite. However, the unsympathetic attitude and lack of information on eating related disorders provided by some doctors was reported as distressing to both patients and caregivers (McGrath, 2002).

The findings from McGrath (2002) indicate that issues surrounding food and eating are considered to be significant not only to patients who are undergoing intensive treatment therapies, such as chemotherapy, but also for their caregivers. Food is not seen solely in terms of its nutritional value, but as an important quality of life issue (McGrath, 2002).

The clinical implications of McGrath's study would indicate that patients should have routine access to a dietitian, particularly during intensive treatment such as chemotherapy. Also patients and caregivers should be given well-written and informative material about eating problems and how they can be overcome (McGrath, 2002).

A study by Wilson et al (1991) found that the side effects of cancer treatments further compromise patients' nutritional status and these patients suffer with further malnutrition because of eating problems. The study included 11 participants with head and neck cancer who were interviewed during a follow up clinic appointment within six months of completing radiotherapy. Seven of the 11 participants in this study reported major eating problems with radiotherapy, which led to changes in eating strategies, such as selecting softer foods or modifying food textures. The findings also reported patients selected foods on a trial and error basis and found they consistently ate that particular food if it solved problems they were having during treatment. However, for some, the foods that they choose to eat were not part of their regular diet, or they were foods disliked before treatment (Wilson et al., 1991).

Some took pain medication before trying to eat, while others persisted in forcing the food regardless of the pain. Once again as found in other studies cited in this review family members prepared the patients favourite foods to try and encourage them to eat (McGrath, 2002, Strasser et al., 2007). This study did not look at the interrelationships between the physical and emotional effects of malnutrition, but focussed on strategies of difficulties of eating food rather than the meaning of food (Wilson et al., 1991).

The findings from the studies by McGrath (2002) and Wilson (1991) found that the importance of maintaining a good nutritional intake after intensive treatment therapies such as chemotherapy, for patients with cancer, was seen to be significant during treatment. The role of the dietitian and the importance of receiving access to a dietitian during intensive treatment was seen as a potentially significant role with regard to alleviating eating distress for this group of patients.

2.2.19 Healthcare assessment and management of patients' weight loss

An exploratory study by Dewey and Dean (2007) aimed to explore the views and experiences of 14 nurse practitioners nutritional management of patients with advanced cancer, employed in the south of England. They were either District/Community nurses or Specialist Macmillan nurses who were invited by letter to take part in the study. Each nurse had to have been in post for approximately one year, and during this time nursed a minimum of five patients with incurable cancer and a documented history of weight loss. Data were collected using semi-structured interviews either at their place of work, the researcher's office or one nurse chose to be interviewed at home. Seven major themes emerged from the analysis of the data (see Table 1). Theme 1 refers to how nurses assess patients' nutrition, which is broken down into three approaches: structured semi-structured and an informal approach. A structured approach to nutritional assessment was used on a regular basis by one of the nurses interviewed. However, the majority reported that although they were aware of structured nutritional tools to assess patients, this was something that they did not currently use, but were looking into using in the future. Reasons given for not using a structured assessment was that patients could be weighed unnecessarily, especially if they were at the end stages of disease and this could cause more distress to the patient (Dewey and Dean, 2007).

Informal assessment consisted of visibly noticing the patient's weight loss by the majority of the nurses. Another form of assessment reported was that some nurses relied on the patient or their relative expressing their concerns. Some patients brought up the discussion of their weight loss by talking about clothes they had brought that were now too big (Dewey and Dean, 2007).

Nurses also reported being reluctant to initiate a discussion about the patients weight loss as it may lead to an unrealistic expectation about achieving nutritional goals and cause further anxiety to both patients and family members. Concerns were also expressed by nine of the nurses interviewed about their lack of specialist training in nutritional assessment and felt this meant there were gaps in their knowledge base, but none stated they felt the need to refer the patient for further support. However, some were keen to update their skills and knowledge (Dewey and Dean, 2007).

Another study looking at nurses' management of weight loss, also found that specialist nurses avoided discussions on weight loss and adopted an unsystematic reactive style of management (Hopkinson et al., 2006a). It is possible that patients avoid talking to nurses about nutritional problems and concerns with weight loss in an attempt to conceal negative feelings and perhaps this is perceived by healthcare professionals as a loss of control and contributed to their reluctance to initiate a discussion about the symptom (Hopkinson et al., 2006a).

Critically, the failure to acknowledge cancer patients continued weight loss and poor nutritional status might mean that when advice is given it is too late in the cancer journey to have maximum effect. The findings reported a positive caring attitude for patients in the palliative stage, except towards nutrition as this was seen as a sensitive area of discussion. There are also many other sensitive topics to discuss with palliative patients and nurses need to be confident that advanced nutritional planning has a place in the journey of a cancer patient (Dewey and Dean, 2007).

In contrast to the study by Dewey and Dean (2007) found that most nurses did not routinely provide thorough nutritional assessment of cancer patients, neither did they discuss weight loss with patients unless the patient stated their concerns (Dewey and Dean, 2007).

Another article by Dewey and Dean (2008), which utilises data from their previous article (Dewey and Dean, 2007) discusses two more of the dominant themes: nutritional management strategies and expectations of interventions. Nurses reported giving advice on ways to fortify food with extra calories, this led to problems with patients who had followed a healthy eating regime for many years. They felt they were being asked to give 'permission' to patients and relatives to eat an unhealthy diet (Dewey and Dean, 2008).

Nurses also reported, family members wanted to keep trying to feed the patient when it was not in their best interest and again felt they needed to give 'permission' not to feed the patient (Dewey and Dean, 2008). Advice was given if patients had swallowing problems, which included choosing softer options, pureeing food and providing written information on request. However, this was not comprehensive information, but a single page giving information on food fortification. One of the nurses in the study had produced a dietary information sheet for specific types of cancers.

Although nurses reported offering patients nutritional supplements, they usually recommended supplements based on their experience of what had been enjoyed by other patients. One nurse based her decision on current research on new products that potentially could be more acceptable to cancer patients and only two nurses actually prescribed supplements for patients, others recommended contacting their GP (Dewey and Dean, 2008).

Dewey & Dean (2008) found that ten of the 14 nurses interviewed either never or only occasionally referred patients to the dietetic service, with one stating they had not found the need to refer patients, especially cancer patients. However, for those that did refer to a dietitian they felt a great deal of praise for the service, but were aware that clinic times were busy and dietitians were unable to offer domiciliary visits (Dewey and Dean, 2008). Nurses and allied healthcare professionals are in a key position to support patients and family members with the practical and psychosocial aspects of cancer cachexia

2.2.20 Patient experiences of alterations in body image

A study by Wainwright et al (2007) using the constant comparison approach explored oesophagectomy patients' experiences of appetite loss three months after surgery. This study was based on a questionnaire, which was completed three weeks before surgery, six weeks post-operation and at three months intervals during the first postoperative year in an NHS Trust in England. A subsample of 11 patients were selected for interview, from the questionnaires, if they had reported “quite a bit” or “very much” appetite loss three months post surgery. Participants ranged from 54 to 74 years and more men than women were interviewed (eight and three, respectively), reflecting the higher incidence of oesophageal cancer in the male population. All participants were interviewed in their own homes and some requested family members were present because they had been involved in the recovery process of the patient and were therefore able to provide useful information.

Three key themes emerged from this study from the reflections of participants. Firstly the meaning of weight loss and physical change, secondly remapping the body and thirdly eating as a social activity was seen to cause stigma and embarrassment (Wainwright et al., 2007). The findings of reported weight loss by cancer patients had different meanings along the disease trajectory and changes in body weight were often seen as predictors of disease progression or the recovery process.

Weight loss prior to diagnosis and treatment can be seen as worrying, but once a diagnosis of cancer was made then this was seen as an expected side effect. However, continued weight loss after treatment was seen as a marker for the effectiveness of the treatment and the patient’s ability to fight the disease. Additional, weight loss during the post treatment phase, was thought of as losing the battle and that they should try to resist seeing this further weight loss as recurrence. This would help them determine, if they were a victim or a survivor (Wainwright et al., 2007).

Participants reported a constant monitoring of body weight in an effort to return to pre-illness or preoperative weight together with increasing food intake, as this was seen as a return to ‘normality’ and recovering from the disease. However, the patients who thought of themselves as overweight prior to cancer, considered the weight reduction as healthy, if their weight was stable and did not continue to decrease. Previously overweight patients were also more reluctant to follow a high calorie diet, suggested by healthcare professionals in order to regain weight. They felt they were being told to eat ‘junk food’ which went against the principles of healthy eating.

The experiences of oesophagectomy patients post surgery (Wainwright et al., 2007) also reported changes in how they experienced appetite, taste, the smell of food, swallowing and sense of satiety because of their altered physiology due to the surgical procedure. For many patients after surgery, this meant learning what these symptoms were telling them about how their body was healing itself and ‘settling down’ and how to adjust to their new post-operative status. Symptoms such as pain, diarrhoea, nausea, vomiting and reflux were all widely reported and were attributed to the wrong types of food being eaten too soon.

Due to the physiological changes and a remapping of the body, knowing how the body ‘learns to adapt’ meant that for many patients the act of eating became joyless. Foods that were previously enjoyed tasted or smelt different, sometimes caused nausea or vomiting. Also, if the sensation of satiety was not triggered, patients reported symptoms of pain, nausea, vomiting or diarrhoea (sic) (Wainwright et al., 2007). This led to feelings of stigma and embarrassment at eating in front of others and some patients reported wanting to eat alone out of public view and away from family members.

The most important finding from this study was that these patients needed to learn to eat again and were only give a brief consultation by a dietitian. These patients require further input from a dietitian, to aid with rehabilitation, than just a small amount of input whilst they are in hospital, as is the case with most surgical patients (Wainwright et al., 2007) in the UK. Any increased contact could reduce the stress experienced by family members, who feel they are solely responsible for their relative’s nutritional needs (Orrevall et al., 2004).

The physical and psychosocial issues experienced by oesophagectomy patients after surgery has revealed that there is a complicated process of adaption and rehabilitation for patients to achieve optimum quality of life during recovery.

2.2.21 Improving practice and nutrition in hospitals

A pilot study by Warnock et al (2005) looked at how to improve practice and ensure patients receive the nutrition they require whilst in hospital. The study was conducted on two 30 bedded wards in a UK cancer centre. The two particular wards were chosen to give a range of patients in terms of age, clinical diagnosis, and type of intervention the patients were receiving. The study used non-participant observation methods and emphasised the need for using encouragement during mealtimes by the use of gentle persuasion, which highlights the need for a positive and proactive approach to nutrition in hospitals.

An important factor that emerged from this study was the need for individualised care in order to meet a patients nutritional needs, however the practicalities of this was not always possible due to the ward being too busy at mealtimes. Non-participant observation was found to be a useful approach for exploring the actual care given in relation to nutrition and was not considered to be intrusive by patients or ward staff (Warnock et al., 2005).

2.3 Overall conclusion and rationale for the study

In conclusion, the critical purpose of conducting this literature review was to summarise existing qualitative research on weight loss in patients with cancer and to identify gaps in the existing literature to support the development of the proposed research. The research to date has predominately, examined patients with cancer at the end of life and in the palliative stages of the disease. The mentioned studies have not routinely included the patients' experiences of weight loss. This critical review of the literature would indicate that cancer cachexia, particularly in the later stages of disease is more problematic to carers than to patients themselves, especially within the home environment. However, due to the dearth of research in this field, it would be sensible to note that these questions have not been fully answered by this review.

Qualitative studies looking at the nutritional aspects before and after surgical management of patients with cancer is lacking. Only one of the studies, included in this review, discussed a cohort of postoperative oesophageal cancer patients. The findings revealed a complicated process of adaptation and rehabilitation after surgery. Despite improvements in cancer treatments, the experiences of patients rehabilitation after surgery remain sparse.

Primarily nurses working within the healthcare service or researchers with a nursing background mainly conducted the studies included in the review. Nurses have an important role to play in delivering cancer care services in the UK and dietitians have an important role to play in the management of patients' nutritional needs (Dewey and Dean, 2008). However, both professions have different experience and knowledge when assessing patients' nutritional needs and for dietitians this is their primary role. Only two of the studies included in the review were conducted by a dietitian, which looked at the use of parenteral nutrition in palliative care patients. It should be noted that, the same dietitian conducted both studies. The nutritional management of patients has mainly been described from a nursing stance and the opinions of other healthcare professionals, including dietitians, has not been well represented in these studies. As found in the studies by Wilson et al (1991) and Wainwright et al (2007) the role of the dietitian after surgical intervention or intensive treatment therapy for cancer was found to be beneficial when patients received advice regarding weight loss and a change in appetite. However, the voice of the dietitian is missing from these studies and therefore, to improve dietetic practice, it would be advantageous for dietitians to conduct studies with patients with cancer. This could help dietitians to understand how patients perceive the dietary advice given to them and the personal nutritional experiences of patients with cancer

Food has multiple functions in a person’s life, it is often used to express love, provide great pleasure at times of stress and it can play a role in how humans communicate socially. This is the field in which dietitians work, in trying to bridge the gap between unambiguous scientific data and providing patients with information about the multiple functions food has in their daily lives (Swift and Tischler, 2010). Qualitative research has much to offer the understanding of health and how health care is delivered from the patient’s perspective. However, it would seem from this critical review of the literature that dietetics has yet to embrace the field of qualitative research, although it certainly has much to offer nutrition and dietetics.

The qualitative studies in the review deepen and expand our understanding of the way patients experience loss of appetite and weight loss and strongly indicate a need for further exploration. The proposed study aims to add to the current literature, as few studies (see Table 2) have included patients with pancreatic cancer in their research and these have been patients with palliative cancer. Therefore, a qualitative study exploring the nutritional experiences of patients with operable pancreatic cancer before and after surgery has not been previously investigated and thus the present study aims to add to the current literature.

2.4 Aims and objectives

Aim

- To establish the views and experiences of patients about food and weight loss before and after surgical intervention for the treatment of pancreatic cancer.

Objectives

- Explore patients' views on any nutritional symptoms they experience during treatment for pancreatic cancer.
- Determine the effects of pancreatic cancer and surgical intervention on appetite, food intake and dietary habits from the patient's perspective.
- Determine patients' views on nutritional support interventions including oral supplements, dietary counselling and written information.

In the following chapter, the research approach and methodologies used to support the proposed study are discussed.

Chapter 3: Research Methodology and Methods

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3. Introduction to research methodology and methods

The previous chapter discussed the literature reporting studies already carried out within this area. In this chapter the qualitative interpretive methodology that underpins this research will be discussed. The method of data collection for this study will be described, including the way in which the sample of participants were recruited for this study. The essential values of ethical research and the way in which these relate to the project will be explained. This chapter will be divided into two parts; part 1: the methodological foundation and research approach and part 2: the methods for data collection and analysis in this study.

Part 1: Methodological Foundation and Research approach

3.1 Theoretical Paradigms and perspectives

Quantitative research has traditionally dominated health care, including nutrition and dietetics (Fade, 2003), however, the methodologies are different in the type of inquiry they are suited to and the methods used to carry out the research. Research involving health and health services aims to produce reliable and valid research data, to improve the provision and effectiveness of heath care services (Bowling, 2009). Increasing advances and specialities in medicine, means that patient expectations of service provision are higher (Pope and Mays, 1995). In order to ensure that standards of care are met, health professionals need to contribute to the body of scientific knowledge. By using rigorous methods of conducting research, such as qualitative or quantitative methodologies, a wide range of research questions can be answered.

Research is informed by a particular worldview or perspective that is held by the researcher within the discipline they work. These perspectives are known as paradigms and enable researchers to understand phenomena about ways that science should be conducted (Creswell, 1994). The different paradigms are characterised by ontological, epistemological and methodological differences in their approaches to conceptualising and conducting research (Weaver and Olson, 2006). They are described as a “set of basic beliefs that guide action” (Guba, 1990) which control inquiry and act as the foundation and rationale for why a certain method of investigation is used. Paradigms can also be defined as sets of philosophical perspectives depending on the specific research approach, for example quantitative or qualitative methods (Weaver and Olson, 2006).

Guba and Lincoln (1994) suggest that social sciences have passed through a number of “paradigm eras”, these are periods in which certain sets of basic beliefs guided inquiry in quite different ways. The four paradigms positivism, post-positivism, critical theory and constructivism, each has its own set of “basic beliefs” and are referred to as competing paradigms.

Positivism has a long tradition in quantitative research, positivists test theories and hypotheses following the natural scientific approach, in which a belief in a universal system of laws has been established (Holloway, 1997). It was suggested by Comte a French Philosopher that the emerging social sciences should also follow the natural science methods, whereby researcher and subject are kept at a distance to avoid biases (Holloway, 1997). However, the traditional approach to quantitative research, does not always answer complex questions about the character of human circumstances.

Post-positivism emerged as a modified form of positivist ideas and assumes that reality cannot be completely known and is limited by human understanding (Holloway, 1997). Post-positivists believe that reality can never be fully comprehended and consider the use of multiple methods in their investigations to gather as much of the truth as possible (Guba, 1990).

Positivist or post-positivist researchers are not usually concerned with human interaction or feelings, or people’s perceptions, but are interested in measurable facts that can answer questions of cause and effect. The types of research questions that can be answered with this type of approach are not suitable for qualitative research.

The pragmatic paradigm provides the underlying philosophical framework for mixed-methods research. It is not committed to any one system of philosophy or reality, but it used to focus on the ‘what’ and ‘how’ of the research problem (Creswell, 1994, p.11) and it is the research question that is of paramount importance, not the paradigm that underlies the method (Tashakkori and Teddlie, 2003). Mixed method research combines quantitative and qualitative research techniques and uses multiple approaches and concepts to answer the research question (Johnson et al., 2007). Pragmatism may be more significant to applied research, including heath services research (Bowling and Ebrahim, 2008).

The paradigm often used for qualitative research is the constructivist or naturalistic approach (Lincoln and Guba, 1985), postmodern or interpretative. Interpretivism emerged in opposition to positivism as it tries to understand and explain human and social reality (Crotty, 1998). Interpretivism centres on how human beings interpret and make sense of their personal reality and has its roots in philosophy and the human sciences (Holloway, 1997). From a constructionist point of view, meaning is constructed not discovered by human beings, when they interact with the world, which they are trying to understand (Crotty, 1998).

The philosophical assumptions of ontology and epistemology, as suggested by Creswell (1998), should also be addressed. The issue of the ontological assumption addresses, what is the nature of reality. Quantitative researchers think of reality as objective and independent of the researcher, it is only something which can be measured with instruments or questionnaires (Crotty, 1998). In, contrast qualitative researchers believe that reality is constructed by the participants involved in the study and therefore multiple realities exist (Creswell, 1994).

The epistemological assumption of the relationship between researchers and the subject being researched, is also different between the two traditions of quantitative and qualitative research. Quantitative researchers strive to remain distant and independent of what is being researched to avoid bias. Whereas, qualitative researchers interact with the participants being researched (Creswell, 1994) and try to minimise the distance, between the researcher and those being studied (Guba, 1990).

Several methods used in studies on health care and health have been produced by positivist traditions, these are usually quantitative studies (Guba and Lincoln, 1994). It is believed that adhering to one paradigm will determine how theory is developed and therefore limit knowledge available for use in practice (Weaver and Olson, 2006). Guba and Lincoln (1994) argue that quantitative and qualitative methodologies should be considered separate to paradigms and that either can be used with any paradigm.

However, the most practical argument is to choose the methodology, which will best facilitate the answer to a study's question, independently of the researcher's philosophical beliefs (Morse, 1994).

The philosophical belief underpinning this study is the perceptions of patients with operable pancreatic cancer views and experiences of food and weight loss before and after surgical intervention and the meanings attributed to their personal experiences. Therefore interpretive philosophy underpinned this study and influenced various choices for the study design. Considerations will also be given to the researcher's knowledge and experience and its effect on the interpretation of the data.

The justification for selecting a qualitative methodology as a specific design strategy and phenomenology as a philosophical approach for the study will be discussed in the following sections.

3.2 Why qualitative research methodology

Qualitative research involves a variety of data collection methods, such as interviews, observational methods, case study, and visual texts. By using one or several of these methods a qualitative researcher can attempt to make sense of, or interpret a phenomena that gives meaning to individual's lives (Denzin and Lincoln, 1994).

Qualitative researchers study individuals in their natural setting, which involves the researcher going out into the field and gaining access to participants in order to gather information (Creswell, 1998). Qualitative researchers are interested in the individual's point of view, they feel they can get closer to the participants perspective through detailed or in-depth interviewing or observation and they make no attempt to introduce experimental controls on the phenomenon under study. Qualitative researchers argue that this will provide them with rich descriptions of the social world (Denzin and Lincoln, 2003).

In comparison, although quantitative researchers use similar methods of data collection, they are more interested in measurements and would be concerned with gathering information about characteristics and statistical factors associated with the phenomenon being studied and not the experience or meaning attached to it by the individual (Ritchie and Lewis, 2003). Qualitative researchers can therefore explore complex phenomena that are not amenable to quantitative researchers (Pope and Mays, 1995).

By focusing on patients' feelings, meanings and experiences, the researcher, as a health care professional, is able to understand how patients perceive health services (Bowling, 2009). It is only the qualitative approach that takes the subjective experiences of the research participants as its focus (Hallett, 1995). This study aimed to explore and understand the lived experiences of patients with operable pancreatic cancer and the nutritional issues experienced, before and after surgery and what it meant to those individual patients. Therefore there was no need for experimental controls and thus a qualitative approach was seen as the best way of gaining an insight into the naturalistic everyday experiences of patients with pancreatic cancer.

3.3 Qualitative Research Strategies

Qualitative research is a field of inquiry that is encompassed by a complex interconnecting family of terms, concepts and assumptions (Denzin and Lincoln, 2003), with a wide range of differing techniques to collect data (Swift and Tischler, 2010). It involves an interpretive, naturalistic approach to participants and covers a variety of research methodologies originating in the traditions of philosophy, anthropology, history and sociology (Creswell, 1998, Holloway, 1997). However, there are few similarities between the methodologies, as they differ in terms of their philosophical underpinnings, theoretical, ontological and epistemological orientations, shared understandings and purpose (Guba and Lincoln, 1989). This includes the traditions associated with ethnography, grounded theory, case study and phenomenology. The following table is a simple overview, which highlights some of the differences between the traditions in qualitative research and shows how some of the methods overlap each other.

Table 6: Comparison of research traditions used in qualitative research

Research design	**Discipline origin**	**Focus**	**Typical data collection method**
Ethnography	Cultural anthropology, Sociology	Describing and interpreting a cultural and social group	Participant observations, interviews, artefacts and documents
Phenomenology	Philosophy, sociology, Psychology	Understanding the essence of experiences about a phenomenon	Long interviews with up to 10 people
Grounded theory	Sociology	Developing a theory grounded in data from the field	Interviews with 20-30 people to achieve detail in the theory
Case study	Political science, sociology, evaluation, urban studies, other social sciences	Developing an in-depth analysis of a single case or multiple cases	Extensive forms such as documents and records, interviews, observation, and physical artefacts

Adapted from Creswell (1998, p.65 & p.148).

Ethnography is used as a research strategy to understand things from the point of view of the people involved, rather than the outsiders view. Ethnographers are involved in extensive fieldwork with social groups and learn about the culture and philosophy of the group members which guides their experiences (Denzin and Lincoln, 2008, Hammersley and Atkinson, 1983). The term literally means a description of peoples or cultures and its origins are based on the work of social anthropologists. Ethnographers use participant observation, which was originally designed as a method of studying small homogeneous societies, whereby an ethnographer lived in that society for an extended period of time (Hammersley and Atkinson, 1983). The ethnographer would learn the local language, participate in daily life, as an impartial observer, but would immerse themselves into the cultures of the society (Atkinson et al., 2003). It was broadly thought that this methodology would produce data that strongly reflected the societies own point of view (Denzin and Lincoln, 2003). This approach uses interviews and field notes, but almost exclusively utilises participant observation (Denzin and Lincoln, 2008).

Examples of ethnographic studies are Bell (2009) this study used ethnographic fieldwork over an 8-month period to explore patient perceptions of adjuvant chemotherapy, by utilising participant observation. Another example is the work of Walshe et al (2011) who used observational data collection methods to understand patient and professional roles in the palliative care setting. This study did not intend to use participant observation as a method of data collection and thus ethnographic methodology would not answer the question the researcher was interested in.

Grounded theory as a methodology, has emerged from the discipline of sociology, it is an area of enquiry that is focused on society and the individual. It is characterised by its use of a qualitative approach to explore the phenomenon in its natural environment (Glaser et al., 1967). Grounded theory methods, involve the application of systematic steps and procedures, that result in the development of an inductively derived theory that is “grounded in the data” and provides theoretically complete explanations about a given phenomenon (Strauss and Corbin, 1998).

Grounded theory methods were used in five of the studies included in the critical review of the literature (Dewey and Dean, 2007, Dewey and Dean, 2008, McClement and Harlos, 2008, McClement et al., 2003, Shragge et al., 2007). Each of these studies aimed to generate an inductively derived theory from the data. This study was not aiming to generate a theory, but aimed to explore the lived experiences of the individuals and the meanings given to those experiences. Therefore grounded theory was not used as a methodology.

Case study research is a method often used in qualitative research. It is used to examine and focus on individual cases and has clear boundaries in the types of questions asked, the data sources used, the setting and participants involved (Yin, 2011). A number of data sources can be used, such as observation, documents and interviewing and researchers mainly investigate cases tied to a specific situation and locality (Holloway, 1997). Case study research strategies can be used to evaluate complex interventions, such as a study by Walshe (2011), which evaluated palliative care services. Although this type of inquiry can be used to explore individuals or groups that share common experiences, the main form of data collection is intense observation. This study, as previously discussed did not intend to use observation as a form of data collection, because it was interested in the experience of individuals.

Phenomenology, examines the meaning of experiences for individuals, although this strategy also uses interviews and field notes, it does not exclusively use participant observation (Creswell, 1998). It has been widely used in qualitative research when the aim of the study is to describe particular phenomena or the appearance of things, and interpret these meanings to a certain degree of depth and richness (Van Manen, 1994). As a research method in nursing it has been used in a variety of studies discussed in the critical review of the literature (Hopkinson and Corner, 2006, Hopkinson et al., 2006a, McGrath, 2002, Reid et al., 2009a, Reid et al., 2009b, Reid et al., 2010) and these studies have underpinned their research, using this method to gain a deeper understanding of patients', families' or carers' own perspectives. The focus of the studies cited above was on experiences and meanings, and attempted to identify what was unique about those meanings and also the possibility of identifying the 'essences' of the lived experience.

3.4 Why phenomenology

Phenomenology differs from the other approaches, in that it does not aim to generate a theory (grounded theory), describe a bounded phenomenon (case study) or expand on a meaning to specific cultures (ethnography). Rather, phenomenology is the study of lived meanings and tries to explain and describe in depth the meanings lived everyday in our existence as human beings, our lifeworld (Van Manen, 1994). Therefore, Van Manen (1994) suggests phenomenology is a human science since the subject matter is the structures of meaning of the human lived world.

By reviewing qualitative literature and critically assessing the qualitative methodologies, the researcher chose phenomenology, because it examines the lived experience of humans. Lived experiences provide a basis for self reflection and learning as individuals think about their actions and participation in a particular event and store their experience in the consciousness (Van Manen, 1994). Phenomenology, therefore aims to explore the essential meanings of the experience as they are lived by the individual in order to understand and seek meaning (Finlay, 2009).

The proposed research was an exploratory study and aimed to understand and explore patient's perceptions, and their experiences that happened to each individual and to gain a detailed understanding of each individual experience, through their rich descriptions and meanings of the phenomenon (Finlay, 2009).

3.5 Introduction to phenomenology

Phenomenology is frequently considered central to the interpretive paradigm (Denzin and Lincoln, 2005). Phenomenology is a philosophical method to study phenomena and human experience and has been used to explore the lived experience or existential meaning of people. It is not a research method, as such, but a philosophy and attitude to human existence (Wojnar and Swanson, 2007).

Human beings reflect on lived experience because it is not possible to reflect on an experience whilst it is occurring. Phenomenology is therefore retrospective because it is a recollection of the experience that has already been lived through (Van Manen, 1994). The process is inductive and descriptive; it seeks to record experiences from the viewpoint of the individual who had them, without imposing a specific theoretical or conceptual framework on the study before collecting data.

Conducting research from a phenomenological point of view is to question, as human beings, the world in which we live, wanting to know the world and the way it is experienced. This knowing the world, means one has to be in the world in a certain way and questioning, researching and theorising is an intentional act to become fully immersed in the world and to become the world. This inseparable connection to the world is known in phenomenology, as the principle of "intentionality" (Moran, 2002, Moustakas, 1994, Van Manen, 1994).

Phenomenological research is characterised by the study of the life-world or lived experience, a concept introduced by Husserl. The world which Husserl described as the “world of immediate experience”, the world as “already there”, “pregiven”, the world as experienced in the “natural, primordial attitude” that of “original natural life” (Husserl, 1970, pp.103-183). The aim of phenomenology is to gain a deeper understanding of our daily experiences and tries to gain insightful descriptions of how the world has been experienced pre-reflectively. Therefore phenomenology does not provide a theory of how the world can be explained or controlled. It offers a more insightful way to be in direct contact with the world and answers questions of meaning in understanding an experience from those who have experienced it (Van Manen, 1994).

The following section will discuss the differences between the phenomenological approaches and the differences between Husserlian, Heideggerian and Gadamerian traditions.

3.6 Phenomenological traditions

3.6.1 Edmund Husserl (1859-1938)

Phenomenology has its roots in philosophy and is both a philosophical theory and a research method. It was founded as a philosophy by Edmund Husserl (1859-1938) a mathematician, who after attending lectures by a psychologist and philosopher Franz Brentano on the notion of “intentionality”, set him on the path to phenomenology (Cerbone, 2006). Intentionality is described as the way in which the consciousness is inseparable from the world (Koch, 1995). Husserl critically analysed Bretano’s work and set out his own concept of intentionality, that every conscious lived experience intends something (Moran, 2002). Thus from a Husserlian meaning, whatever has actually been thought or remembered is an experience and more specifically a lived experience (Macann, 1993, Zahavi, 2003).

Husserl thought it was entirely possible for two people to have the same experience in terms of structure, but the causal structure of the experience would be entirely different (Cerbone, 2006). Husserl called his phenomenology “pure” or “transcendental”, meaning that the first step in isolating a conscience experience is to suspend any questions of the experience in relation to environmental influences (Cerbone, 2006).

Any phenomenon can represent a suitable starting point for an investigation, as phenomena are the building blocks for human science and thus the basis for all knowledge (Moustakas, 1994). Husserl wanted to discover the meaning and essences in knowledge. His phenomenology is guided by the idea of essence, the immediate experience and getting back to that immediate experience can provide clarity and a deeper understanding of the experience (Crotty, 1996).

Husserl developed the concept of Epoche, this means the idea or statement assumed to be true needs to be removed or bracketed a term taken from mathematics. Either of these terms can be used to refer to the process of reduction, of consciousness being achieved (Crotty, 1996). In other words a detachment or disengagement rather than an absorbed attitude, to bring the nature of the experience to light (Moran, 2002).

Husserl's fundamental construct of reduction in order to gain a deep understanding of the essence of the phenomenon studied is essential to Husserlian phenomenology. He claimed that through reduction, which means bracketing scientific theories or concepts as well as the researcher's preconceptions, the essence of the phenomenon could be discovered. However, the question is whether it is possible to 'put aside' or 'bracket' one's own preconceptions and knowledge about a phenomenon being studied (Koch, 1995, p.829) and enter the field without prejudice. The researcher would make every effort to set aside prejudgements of the phenomena being studied, so that the study, could be conducted as far as possible free of preconceptions, beliefs and knowledge of the phenomenon from previous experience (Moustakas, 1994). Meaning the researcher puts aside their professional background in order to be completely open and naïve when listening to participants describe their experiences. Thus, Crotty (1996) suggests that the researcher does not influence the data collection with their personal beliefs.

3.6.2 Martin Heidegger (1889-1976)

Martin Heidegger (1889-1976) a former pupil of Husserl wanted to present his own conception of phenomenology and break away from the principles set out by Husserl (Macann, 1993). His first and most noted publication in 1927 was Being and Time, in which he sought to set out the basic principles of his own notion of phenomenology and it is through this that he claimed to understand phenomenology in a more radical way than Husserl (Moran, 2002). Heidegger thought that humans are hermeneutic (interpretive) beings, who are capable of interpreting an experience, however the interpretation is based on the person's background or historicality (Laverty, 2003). Heidegger described historicality as a person's history or background this includes a person’s culture and how what is handed down through generations affects their view on the world (Laverty, 2003).

Heidegger’s guiding question in Being and Time is what it means to “be”, and the understanding that “being” is not a way that human beings think, but how we act. Heideggerian phenomenology therefore seeks to interpret our everyday experiences rather than trying to isolate conscious experience (Cerbone, 2006). After the publication of Being and Time, Heidegger deserted the transcendental approach (Moran, 2002) to phenomenology in favour of hermeneutic phenomenology, meaning interpretation.

Hermeneutic phenomenology is concerned with the life-world or human experience as it is lived. However, it focuses on highlighting what appear as insignificant aspects, that are taken for granted in the lives of human beings and creating a meaning and understanding of these experiences. This is the difference between the phenomenology of Husserl and Heidegger (Laverty, 2003). Husserl concentrated on understanding beings or phenomena, whereas Heidegger introduced the concept of ‘Dasein’, which translates as ‘the mode of being human’ or ‘the situated meaning of a human in the world’ (Laverty, 2003, p.24). The basis of his argument is that peoples’ worlds are formed through background or culture and family values. These are handed down through generations and this accounts for how people live and experience their lives (Wojnar and Swanson, 2007).

Heidegger thought the interpretive process was circular, moving back-and-forth between, what the researcher and the participant bring to the investigation from their own background and experiences (Koch, 1995). Therefore, through a process of interpretation and interaction an understanding of the phenomenon being studied is generated (Wojnar and Swanson, 2007).

3.6.3 Hans-George Gadamer (1900-2002)

Hans-George Gadamer a German philosopher (1900-2002) who made important and influential contributions in the area of hermeneutics claimed, that Martin Heidegger was a major influence in his thinking and reasoning. He promoted the idea that our biases and beliefs are the product of our history and the process of learning and re-understanding never ends, but hopefully comes closer to the truth as our understanding progresses (Moran, 2002).

Gadamer is best known for his work Truth and Method (1960) it is the leading work in hermeneutic philosophy of the 20th Century. It follows in the footsteps of Husserl and Heidegger and acknowledges the possibility of a true or authentic experience (Bleicher, 1980). For Gadamer, hermeneutics is an historical understanding of past and present, there is no present without the past (Crotty, 1998), and understanding and interpretation are always bound together and interpretation is an evolving process. Thus, a definitive interpretation is not possible (Laverty, 2003).

Hermeneutics involves being capable of reading a text in a way that the intention and meaning behind how it appears are fully understood. Thus, there is an interrelationship between the description of an experience and the underlying dynamics or structures that account for that experience, providing a fundamental meaning enabling the substance and essence to be understood (Moustakas, 1994). Gadamer argued in his work, Truth and Method (1960) that humans live in a world that is encountered and inhabited through language and as such, language is the medium through which understanding is realised. Therefore, for Gadamer, language has it's true being in 'speech', the kind that occurs in the context of a conversation leading to a mutual understanding (Gadamer et al., 2004). He felt bracketing was impossible and totally ridiculous; as our understanding is based on historicality and will inevitably involve some prejudice (Laverty, 2003). His view acknowledged the presence of historicality in understanding and he argued that these perspectives have a positive role to play when searching for meanings (Gadamer, 1976).

In summary, phenomenology as a research method has been highly debated in recent decades. The transcendental phenomenology of Husserl and the hermeneutic phenomenology of Heidegger and Gadamer, do share some similar concepts and each philosopher influenced one another. They all sought to uncover the life-world or lived experience (Laverty, 2003). Later phenomenologists where inspired by Husserl as an initiator of phenomenology (Zahavi, 2003), but many branch off in different directions, while some complement his original vision (Cerbone, 2006). His successors have widely criticised his interpretation of phenomenology and it is now considered to be outdated (Zahavi, 2003).

The next part is this chapter will discuss why the interpretive framework of hermeneutic phenomenology approach was selected to underpin this study.

3.7 Choice of phenomenological strategy for this study

In this proposed study, participants were aware of the researcher's professional background, because the surgeons and specialist nurse at clinic introduced them during the recruitment process. Also the Patient Information Sheet stated who the researcher was and their interest in the study topic. Therefore, using bracketing as suggested by Husserl, for this study could have affected the participant/researcher relationship and if the researcher did not acknowledge their professional experience of the phenomenon being studied, this could also have affected the validity of the study.

Heidegger argues that a person's background and knowledge cannot be bracketed and that a researcher needs to be conscious of their pre-existing beliefs, thus making it possible to examine and question any new data that may arise during the interpretation (Finlay, 2009). In a similar vein to Heidegger, Van Manen (1994) does not embrace Husserl's view of bracketing. According to Van Manen (1994) the researcher should be clear and open about their understandings, beliefs, biases, assumptions, presuppositions and theories. It is not possible to simply ignore or forget what is already known, about the experience that has been selected for study, in order for the researcher to reflect on the essential themes, which characterise the phenomenon.

Koch (1995) suggests that the starting point of any study should begin with the research methods being consistent with the researcher's assumptions and Van Manen's (1994) theory that the chosen method should be harmonious with the interest that makes a person, for example, a dietitian or nurse or their chosen profession. Taking this into consideration and after further reflection on the aim of the research, which was to explore the experiences of nutrition for patients with operable pancreatic cancer before and after surgical intervention and focus on the lived experience, though direct contact with this group of patients. The researcher decided to adopt the interpretive framework of hermeneutic phenomenology, which as Koch (1995) suggests is most useful as a constructive framework to examine contextual descriptions of a lived experience generated from meaning and understandings articulated by the researcher and participants. Interpretation, according to Heidegger (1962) constitutes our basic structure of being in the world, and we experience something that has already been interpreted. This stance incorporates the phenomenological philosophies of both

Heidegger (1962) and Gadamer (1975). This reflective approach would not have been possible with the transcendental phenomenology of Husserl.

The Study Design

The following section will discuss why interviews were chosen as the method of data collection.

3.8 Theory in interviewing strategy

Interviews in research can be structured, semi-structured, or unstructured (Kvale, 1996, Mason, 2002). Structured interviews are composed with predetermined categories for the answers, they do not leave any room for descriptive responses, and each respondent is asked the same questions (Britten, 1995). These are typically associated with quantitative approaches. Unstructured interviews are used when the research has no pre-determined questions or expectations of the data and are associated with a qualitative approach. Although the same topic is covered with each respondent, there is flexibility in the language used and the responses are articulated to the depth the respondent wishes. This allows the researcher the opportunity to clarify the respondents answers or question further if necessary (Ritchie and Lewis, 2003). Semi-structured interviews are more focused to the research plan and offer a balance between flexibility and structure, even though the researcher does not ask each participant the same question, worded in exactly the same way (Holloway, 1997). Semi-structured interviews provide greater breadth or richness in data compared with structured interviews and allow participants freedom to respond to questions and probes, and to narrate their stories without being tied down to specific answers (Morse and Field, 1995).

The various strategies of inquiry in qualitative research differ in their philosophical assumptions and the theoretical perspective of the phenomena being studied (Cohen et al., 2000). The interview has very different purposes, within the social and human sciences, for example studying the ways of particular cultures for an ethnographic study, uses a different interview method and has a different function to conversational interviewing (Van Manen, 1994) .

In hermeneutic phenomenology, the interview has a very specific purpose (Cohen et al., 2000). First, it is used as a means for exploring and gathering of narratives (stories) of lived experiences. Second, it is a means by which to develop a conversational relationship with the participant about the meaning of the experience. This may be achieved through reflection with the participant on the topic at hand (Van Manen, 1994). Interviews also allow participants to share their experience and stories in their own words (Kvale, 2007).

For a study underpinned by phenomenology, Moustakas (1994) suggests that typically a long interview, that lasts up to an hour and a half would be the method of data collection, as it gathers stories or anecdotes that can be used to develop a richer and deeper understanding of the phenomenon. However, as suggested by Van Manen (1994) in-depth interviews enable the researcher to develop a richer and deeper understanding of the phenomenon being explored. This would be an informal, interactive process and the interviewer devises loosely, open-ended questions, with some closed questions that will focus the interview and lead to a detailed discussion of the participant’s experience of the phenomenon (Moustakas, 1994). The questions will need to be open-ended and non-judgemental to encourage information to emerge. How this is constructed will depend on how well a balance is achieved between making the interview open-ended and focusing on a significant statement (Charmaz, 2006).

Qualitative interviews, especially in-depth interviews are often described as a mode of conversation (Lofland and Lofland, 1984, Lofland and Lofland, 1995), whereby a researcher will gently guide an interviewee into an extended discussion, but the researcher, although wanting the interview to flow naturally will not want the in-depth interview to bear any resemblance to an everyday conversation (Ritchie and Lewis, 2003). This is a conversation that needs to be guided by the research question that prompted the interview in the first place (Van Manen, 1994).

Qualitative interviewing therefore builds on conversation skills that a researcher already possesses, but to conduct a qualitative interview and hear the meaning of what the interviewee is saying requires skills beyond that of ordinary conversations (Britten, 1995). Developing these skills takes a great deal of practice (Mason, 2002) and healthcare professionals receive training in communication skills and are experienced at eliciting information from a variety of patients (Draper and Swift, 2011), compared to novice researchers.

Qualitative interviewing was chosen as a method of data collection, for this study because the ontological position that peoples' knowledge, views, understandings, interpretations, experiences and interactions are meaningful properties that this research was designed to explore. However, the epistemological implications of this approach needs to be considered and the researcher needs to be very self-critical in judging how well an interview can supply this (Mason, 2002). For example, this study is based on peoples' experiences of nutrition and weight loss before and after surgical intervention and interviews as a method of data collection are very dependant on peoples' capacity to verbalise and remember.

Hermeneutics as previously discussed is the study of the interpretation of texts and the aim of hermeneutic interpretation is to gain a universal understanding and meaning of a text. The research interview is a conversation which focuses on the human life world and the recorded words of the interview are then converted into texts to be interpreted (Kvale, 1996). Therefore, making hermeneutics highly relevant to interview research.

3.9 Summary of part 1

The phenomenological traditions have been discussed and their links with the phenomenological philosophy underpinning this study. The use of qualitative interviewing to provide an open-ended in-depth exploration, of an aspect of life about which the interviewee has substantial experience, has been justified. Interviews can elicit views of a person's individual world and interviewing is a flexible, emergent technique, which allows the researcher to focus on rich descriptions of lived experience and meaning. The study intends to look deeply into the participants' experiences. Thus by returning to the phenomena and re examining the experiences meaning can be given to these experiences and perhaps also uncover new or forgotten meanings.

Part 2: Research methods of sampling, data collection and analysis, conducted for this study.

3.10 Sampling strategies

Sampling is a general feature, when designing both qualitative and quantitative studies, no matter what size of population the study involves. However, choosing a sample is an important stage in the research design (Marshall, 1996). This is because a decision needs to be made about the people and setting of the research and the researcher cannot include everyone (Mason, 2002), as it is not practical or ethical to study a whole population.

Probability sampling is generally considered to be the most rigorous approach, as it aims to produce a statistically representative sample of a small-scale population from which it was drawn (Marshall, 1996, Ritchie and Lewis, 2003) and is most appropriate when the aim of the study is to test an hypothesis. In contrast, the samples from qualitative studies are not intended to be statistically representative and therefore non-probability samples are selected in order to reflect certain characteristics of the sampled population (Mason, 2002, Ritchie and Lewis, 2003).

In quantitative studies the aim of the study will usually determine the selection of the sample. The most frequently used samples are probability samples, where the population to be studied is chosen at random (Mason, 2002). Quantitative samples also aim to draw a representative sample from the population, in order for the results to be generalised to a larger population (Marshall, 1996). However, in qualitative research generalisability is not as important, as choosing samples that can provide a collection of rich data (Holloway, 1997). The issue of generalisability is the key distinguishing factor between qualitative and quantitative research.

Selecting a random sample is not the most valuable way to explore the complex issues of human experiences. Therefore the researcher is guided by the research question, when selecting a sample. This study is using qualitative methods to answer the proposed research question, the next section will discuss the qualitative sampling techniques used and the particular sampling strategy used for this study.

3.11 Sampling strategies in qualitative research

In qualitative research the type of sampling used is determined by the methodology selected and the topic under investigation, not by the need to create generalisable findings (Holloway, 1997). Research samples in qualitative research are not static or shaped by the original conceptualisations in the research design, but are recurrent and emergent in nature. This is referred to as an iterative process (Mason, 2002, Ritchie and Lewis, 2003). The study sample is identified at the start of the research and during the emergent research design, however it may not be possible to exactly specify the number of participants required at the start of the study (Ritchie and Lewis, 2003). This decision should be reflected in an audit trail and as selective sampling procedures are outlined prior to the start of data collection, the researcher should be able to clearly describe this procedure when describing their methodology (Draucker et al., 2007).

There are different approaches to purposive sampling, as suggested by Miles and Huberman (1994) and the rationale for choosing criterion-based sampling will be discussed. Convenience sampling, could save time and money because it maybe convenient to study the participant, as they are available. However, for a phenomenological study a much narrower range of sampling strategy is required (Creswell, 1998). Theoretical sampling minimises possible bias from selecting a sample on the basis of convenience (Mays and Pope, 1995). However, theoretical sampling is a term used in grounded theory and the researcher examines participants who can contribute to the evolving theory, it is a pivotal strategy in grounded theory methodology (Charmaz, 2000, Glaser et al., 1967).

Purposive sampling as suggested by the name is a sample of the population chosen with a ‘purpose’ (Mason, 2002), because they have key characteristics, which enable an in depth exploration and understanding of the fundamental themes the researcher is studying (Ritchie and Lewis, 2003). It is sometimes termed criterion-based sampling (Creswell, 1998), as the researcher chooses certain criteria, before the study commences, on which the selection of the sample is based (Holloway, 1997). However, this does not mean the researcher can simply choose any sample, purposive sampling requires the researcher to think critically about the key characteristics of the population, they wish to study and carefully choose a sample on this basis (Silverman, 2005).

By utilising purposive sampling, the researcher is seeking to gain as much knowledge as possible about the phenomenon being studied, therefore sampling is not preset in advance, but is an iterative process guided by emerging ideas (Holloway, 1997).

Purposive samples are the most commonly used samples (Gadamer et al., 2004, Marshall, 1996, Miles and Huberman, 1994) as they are able to produce the most valuable data (Bryant and Charmaz, 2007) in order to answer the research question. The goal of this, hermeneutic phenomenological research, was to develop a rich or dense description of the phenomenon being investigated (Van Manen, 1994). Therefore a purposive sample of information rich participants was required (Denzin and Lincoln, 2000, Patton, 2002), who could explain the phenomenon of perioperative nutrition and weight loss in pancreatic cancer patients. The quality of the research is affected by the selection of the sample, therefore two factors need careful consideration, the appropriateness of the sample and the adequacy of the sample to provide rich data (Morse, 1994).

The particular sampling technique and the sample for this study will now be discussed.

3.12 Purposive Sampling

Sampling strategies are determined by the purpose of the research (Curtis et al., 2000) and for a study underpinned by phenomenology, it was essential that all the participants had experienced the phenomenon being studied (Creswell, 1998). Therefore, only people having surgery for pancreatic cancer could provide first-hand accounts of the experience and the meanings attributed to it. Thus, the qualitative method of sampling chosen for this study was purposive (Mason, 2002), as all participants were chosen because they had characteristics which enabled detailed exploration and understanding of the central themes and puzzles the researcher was studying (Ritchie and Lewis, 2003). The key questions that were considered when defining the population for this study were which group of the population could provide the richest and most relevant information to clarify the different aspects of the research question. Also which groups should be excluded because their specific experiences were outside the scope of enquiry and it would have been inappropriate to include them in the study (Ritchie and Lewis, 2003).

A sampling frame using existing information from medical records and the list of surgical patients were used to provide details for selection of this sample. As purposive sampling requires an advance knowledge of potential participants, it was essential that the information provided by the sampling frame was appropriate for the selection of the sample (Ritchie and Lewis, 2003).

3.13 Sample size

Qualitative samples are usually small in size, but consist of information rich cases (Holloway, 1997) and each one typically generates a large amount of information (Curtis et al., 2000). An appropriate sample size is one that adequately answers the research question, this could be in single figures (Flick, 2009, Marshall, 1996) or a larger sample depending on the question being asked. According to Morse (1994) a sample of about six participants are usually enough, for a phenomenological study, as the researcher is searching for the essence and richness of the participants' experience, whereas Creswell (1998) suggests it can be as many as up to 10 participants. However, Rubin & Rubin (2005), argue that there should be completeness in the sample, and as qualitative researchers do not have a preset sample size before the research commences, since they are field orientated (Guest et al., 2006), the sample may change in size as the research is conducted.

In summary, the sample for this study consisted of thirteen patients with pancreatic cancer after surgery, which as suggested by Patton (2002) were information rich cases for in-depth study. Thus, sampling continued until no clearer understanding of the experience could be achieved through further discussion.

In the following sections, the factors that influenced and guided recruitment to this study will be discussed. To ensure participants had the relevant clinical and treatment related experiences to answer the research question.

3.14 Factors influencing participant selection

Eligible participants were adult patients with pancreatic cancer where surgery to remove their tumour, was their planned treatment option and who were accessing health services at the approved recruitment site. For this research, 'adult" was defined as being aged 18 years or older, able to communicate and read in English and give informed consent.

3.15 Exclusion criteria

As there were criteria influencing inclusion, there were also criteria for exclusion. Patients whose surgery was palliative for an inoperable tumour were excluded.
The rationale for criteria excluding particular participants needed to be explicit, because of the ethical implications arising from choices to include some participants, whilst excluding others.

It was very important that the researcher and the participant spoke the same language, thus non-English speaking participants were not recruited to the study, because of the need to involve an interpreter. This could be considered an ethical weakness, but the justification for not using an interpreter, was that, the emotions and meanings expressed by the participant could be lost and potentially not be translated exactly as meant by the participant.

Patients, whose surgery was palliative, did not meet the criterion, of having undergone a pancreatic duodenectomy operation, as surgery for these patients was a palliative by-pass and their tumour was not removed. Therefore this group of patients do not experience the same perioperative nutritional difficulties and were excluded from the study.

Patients having treatment for pancreatic cancer are often under a lot of stress, which needed to be taken into consideration when sampling the patients. They may be undergoing chemotherapy or have developed complications from their surgery, all of which were considered at this point and treated sympathetically. Therefore patients were discussed with the surgeons and specialist nurse at the recruitment stage before being approached by the researcher. Thus, over-burdening the most vulnerable members of this population was avoided.

3.16 Sampling access

Prior to gaining ethical approval the researcher discussed the study design with the Pancreatic surgeons and shadowed their outpatients clinics to gain an understanding of how long patients were waiting to be seen and the overall running of the clinic. The researcher discovered that clinics were often running over an hour behind, therefore patients were waiting a long time to be seen and it would not be appropriate to ask them to be interviewed, especially for an in-depth interview, during this appointment time.

Research participants were identified and approached by the Pancreatic Surgical Consultant and Pancreatic Specialist Nurse within their outpatient clinics. The Consultants and Specialist Nurse discussed the study and introduced the researcher to provide further information. The researcher provided the participants with written information, in the form of a Patient Information Sheet, which had been approved by the ethical committee. This will be further discussed in the ethics section.

In summary, the selection and size of the sample was based on the necessity for consistency with the philosophical framework and underlying aim of the study, which was to explore patients' lived experiences of nutritional symptoms and interventions during their surgical treatment for pancreatic cancer. The sample for this study consisted of thirteen patients who met the inclusion criteria, as previously discussed.

3.17 Data collection

Data were collected using semi-structured in-depth interviews, to explore the issues fully and in as much detail as possible. Although the interviews are referred to as semi-structured, they were conducted in an open conversational style, which enabled the participants to freely share their experiences, thus ensuring the richness of the data (Moustakas, 1994, Van Manen, 1994). As this research was investigating experiences and views it was therefore justifiable to use in-depth interviews, as a resource to develop a richer and deeper (Van Manen, 1994) understanding of the phenomenon being explored.

In-depth interviews were conducted in the participants' own homes, but they were offered the choice of being interviewed in an outpatients room in the hospital or their own homes. It has been suggested that the setting of an interview can affect the data collection (Denscombe, 2003, Gillham, 2000), therefore the researcher was pleased that although participants were offered to be interviewed in a clinical environment, to give them the choice that was most convenient for them. All opted to be interviewed at home, which helped them feel at ease and more comfortable sharing their experiences.

One participant commented that they would be help to be part of the study if the researcher was able to interview them in their own home

Each participant chose the day and time for the interview to be conducted, which was convenient, and practical and they also choose rooms where they felt at ease and were able to sit comfortably (Denscombe, 2003, Gillham, 2005). As suggested by Birch and Miller (2000) interviewees can sometimes disclose personal information during the interview, which may cause emotional harm. By interviewing participants in their own space, ensured confidentiality and enabled a relaxed atmosphere to develop a rapport. Therefore, following an initial personal introduction where the researcher emphasised their own background, an informal discussion preceded, which as suggested by Johnson (1993) is called 'the entrée'. This was usually a chat about the weather, to try and establish a rapport with each of the participants, as the researcher was aware that participants could find the interview experience demanding and emotional. By building a sense of trust with the participant, it was hoped that the researcher presented herself as someone who was non-judgemental and interested in the area of research. This was particularly important when for some participants, the scheduled interview was the first time they had actually met the researcher.

After the informal discussion, the researcher discussed the aims of the study, how the research was developed and the interest of the researcher in the topic. The researcher confirmed again that the discussion would be digitally voice recorded and assured the interviewee of the confidentiality of the discussion. The researcher then suggested that the participant take a few moments to focus on their experience, the purpose of this was to try and create a comfortable environment, so that the participant would feel at ease talking about their experiences.

The interviews were recorded with the participants' permission using a digital voice recorder, which was used in the transcription of the interview. The interview was recorded to capture a permanent and complete record of the discussion, because the researcher could not rely on memory alone (Denscombe, 2003). However, it has been argued that recording interviews can change the quality of the data, due to the intrusiveness of the recorder (Lincoln and Guba, 1985). On the other hand after the first few minutes many participants appeared to ignore the fact that the interview was being recorded (Cohen et al., 2000).

The purpose of the qualitative research interview for this study was to understand themes of the daily lived world from the participants' own perspectives. As discussed earlier the structure of the research interview is similar to an everyday conversation, however as a research interview, a specific approach and technique of questioning was used (Kvale and Brinkmann, 2009). The first interview was conducted using an unstructured approach and being a fairly novice researcher, led to an interview with lots of responses from the interviewee that were too short and lacked sufficient depth in the form of a story (Van Manen, 1994). The researcher reflected on this experience and the subsequent interviews were conducted using a conversational semi-structured interview, with the use of an interview guide, to enable the experiences to be explored to the fullest.

The researcher guided the participants during the interview, with the use of an interview guide, which focussed on certain themes and suggested questions, but the researcher did not give specific opinions about these themes (Kvale and Brinkmann, 2009). Thus the guide was adaptable (Denscombe, 2003), but it also allowed room to probe and phrase questions spontaneously (Gillham, 2005).

Each participant was asked the same initial question, by the researcher, to set the context of the interview, "Can you tell me how you found out that you had a diagnosis of pancreatic cancer?" This opening statement allowed the participants time to recollect their thoughts and focus their minds on their experiences.

The following are issues to be addressed during the interview and were used, as prompts, when needed to guide the flow of the conversation.

1. How was your appetite prior to your surgery?

2. Can you tell me if you had any weight loss?

3. What other symptoms did you notice?

4. Did you have any problems with any foods/drink prior to surgery?

5. How did you feel about being fed by a tube after surgery?

6. Did you see a dietitian either before or after your surgery?

7. What dietary advice were you given?

8. What were your initial thoughts about changes to your eating habits after surgery?

9. How long did it take to start eating normally again after surgery?

10. Can you tell me if you had any nutritional supplements either before or after surgery?

11. How long did it take you to get back to your normal level of fitness?

12. Would advice in relation to prevention of recurrence of cancer be useful after surgery?

13. Have you considered or followed any alternative diets?

The questions were not fixed, but were guided by the participant’s response and therefore each interview was a unique story of the participant’s experiences. Often lots of questions were not required during the interview. Patience or silence (Gillham, 2005, Van Manen, 1994) allowed the participants time to gather recollections and continue with their story.

The researcher defined the focus throughout the conversation and all participants remained quite focused during the interview, but there were occasional generalisations about the experience, such as, during the discussion about hospital food, most participants stated “well you know what hospital food is like”. The researcher, asked participants for an example, to turn the conversation back to a more concrete experience (Van Manen, 1994). This required the researcher to have good listening skills and remain very focussed during the interview process. If the researcher was not concentrating on the interviewee, the thread of the discussion could have been lost.

The knowledge gained by the researcher from the participant during the interview was dependant on the social relationship created by the interviewer and interviewee. This relied on the researcher creating an atmosphere where the participant felt comfortable to talk about their personal experiences that were recorded and would be read by others. The researcher although listening to the participant’s experiences and meanings, was also sensitive to any vocal changes, facial expressions or other bodily gestures, by retaining an ‘active listening posture’ (Green and Thorogood, 2009), which involved the researcher sitting forward and nodding both to give agreement and encouragement.

The researcher was empathetic towards the interviewee’s feelings to build rapport and trust with the interviewee to glean as much relevant information as possible during the discussion. By creating trust the interviewer was able to create an atmosphere where the participant felt comfortable to reveal their private world and share their experience (Kvale, 2006). This is not implying that a deep friendship was built up during the interview, where the participant was encouraged to disclose information they might regret later (Mitchell and Irvine, 2008), but a sharing of ideas and negotiation (Birch and Miller, 2000). This enabled the participant to feel they could ask questions and comfortably disclose their experiences.

In-depth interviews can be emotionally draining and it was important that the risk for participants was minimised. Throughout the interview, the researcher was alert to any verbal or non-verbal cues, which signalled tiredness, distress or emotional fatigue. The skills the researcher has developed through experience of talking with cancer patients about a range of topics (including body image, dietary counselling and fear of mortality) were conscientiously applied.

Regardless of whether stress was identified or not, participants were reminded that the process was voluntary and that the interview could be terminated at any time, if they wanted to stop for a brief rest, or stopped altogether if they felt uncomfortable answering any particular questions, or felt answering the question would cause undue anxiety. Participants were also reminded that they could withdraw from the research at any time without the need to give a reason.

One participant asked for the tape to be stopped, as they did not realise how talking about their experiences brought back all their feelings of the difficulties they had gone through, but after a couple of minutes, requested the interview continue and was alright throughout the rest of the interview. Two other participants were obviously emotional at times when speaking, which was noted by body language, but neither requested the interview to be stopped (see section 3.19.2).

The use of debriefing time was promoted at the end of each interview, with the researcher making sure all the required areas of discussion had been covered (Kvale, 1996), by mentioning some of the main points discussed in the interview. The interviewee was asked if they had expressed all their views and no points had been missed. The debriefing time also allowed participants to ask questions or express any concerns and this time also enabled the researcher to make sure the participants were not left feeling that their questions would not be answered. They were also thanked for their time and taking part in the interview.

3.18 Field notes and reflections of the interviews

After each interview, the researcher reflected and recalled what had been learnt from the interview and field notes were created to supplement the raw interview data. These are textual translations of the researcher’s feelings and impressions about each interview, each participant and the interview process experienced by the researcher and the participant.

Each of the interviews continued until the participants felt they had told their stories. Most were keen to tell their stories, but some participants needed more prompting, using searching questions. According to Van Manen (1994) some descriptions of lived experience are richer than others and more can be discovered about an experience, from some participants, than others. This was found to be true is this study, the researcher discovered after one of the interviews that the participant felt they had shared their experiences in as much detail as possible. The participant had not asked questions, or questioned any of their treatment decisions throughout their cancer journey therefore there was a different experience for the researcher to gather here.

This is an excerpt of the field notes written by the researcher after the interview with Anthony.

> When the interview started a lot of his replies seemed very brief the interview was fairly short.
>
> After the interview again I was offered a coffee and biscuit, which I accepted. I was invited into the kitchen, which is when I noticed the garden. The participant finds this very tranquil and calming, which is why he wanted to sit looking out the window during the interview. He found it a big change not being at home as he had never been in hospital before. He was in for a total of 7 weeks, with only a couple of days home leave during that time. He found it a huge shock and worry when he was diagnosed, and he feels it has changed the way he feels about money, that it is not everything and it is better to be healthy.
>
> He felt that the interview was short, but said he could not have elaborated further. He did not want to know what was being done to him, what the operation involved, so he had not asked many questions.

The field notes included a description of the setting and interactions, which were not recorded, also any non-verbal communication (Cohen et al., 2000), which was relevant to the context of the interview and felt to be potentially relevant to the research topic. An example is shown below of the reflective notes taken by the researcher after the interview with Pauline.

Excerpt from field notes from the interview with Pauline.

> We sat in the lounge no-one else was home, we each sat opposite it other, all the time she was talking she wasn't looking at me but straight ahead. At one point she turned her head and was looking out of the window, her chin started wobbling and I asked her if she wanted me to turn the recorder off, which she did. She said she couldn't believe how talking about her experiences brought it all back again and how deep it actually goes. She said she was OK after a couple of minutes and the interview carried on with no more tears or upsets.

The debriefing from the interview often continued after the recorder had been turned off and occasionally the interviewees discussed topics they had not included during the interview and might have felt uncomfortable discussing the topic with the recorder on. These discussions were included in the field notes and provided a valuable context for the later analysis of the transcripts, examples are shown below.

Excerpt from field notes from the interview with Dawn.

> Unfortunately I turned the recorder off too soon, because the participant and her son then talked for approximately 15 minutes
>
> She talked about how she preferred the meals on MAU because these are individually heated meals and are served hot at the patients bedside, but when she was on the surgical ward the meals were served from a large trolley and she was sometimes not keen on the choice of food or it was cold. She wanted to know why these meals were different and if all the hospital wards would adopt the same system

Taking field notes during an interview can be difficult (Wolfinger, 2002), as participants may feel uncomfortable, if the researcher is writing notes while they are talking and not looking at them (Holloway, 1997). The researcher therefore wrote field notes immediately after each interview to capture all the information from the interviewee (Cohen et al., 2000). It has been argued that writing field notes immediately after the interview the researcher has to rely on memory and accuracy of recollection (Denscombe, 2003, Lofland and Lofland, 1984). However, as these were all written immediately after each interview it was still fresh in the researchers memory.

3.19 Ethical issues

Ethics in research relates to a set of guiding principles, which govern how research concerning interaction between the researcher and humans, or data relating to humans is designed, managed and conducted. These principles are designed to protect people who agree to take part in research, in terms of their own privacy and in relation to protection from manipulation by the researcher (Bowling, 2009).

This study was carried out with honesty and integrity, in order to do this the researcher was honest and open about the purpose and content of the research and ethical consideration was given to how the data was collected, analysed and disseminated and the potential impact of this research on those participating.

Prior to commencing this study ethical approval was applied for using the National Research Ethics Service, this is an online service and associated documentation, including the protocol of how the study would be conducted, was submitted to the Regional Research Ethics Committee. After minor changes, which did not affect the research design both the Regional Research Ethics Committee and the Research and Development Department of the Health Trust where the study was conducted, gave a favourable opinion and granted approval (see appendix 3 & 4). The researcher had an Honorary Contract to carry out the research at the Health Trust where the study was conducted.

The research ethics principles will now be discussed and how these were carried out for this study.

3.19.1 Fully informed voluntary consent

Fully informed voluntary consent meant the participants had been fully informed about the purpose of the investigation and the main features of the research design, this process is firmly set within the principle of respect for autonomy. However, there is an issue with exploratory interview studies where the researcher does not have prior knowledge of how the interview will progress (Kvale, 2007).

Fully informed consent involved informing the participants about the overall purpose of the study, what the research involved, how much time and effort would be required if they participated in the study and the possible risks or benefits of participating (Gregory, 2003). Fully informed consent also involved informing participants that it was voluntary and informing them about their right to withdraw from the study at any time, without giving a reason. Members of this vulnerable group might have felt obliged to consent, if they thought it could affect any future treatment from the hospital. Therefore participants were advised that any treatment would not be affected and if they took part in the study, they could withdraw at any time without hindrance or detriment to their future treatment.

Consent was carried out in a consistent manner, which was specified in the protocol. Patients were provided with written information in the form of an Information Sheet (see appendix 5) about the research and what participating in the research would involve. Patients were given two days or longer if needed to consider the written information given in clinic or sent via the post. The participants were telephoned to check they had received and read the written information and answer any initial questions they had about the study.

Participants were given consent forms to sign (see appendix 6), which outlined the aims of the study and the implications of taking part in the study (Holloway, 1997), as it a requirement of the ethics committee. Participants were reminded again that taking part was voluntary and were advised that any sensitive questions that they were uncomfortable answering, which would cause them undue anxiety could be omitted. Each participant signed the consent form in triplicate, in line with research governance. One copy was filed in the participants' medical notes; the participant kept one copy and the final copy was kept in the Site File for the research.

3.19.2 Risk versus benefit

The rights and dignity of the patients participating in the research also needed to be respected. No harm must come to any patients, due to their involvement in the research. However, if due to any unforeseen circumstances, harm did arise to any of the patients from either the management or design of the research, this would be covered by the NHS indemnity scheme.

The issue of safety for participants in a qualitative study should be evident in the discussions of the research methodology due to the extent and depth of involvement by the participants (Morse, 1994). In-depth interviews can be emotionally draining and it was vital that the risk for participants was minimised. Throughout each interview the researcher, remained alert to verbal and non-verbal cues, which signalled tiredness, distress and increasing emotional fatigue. Participants were reminded that the interview was voluntary and therefore it could be stopped at anytime.

The researcher needed to consider strategies of protecting participants from harm, as taking part in the research may emotionally distress participants (Barnard, 2005) and the researcher had an ethical responsibility to lessen this emotional experience. They needed to have access to other services, for example counselling and this study gave contact information for Patient Advice and Liaison Service (PALS) on the information sheet as requested by the ethics committee. The researcher also had access to the on call psychiatric liaison specialist nurse at the Health Trust, for advice on dealing with any unexpected events which arose in relation to the participants' mental or emotional well-being, during the interview. Neither of these services needed to be utilised in this study.

3.19.3 Confidentiality

Confidentiality relates to the protection of data collected during the study and how it will be used in the dissemination of the research results (Holloway, 1997). As this was a qualitative study, accessing participants' personal experiences and feelings, told in their own words. It was very important that the researcher made clear how the privacy of the data would be respected and the level of confidentiality used to make the data anonymous as possible (Gregory, 2003).

Confidentiality was protected in several ways, in order to conceal the true identity of the participants (Christians, 2000) involved in the study. Any identifying features mentioned during the interview were removed from the transcriptions, including participants' names, name and locations of any hospitals and doctors names. The participants were given a pseudonym by the researcher, during the transcription process, to protect their identities. Participants were also advised of the confidential nature of the interview session and how the data would be used. For example, your comments may appear in published work but you will not be named or identified.

Interviewees can become very responsive to the interests of the interviewer and disclose personal and private information to someone they have not met before (Birch and Miller, 2000). This can occur in a qualitative study, due to the intensive nature of the interview and they may regret this disclosure afterwards. The interviewer must respect the participants' wishes for confidentiality of any disclosure they do not want published. As qualitative studies use direct quotes from participants, they need to be informed of this and only used with their permission.

Participants were also advised that the researcher would be undertaking the transcription of the interviews and professional services would not be utilised, however, the researchers supervisors may have access to the transcriptions.

In order, to further protect the participants' identities, any personal data collected were inputted anonymously onto a password-protected computer. Recorded interviews were stored on the researchers encrypted laptop and will be deleted after completion and acceptance of this thesis. After completion of this thesis, data will be held in secure archives at the University for 10 years, in accordance with the Regional Ethics Committee and University requirements.

3.20 Quality assurance and rigour

Health studies have a strong tradition using quantitative methods and qualitative research is often criticised as lacking scientific rigour (Mays and Pope, 1995), when compared with quantitative experimental studies. The criticism relates to the fact that rigour in qualitative research is measured differently from rigour in quantitative research. There needs to be criteria for the evaluation of rigour in all types of research, but it must be appropriate to the nature of the research methods used (Davies and Dodd, 2002, Mays and Pope, 2000). It has been suggested by Morse (2002) that rigour in quantitative studies is evocative of exactness, measurability, validity and clear standards, whereas in qualitative studies it is to do with demonstrating and achieving research that is logical, consistent and replicable. According to Koch (1996) the issue of rigour needs to be addressed by the researcher in making the research trustworthy and believable and to Van Manen (1994) when the researcher provides pragmatic textual data that is "strong in a moral spirited sense". Mays and Pope (1995) suggest the qualitative researcher has two goals to achieve rigour. Firstly, to create an account of methodology used and data generated within the research, which could be followed by another trained researcher, who could analyse the data in the same way and essentially come to the same conclusions and secondly, to produce a credible and coherent explanation of the phenomenon under study.

3.21 Achieving reflexivity

In order to promote rigour, as both a researcher and a clinical dietitian, there was a need to be reflexive in conducting this study (Koch, 1996). Reflexivity refers to consideration of the researcher's own background, perceptions and interest in the area being studied, thinking critically about how the thoughts and actions of the researcher shape the research (Mason, 2002). It can involve a reflective self-examination of the relationship between the researcher and participants in the study (Fade, 2003), as previously discussed in section 3.18 by the use of field notes. As an experienced clinical dietitian with knowledge of nutritional issues of patients with pancreatic cancer before and after surgery, the researcher was aware that it would not be possible to be fully detached from these experiences. It is these experiences that have formed the basis for wanting to explore this phenomenon. However, throughout the interviews, the researcher was careful not to guide the participants responses with the style of questions, based on the researchers clinical knowledge of the phenomena and allow them to tell their own stories.

In order to be reflexive the researcher was also conscience of the fact that they needed to analyse, how they might affect the research process. To achieve this particular care was taken during the interviews by the researcher appreciating the difference between a clinical consultation and a research interview. As an experienced dietitian, with knowledge about pancreatic cancer, the researcher was aware that, wherever possible, they should avoid commenting on clinical questions asked by participants during the study as this could effect the authenticity of the data. Van Manen (1994) suggests that the participants are showing a greater interest in the study and that sharing information helps to create trust and rapport. However, in sharing information, the researcher was careful to use open-ended questions, which were not guided by the researchers knowledge of the nutritional experiences of patients with pancreatic cancer after surgery and allow the participants to tell their own experiences.

As qualitative research is an interactive process that is always moving back and forth between the design and implementation, rigour is therefore an interactive process that occurred throughout the study.

3.22 Credibility

Credibility poses the questions of whether the explanation of the participants' views, fits the description of them by the researcher and whether the description is credible (Tobin and Begley, 2004). In creating data for a qualitative study, the researcher attributes meanings, from the transcripts of participants interviews to the data (Fade, 2003), thus, the quality of the data will be influenced by the researcher and the interpretation could lead to bias.

Credibility was demonstrated in this study through respondent validation, peer debriefing and an audit trail (Lincoln and Guba, 1985). The researcher completed a form of member checking or respondent validation (Fade, 2003, Mays and Pope, 1995). As time constraints prevented the researcher returning to the participants after the interview transcripts had been analysed and interviewing them again, the participants were given the opportunity to check their interview transcripts, for accuracy and complete any missing data from the transcripts. The researcher asked each interviewee after the completion of the interview if they would like to check a copy of their interview transcript. Of the 13 participants interviewed, six were happy to read the transcript and were sent copies in the post, the researcher rang each of the participants after several days to confirm they had received and read the transcript and discussed with them if they felt it was a true reflection of their experiences. Four participants did not make any comments, but were happy with the transcript. However, one participant commented that their regional accent from where they grew up as a child, but no longer lived and had not done throughout their adult life, but felt their accent was still evident, when reading the transcript. The other participant returned the transcript in the mail with corrections highlighted, especially if a slang word had been used, which they obviously felt was not part of their vocabulary. The researcher re-checked the transcript again the recording and found the transcript to be correct.

Peer debriefing involved the researcher discussing the research process and findings (Krefting, 1991) with the researcher’s supervisors, who have experience with qualitative research methods. It has been suggested by Lincoln & Guba (1985) that searching questions used during peer debriefing may contribute to a deeper reflexive analysis by the researcher. Van Manen (1994) suggests that researchers need to critically analyse their interview style, as many qualitative researchers are novice researchers. Therefore, they should reflect on their participation in the interview, by listening back to the recordings of the interview and ask for feedback from significant others. Taking this into account the researcher’s supervisors read through the interview guide and one of the transcribed transcripts, before we had a discussion about the emerging themes and significant statements. The feedback from the researcher’s supervisors enhanced credibility and ensured the validity of the study, by their suggestions with the quality of the data collection, interpretation of emerging themes and the role of the researcher.

The audit trail is a term developed by Lincoln & Guba (1985) or sometimes referred to as the decision trail (Koch, 2006), it provides a transparent description of the research steps taken from the start of the study to the development and reporting of the findings. This has been demonstrated in this report by a clear description of the research path, the research design and how data was collected. Also the steps taken to manage, analyse and report on the data findings, which will be discussed in the following section, have clearly been described and illustrated.

The following part of this chapter will detail the process of data analysis by justifying why Van Manen's (1994) hermeneutic phenomenological reflection was used to analyse the data and demonstrate how the researcher has attempted to use Van Manen's approach to interpret the participants' experiences.

3.23 Choice of data analysis method

The aim of qualitative analysis is to try and discover the underlying structure or essences of the participants' lived experiences, by immersion in the data and engaging with the data reflectively to generate a rich description of the deeper underlying structures of the participants' experience (Van Manen, 1994). In order to achieve this the researcher chose to adopt Van Manen's (1994) hermeneutic phenomenological reflection to analyse the data and the purpose of this was to try and understand the essential meaning of a phenomenon. The decision resulted from the researchers interpretation of Van Manen's philosophical stance on the value of human science. He suggests in doing research, human science researchers are questioning the world's secrets and intimacies, which are a constituent part of the world. Thus, making human science research a caring act to develop knowledge about what a certain phenomenon means and the uniqueness of how it is experienced. This knowledge is then used to improve the care of others. As a clinical dietitian there is an educational aspect within this role and therefore the researcher felt able to relate to Van Manen's views. The researchers aim is to share the existential meaning of nutritional and weight loss issues of patients with pancreatic cancer, gained from this research, with peers and colleagues, to enhance the nutritional care offered patients before and after surgery. In order to achieve this a methodical approach is required to analysing the data in order to provide the reader with rich meaningful descriptions of participants' experiences.

The approach adopted by Van Manen (1994) does not prescribe a set of mechanistic procedures but highlights the importance of using any lived experience description, such as stories, taped interviews or conversations, to discover themes and significant statements of the phenomenon being studied. Van Manen (1994) suggests that the meaning or essence of a phenomenon is not simple or one-dimensional, but multi-dimensional and multi-layered. Therefore, to understand and grasp the structure of meaning of the text, it is important to think of the phenomenon described in the text as meaning units, structures of meaning or themes. By reflecting on the lived experience a reflective analysis of the structural or thematic aspect of that experience can be achieved.

Phenomenological themes, suggests Van Manen (1994) can be understood as the structures of experience, therefore by seeking to interpret the meaning of the text, the researcher is aiming to formulate a thematic meaning and translate the findings to the reader in a such a way that the phenomenological text invites the reader to understand the meaning (Van Manen and Li, 2002). From a phenomenological point of view, the researcher does not just report the findings, but uses sensitive interpretive and creative talents, if the findings from the research are to be valued and understood (Van Manen, 2006).

3.24 Interpretive stages of data analysis for this study

The approach to the analysis of the data was undertaken in three stages and an interpretive process was adopted. This process is shown in the table below. However, the steps were complex and overlapped each other, and were not separate steps. In order to visually present the stages, the table has been shown as separate individual steps.

Table 7: Interpretive stages of data analysis

Stage 1	Interpretation of individual transcripts
Stage 2	Interpretation of collective data from all the interview transcripts
Stage 3	Interpretive story and emerging themes

Stage 1: commenced with listening to the participant tell their story and continued throughout each individual transcript;

Stage 2: was concerned with comparing and contrasting the data generated, during the interviews to get a feel of the experiences and any consistencies and recurring information in the descriptions;

Stage 3: focussed on all the interviews, with the aim of identifying significant statements/themes from the experiences of patients with operable pancreatic cancer. (see figure 2-interpretive stages of data analysis [pg.108]. This figure has been adopted from that used by Evans and Hallett (2007) in their hermeneutic phenomenological study of hospice nurses. It provides a step by step breakdown showing the iterative process of moving back and forth between the stages of the data analysis.

Each of these stages will now be discussed in more detail.

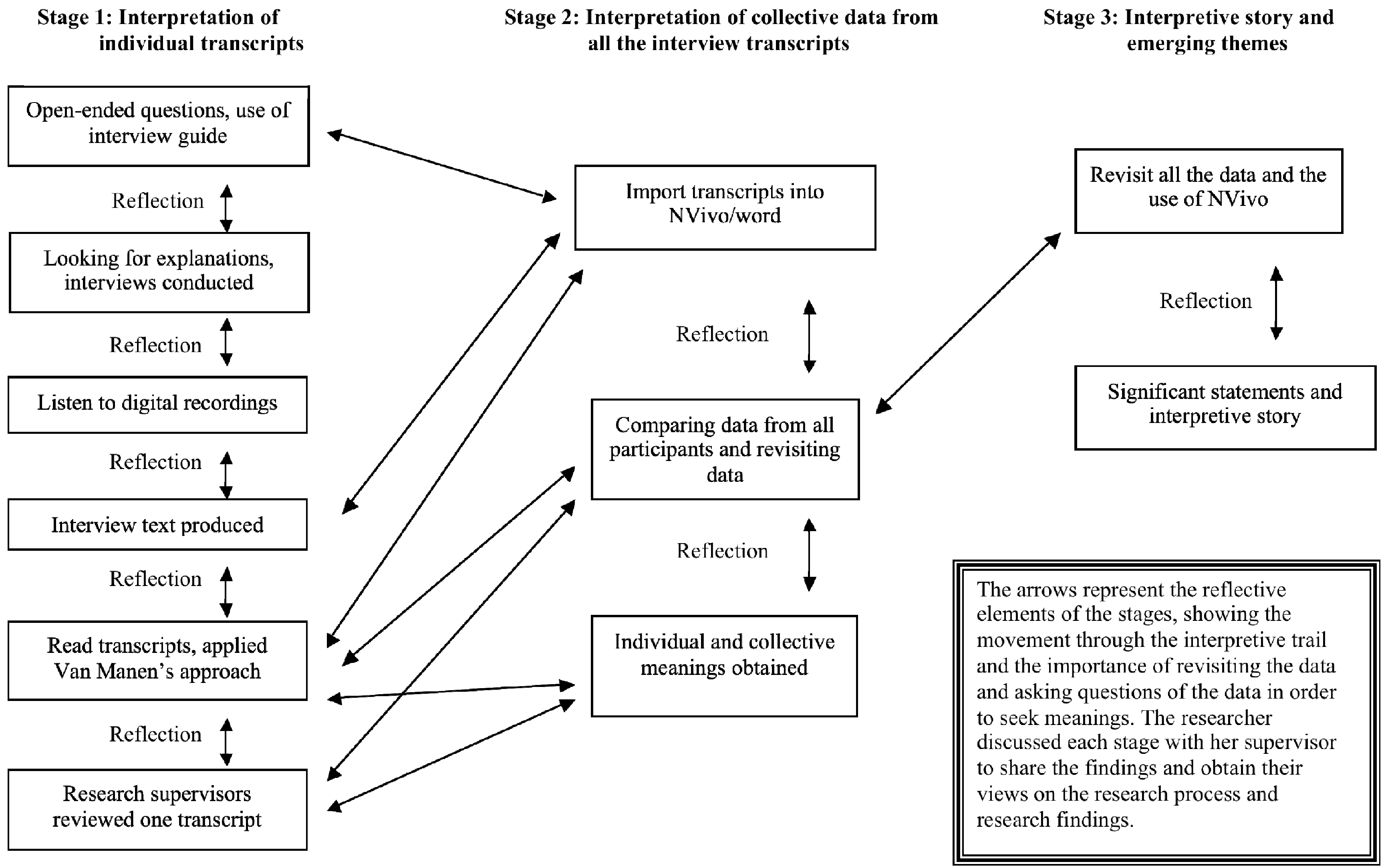
3.25 Stage 1: Interpretation of individual transcripts

3.25.1 Reading of all the participants' descriptions

This stage of data interpretation started as soon as the researcher listened to each of the individual interview recordings. The researcher absorbed the participant's story as they began to share their experiences of how they were diagnosed with pancreatic cancer. This reflective story telling as suggested by Heidegger (1962) enabled the participants to describe their experiences and appeared to help the participants make sense of their diagnosis and share what living through this time in their lives meant to them. According to Heidegger (19962) it is these experiences that help individuals to make sense of their world and therefore make them important and unique.

The initial transcription of each interview was quite rough and words were skipped over that were not clear. The whole process was then repeated whilst listening and reading the transcript concurrently, filling in the gaps and correcting any words misheard on the initial draft. This meant each transcript was the result of multiple drafts, which enabled the researcher to become familiar with the data. Although, this was a lengthy process and a lot of time was spent transcribing each interview (Gibbs, 2002), this was essential for developing a comprehensive understanding of the data (Braun and Clarke, 2006). As the researcher listened and transcribed the interviews, key words and phrases seemed to stand out, these are described by Van Manen (1994) as "lived-experience descriptions", that would need further probing and seemed to be thematic of the experience. However, Van Manen (1994) suggests that expressing the overall meaning of a text is judgemental and different readers might perceive a different meaning, but it does not make one interpretation more accurate than another.

When the researcher was listening to the recorded interviews, it was surprising to find that some participants asked questions during the interview and answering the question (Britten, 1995) meant the researcher might impose their own concepts on the interview. However, ignoring the question, potentially imposed a power imbalance into the interview and participants may have become guarded, about how open or critical they could be during the interview (Draper and Swift, 2011). Gadamer (1976) suggests the art of the researcher in a hermeneutic interview is to keep questions open, to keep the interviewee orientated to the topic being questioned and thus participants become more interested in the study. On reflection, the participants were showing a greater interest in the study and therefore the researcher viewed this as giving something positive back, to the participants who had volunteered their time to be in the study. This interaction would not have been possible with the transcendental phenomenology of Husserl and confirmed that hermeneutic phenomenology was the right approach for this study.



The arrows represent the reflective elements of the stages, showing the movement through the interpretive trail and the importance of revisiting the data and asking questions of the data in order to seek meanings. The researcher discussed each stage with her supervisor to share the findings and obtain their views on the research process and research findings.

Figure 2: Diagrammatic representation of the interpretive stages of data analysis.

Adapted from Evans and Hallett (2007)

3.25.2 Interview text produced

The researcher transcribed the recorded interviews verbatim, with no attempt made to clean up the data, to uncover the aspects of the phenomenon the participants were describing (Moustakas, 1994). The recorded interviews are records of naturally occurring interaction, thus allowing the researcher to return to the data, in its natural form at any point during the analysis (Silverman, 2005). The interviews were transcribed as soon after each interview as possible, before the next participant was interviewed. This allowed for reflection on the transcript, in order to try and gain as much interpretive insight as possible (Van Manen, 1994).

The researcher transcribed each interview including all the ums, mmms and repetitions (Cohen et al., 2000), with the aim of being as close to the actual conversation as possible (Bazeley, 2007, Kvale, 1996). According to Bazeley (2007) the use of repetitions by the participant during the interview, were possibly a means of conveying their emotions about the topic. Participants might also have used ‘ums’ as a form of hesitation about the topic being discussed or this could be their usual pattern of speech. Any incomplete sentences, poor grammar or mispronounced words were all transcribed verbatim, as it was important to capture how the participants expressed themselves, during the interview (Bazeley, 2007).

Any nonverbal elements during the interview were also recorded, such as long pauses and emotional elements for example laughter (Bazeley, 2007, Fade, 2004). Also interruptions to the interview were noted, for example the recorder was turned off if the telephone rang, relatives entered the room and started speaking not realising the interview was being recorded or the participant became emotional and requested the recorder turned off.

The researcher reflected on the transcripts and also on the vignettes written by the researcher of each participant after the interview (see chapter 4) in order to get a feel of how the researcher felt they were coping with their experiences of pancreatic cancer. By creating different styles of text, for example, the interview transcripts, field notes and thoughts of the interview process this supported the researcher’s reflexive journey. Van Manen (1994) suggests that a stronger element of interpretation is involved by using different styles of text generation.

3.26 Stage 2: Interpretation of collective data from all the interview transcripts

The next process, which was a fundamental requirement of qualitative analysis, was the reading and re-reading of the transcripts (Bowling and Ebrahim, 2008, Creswell, 1998), in order to get a sense of their total content and enable the researcher to become immersed in the data (Braun and Clarke, 2006). This immersion in the data, involved the researcher engaging with the meaning of the texts, with the aim of getting a ‘sense’ or preliminary interpretation of the texts. The next step was to selectively read the text and ascertain what statements or phrases were particularly essential or revealing about the phenomenon or experience being described (Van Manen, 1994). The researcher then highlighted relevant text, pertaining to descriptions of the lived experience of the participants. The interview transcripts provided an important description of the conscious experience of the participants and reflective interpretation of the text was needed to achieve a deeper, more meaningful understanding (Moustakas, 1994).

After the interviews had been transcribed, an approach to manage the volume of data produced by the transcripts was needed to reduce the quantity of the data (Bowling and Ebrahim, 2008). The approach taken to this was coding (Creswell, 1998). Computer Assisted Qualitative Data Analysis Software (CAQDAS), of which NVivo[8] is an example, encourages an exploratory approach to analysis (Gibbs, 2002). The use of NVivo[8] (QSR International Pty, Ltd, Melbourne) was chosen for this research, in order to make sense out of the verbatim transcripts and raw field notes. A system of classification was needed (Patton, 2002) to organise, manage and retrieve the data that was most significant (Coffey and Atkinson, 1996), to uncover the lived experience descriptions.

Coding, a basic activity of qualitative analysis, was a tag or label used to assign a salient meaning to the descriptive information compiled during the study (Saldaña, 2009). Before all the transcripts were coded, the researcher and the researcher’s supervisors independently coded one of the transcripts. This was then discussed and jointly reviewed, as a means to enhance rigour and reflexivity. Discussion between the researcher and the researcher’s supervisors aided in reflection on emerging ideas and helped to develop and expand these ideas. These discussions provided valuable insight, for considering alternative interpretations (Barbour, 2001) and encouraged a thoroughness in examining the data, which added to the rigour of the research (Koch, 1996).

Coding using NVivo[8] was fairly slow initially as the list of free nodes was constantly being increased. Time was spent reflecting on the newly created codes and the reasoning behind why nodes were created. The use of language to describe and label data from the interviews required reflection to allow the development of nodes and sub nodes, which were used to store ideas about the phenomenon. For example; during the interview with participant 8, they had been talking about the lack of dietary advice once they had been discharged home, they stated ‘we just used our common sense and sometimes it failed us really, because, we thought we were doing the right thing and it turned out that perhaps, it was a bit too rich for my stomach’. This was coded as ‘trial and error’, because of the desire to manage and help their diet after surgery.

After a few transcripts had been coded the amount of new nodes added decreased, which meant a clearer structure was developing. The second stage in the development of the coding system was to sort and connect data into a branching system of tree nodes (Gibbs, 2002) to reflect the structure of the data. Notes were made about phrases and the researcher reflected on “What the data was trying to say? And “What were the participants stories”, in order to try and interpret the significance of the preliminary themes being suggested from the transcripts (Miles and Huberman, 1994) and issues were noted for further investigation. The hermeneutic circle a metaphor taken from Heidegger (Koch, 1996) for understanding and interpretation was a moving back and forth between the data to understand the transcripts (Crist and Tanner, 2003) and the phenomenon under study. Within the circular process narratives were examined simultaneously with the emerging interpretation, but without losing sight of each participant’s particular story and context, thus, the researcher remained open to questions that emerged from studying the phenomenon and allowed the text to speak for itself.

The text then became a creation by the researcher from the interview data collected from the participants to enable a discussion with the researcher’s supervisors about the emerging coding frameworks (Moustakas, 1994). These reflections were discussed with the researcher’s supervisors, this adds strength to reflective thinking about the text and it's interpretation (Bazeley, 2007). These discussions were helpful in generating a deeper insight and understanding of the emerging themes. Thus, as suggested by Van Manen (1994) the researcher was looking for appropriate phrases or single statements, from the lived-experience descriptions, by comparing the "significant statements" from each individual interview transcript. Certain themes were recurring and were commonly found in the various participants' descriptions (see table 8). The constant comparisons helped to confirm the emerging themes and as suggested by Pope et al (2000) using a systematic approach to the analysis of the data enabled the researcher to refine questions as interpretive understanding emerges.

Table 8: Significant statements and meaning units identified from transcripts

Nodes identified in NVivo[8]	**Lived experience descriptions from collective interviews**
Visible weight loss	I mean I've lost a hell of a lot of weight I've lost about like I say 2 stone
Physical weakness	I've lost over 2, I've lost 2 stone 4 whatever it is something like that, nearly two and a half stone, which I can't really afford to plus, as well I eat well
Making sense of weight loss	I'm not going to put on a lot of weight on, one is because of what's happened, but if I worry, if I'm worrying about what I am having to eat that's not going to help
Lack of appetite post surgery	It was 2 spoonfuls that was it, I'd have 2 mouthfuls of a cup of tea, that was it
Taste changes	Yeah, I've found the 3 or 4 things that I eat, I can taste and I'm enjoying and I think oh god I hope I don't get fed up of these
Enteral/Parenteral feeding after surgery	Err, I can't remember how long it was, but it was for quite a, for a few weeks and then when the tube was taken out that was quite a relief to think oh good that'd gone
Bland hospital food	I'd just push everything to one side, no can't eat it, can't eat it
Nutritional support	No, I'm not. I've got some in the fridge, they're sat there but I've never seemed to find a suitable opportunity
Early satiety and adapting to smaller portions	Oh, yes, yes, er I'm on very small portion sizes. Er, my wife commented it was like feeding a toddler, so um they are getting bigger, but I um if anything having to restrain myself I'm finding. I feel I could eat more, but then I suffer for it

Nodes identified in NVivo[8]	**Lived experience descriptions from collective interviews**
Lack of information-dietary advice	Basically the advice I got was eat as much as you can and put as much weight on as you can
Coping strategies to eat whilst in hospital	You're bodies telling you, you can't eat that much and you can only eat certain foods because, nothing'll [nothing will] digest
Lack of clear advice	I mean some people are saying do this and some people are saying do that, people say build yourself up cos [because] you've got to eat and other people say don't eat too much
Trial and error	Trial and error you think you're clever, but you learn
Problems with digestion	I obviously wasn't digesting it properly um even with what I thought was enough Creon
Lack of dietary counselling	Only once, once, I only the saw the dietitian the day I went in to [hospital name] and the morning, the day before I came home, that's the only two times I saw that dietitian
Concerns about healthy eating versus weight gain	I'd seen the dietitian before I had the operation and she'd said that I'd got to eat all these things, that to me were most unhealthy, were all fattening things, you know, doughnuts and all the things that I'd avoided to keep healthy and to keep me cholesterol down um there was a big list of them and it made me laugh because I thought good gracious you know, it said put extra butter on things and what not
Quality of life affected	And I can't cook and I used to do oh perhaps two thirds of the cooking, er and I'm having to be waited on hand and foot

The codes assigned represent the significant statements from the participant transcripts. The lived experience descriptions, assigned to the significant statements are also represented in the table to show the emerging themes that would require further investigation.

3.26.1 Advantages of using CAQDAS

An advantage over manually coding all the transcripts, was the use of the search tools in NVivo^8, which enabled the researcher to search for coded passages and compare them to identify patterns and relationships, to interpret the data (Saldaña, 2009). Thus, the organised storage system enabled the researcher to easily locate material and did not have to “cut and paste” material onto cards and sort them into themes (Creswell, 1998). CAQDAS helped ensure rigour in the process of analysis, as it found every use of a term or coded instance of a concept (Fade, 2003). This ensured a more complete picture of the recorded data set, than working manually (Bazeley, 2007).

3.26.2 Disadvantages of using CAQDAS

A disadvantage of using NVivo^8 was not only the cost, but also the additional learning required by the researcher, to enable the researcher to become proficient enough to use the software. It has been argued, that novice users of CAQDAS, need to carefully consider the volume of data to be analysed, because manually analysing a small data set may be a more efficient use of a researchers time (Fade and Swift, 2010). Both Popay et al. (1998) and Richards (2002) also argue that CAQDAS, is not adequate for rigorous analysis and that the use of qualitative computer software may take the place of careful analysis of the data. This means that, they should not be used as a substitute for close reading of the data, by the researcher, but should be used as an aid in the analysis process.

3.26.3 The use of CAQDAS for this study

Using NVivo^8 to help with the lengthy process of analysis had many benefits, and was a useful aid to organising the data (Pope et al., 2000), but the researcher did not find it helpful beyond the basic descriptive stage. This required the researcher’s analytic skills to transform the findings into meaningful data (Thorne, 2000). Initially, the researcher thought it could support the concepts described by Van Manen (1994) facilitating the process of hermeneutic reflection. At this stage of the analysis, it was found that NVivo^8 was not assisting further in the analysis of the data and was not adaptable to achieving the goal of identifying and interpreting the participants’ meanings from the combination of the researcher’s understanding and the participant-gathered information. Therefore, the researcher transferred the data into files in Microsoft Word and the data were stored in separate files under the theme headings, shown below in figure 3.

3.27 Stage 3: Interpretive story and emerging themes

Thematic meanings emerged from the repeated examination of the thematic statements, as the researcher became more familiar with the data. These were common to all the transcripts and incorporated into loose interpretive themes. Themes are a phrase or sentence that identified and gave meaning to a recurrent experience and was a way to organise the data (Saldaña, 2009). Phenomenological themes can be described as the structures of experience and offer a thick description of phenomena (Van Manen, 1994). For this study themes were a way of capturing the phenomenon, that the researcher was trying to understand (Van Manen, 1994) and analysis of a phenomenon helped the researcher determine the experiential structure that made up that experience. In other words, the researcher was searching for something meaningful from the transcriptions of the participants' experiences, to gain a deeper meaning of the essences of the phenomena. As suggested by Van Manen (1994) not all meanings encountered when reflecting on lived experience are unique to that phenomenon. Therefore, a distinction needs to be made between an essential or key theme and incidental themes. In order to determine the key themes for this study, the researcher needed to determine the qualities or aspects that make a phenomenon what it is and the question needed to be asked" if the theme was changed or deleted would the phenomenon still be the same? For example, the participants in this study had experiences in being in hospital because they had operable pancreatic cancer, whereas, palliative patients would not have the same experiences. The key themes identified are demonstrated in figure 3 and are presented as a representative journey for patients with pancreatic cancer before, during and after surgical treatment.

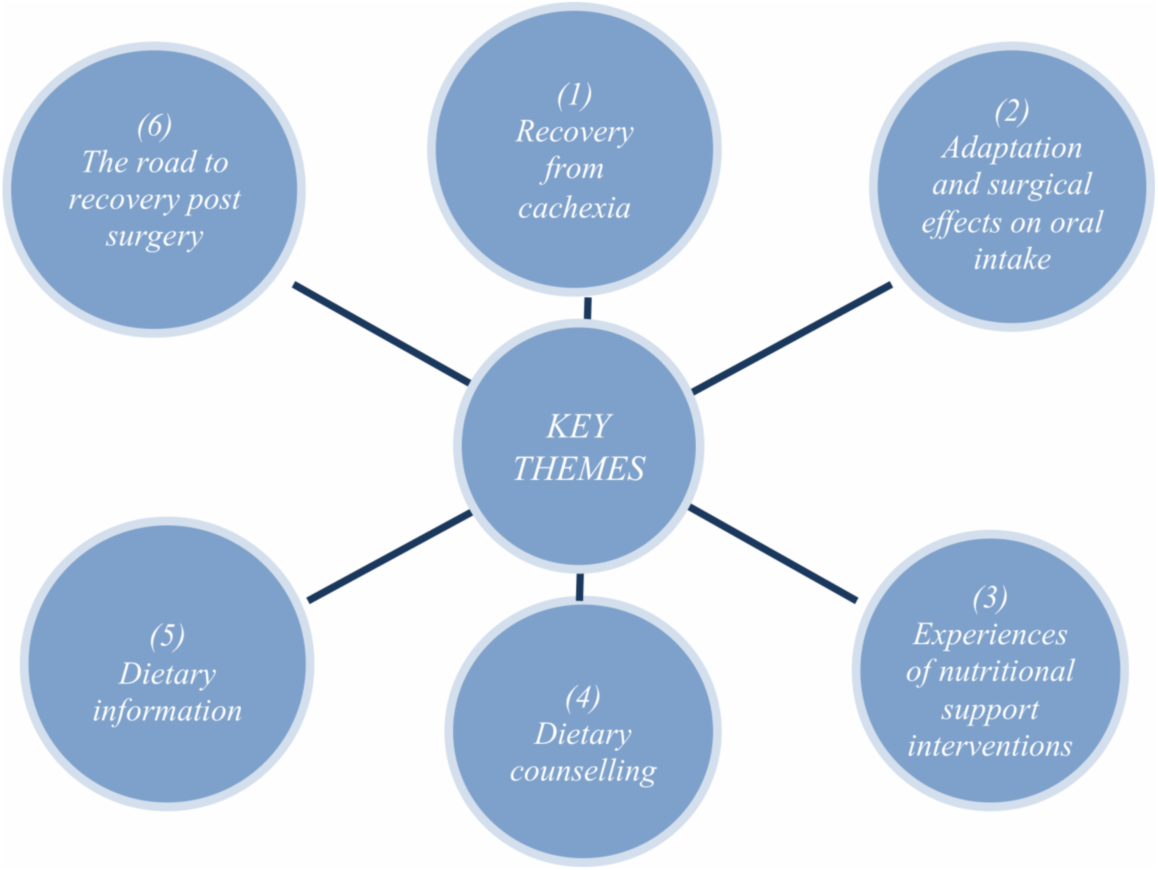


Figure 3: Diagrammatic representation of the key themes from the lived descriptions of the participants' interviews

3.28 Summary of data analysis approaches

The researcher has transcribed the interviews and coded them to establish common themes occurring from the descriptions of the participants' lived experiences of perioperative nutrition. The use of participants' words, thus allowing them to speak for themselves will be illustrated in the following chapter, by the use of quotes from the transcripts. Ensuring that the voices of both the researcher and participants are evident in the text enhances authenticity (Lincoln and Guba, 2000). In order for the researcher to interpret and therefore fully immerse themselves in the data, it has been suggested that the researcher refers to their self in the first person, however to give continuity to this report, the researcher, continued to refer to their self in the third person. In providing an account of how an analysis of the data was developed, further enhanced the audit trial (Koch, 2006, Lincoln and Guba, 1985), by making this transparent in this written report.

3.29 Conclusion

This chapter has explained and justified the methodology and design of the study, in which the nutritional experiences of patients with operable pancreatic cancer before and after surgical intervention were to be explored. The methods have been described and ethical issues, relevant to this study have been identified and discussed. Using qualitative methodology, especially phenomenology with its emphasis on peoples' "lived experience", was essential for locating the meanings participants placed on the events, processes, and structures of their lives: their "perceptions, assumptions, prejudgments, presuppositions" (Van Manen, 1994, p.46) and how they related these meanings to the social world around them. Qualitative interviewing did have limitations in regard to its reliance on talk and text, that had been generated through the specific and refined context of an interview (Mason, 2002). Although it was a very rewarding and fascinating method of data collection to use, the researcher needed to be aware of the practical, social and ethical difficulties facing them. In addition qualitative interviewing was greedy on resources, such as skills, time and effort in both planning and conducting the interviews and the analysis of the data gained. The time-cost implications needed to be thoroughly considered in order to achieve the aims of the research and which methods would answer the research question. The research design has been explained in detail, thus an audit trail of the rationale for the research has been provided, demonstrating quality, rigour and credibility in the research process.

The following chapter will be divided into two parts. In the first part, the participants involved in the study will be introduced and a brief description of their circumstances and characters will be described. In the second part of the chapter the interpretive themes form the data are described and the meanings attached to each phenomenon, are illustrated with sections of quotes form the interviews.

Chapter 4: Findings and interpretation of the data

Chapter 4: Characteristics of the individual participants

4.1 Introduction

This chapter is presented in two parts the first part describes a vignette of the characteristics of the individual participants involved in the study. This has been done to add some insight into the background and personality of each participant whilst still maintaining their anonymity. Each description is written as a reflective account of their personality, as perceived by the researcher during the interview, as well as to recognise their personal contributions and time given to this research, during a difficult period of their lives. Thus, each person exists as a whole person, rather than just a collection of data quotes. The pseudonym assigned to the participants by the researcher, during the transcription process, will be used for each of the descriptions.

In the second part of this chapter the interpretive themes identified from the participants' transcripts will be further explored and presented using participants quotations, in order to demonstrate how the themes were interpreted from their unique stories. Some of the participants were more open than others about their experiences, as previously discussed in section 3.18. For example, Anthony had not asked many questions about his surgical treatment for pancreatic cancer and therefore did not have a great deal to tell about his experiences, however he shared a lot of insight into his nutritional difficulties after surgery. Whereas other participants like Bernard, Daisy, Sandra and Malcolm shared a lot, and gave rich detailed descriptions of their experience. Therefore, it would seem at times, there are more exemplars from particular participants.

4.2 Characteristics of participants

Overall, a total of 18 potential participants were approached, during the six months of data collection and 13 consented to be included in this study. Five patients declined to be in the study for various reasons, which included 'not interested at this point', discussed with family member and decided not to be involved, wanted to complain about hospital food and 'not feeling up to it'. Table 9 highlights the participants characteristics. The study included six male and seven female participants and 85% of the participants were over 60 years old. All the participants in this study were assigned a pseudonym during the transcription process, to further protect their anonymity. Five participants requested a family member was present during the interview. The researcher requested the medical notes for each participant after recruitment and all the interviews were completed. The documented amount of weight loss experienced by participants before, during and after surgery is presented as weight loss in kilograms (kg). Participants were interviewed at various stages in their treatment programme after surgery and seven participants had already experienced a course of post-operative chemotherapy, as part of their cancer journey. It should be noted that all of the participants had advanced disease at the time of surgery, as they were all either stage 3 or stage 4 cancer at the time of surgery.

Table 9: Characteristics of the participants

Participant	M/F	Age	Tumour staging	Amount of weight loss (kg)	Received chemotherapy
Dawn	F	47	3	9	Yes
Dennis	F	60	3	6	Yes
Tracey	F	57	3	16	Yes
Pauline	F	63	3	9	Yes
Enid	F	80	3	6.5	No
Sandra	F	62	3	10.5	No
Beatrice	F	64	3	10	Yes
Daisy	F	64	3	10	Yes
Barry	M	65	3	9.5	No
Anthony	M	66	3	16	No
Bernard	M	76	3	9	Yes
Malcolm	M	61	4	16	No
Harry	M	75	3	7.5	No

4.3 Vignettes of individual participants

4.3.1 Dawn

Dawn is 47 years old she lives with her son and her parents. Dawn was the youngest participant in the study. She was interviewed three months after surgery and had already experienced chemotherapy treatment after her surgery. She requested that her son sat in on the interview he did not speak until after the interview, when he asked some questions. Dawn was very frustrated with her levels of energy post surgery, because she was a very active lady and liked to do lots of walking. Dawn was looking forward to returning to work on a part-time basis later in the year. She is a teacher and had been offered reduced responsibilities and a gradual return to work.

4.3.2 Dennis

Dennis is 60 years old. He is married, but choose to be interviewed when his wife was out at work. Dennis was interviewed ten months post surgery and had already completed a course of chemotherapy. Dennis was a school caretaker and because of his heavy lifting duties he would not be able to return to work, this was causing him some concern because he is not yet of a pensionable age. He had taken up new hobbies to try and relieve some of his boredom, because he was only able to walk to the local shops and do some light shopping.

4.3.3 Tracey

Tracey is 57 years old and married she requested her husband sat in on the interview. Tracey was five months post surgery and was undergoing chemotherapy treatment when she was interviewed. She was very anxious throughout the whole interview, which was evident in her body language. Tracey sometimes referred to her husband as a way of confirmation about what she had experienced. She was not coping well with her lack of energy levels and could only walk small distances with the aide of a stick.

4.3.4 Pauline

Pauline is 63 years old and married. She had chosen to be interviewed when her husband was out. Pauline was 12 months post surgery and being interviewed about her experiences caused some distress during the interview. She had completed a course of chemotherapy. Pauline was concerned with her current nutritional status and had decided that she needed to take some multi-vitamins to improve her health. Pauline is retired and has started enjoying walking again in the local countryside.

4.3.5 Enid

Enid is 80 years old and was the oldest participant in the study. She was four months post surgery and had been advised by the surgeon that she would not require chemotherapy. She lives with her husband, who was busy doing the gardening at the beginning of the interview, but sat in for the end of the interview. Enid was a fit and active 80 year old and she was looking forward to going dancing again with her husband, because this was her main hobby.

4.3.6 Sandra

Sandra is 62 years old she was interviewed five weeks post surgery. She lives alone, but her daughter was present for most of the interview. She was interviewed in her dressing gown and was in some discomfort during the interview, as she shifted around on her sofa to try and get comfortable. Sandra was very worried about being involved in the study because she felt she did not have a great deal to talk about. She was extremely chatty and expressed in detail her story and experiences. Sandra was hoping to return to work because she missed all her work colleagues, but knew it would be some time before she could return to work. Sandra was about to start a course of chemotherapy.

4.3.7 Beatrice

Beatrice is 64 years old and married. Her husband came home from his night shift during the interview, but went straight upstairs to bed. Beatrice was two months post surgery and had just started a course of chemotherapy. She seemed to be coping very well and seemed to have a positive attitude towards her eventual recovery. She went out shopping most mornings with her daughter and felt that the ‘retail therapy’, even if it was only window shopping helped her to relax and get on with her life. Beatrice was hoping return to work with lighter shifts, possibly in four months after the interview.

4.3.8 Daisy

Daisy is 64 years old, retired and married. Her husband was outside gardening throughout the interview. Daisy was eight months post surgery she had already completed a course of chemotherapy. She was very anxious and concerned about her current nutritional status. She was trying to build up her energy levels without much success and was frustrated by the lack of help and information available to her.

4.3.9 Barry

Barry is 65 years old and married, his wife sat in on the interview. He was two months post surgery Barry also had a previous diagnosis of cancer and had to retire early and sell his business, because he could not concentrate and remember things. His wife sat in on the interview to help jog his memory when it failed him. Despite being diagnosed with two cancers he took one day at a time and could see the funnier side of life. He made quite a lot of jokes throughout the interview.

4.3.10 Anthony

Anthony is 66 years old and married. His wife was not present at the interview, she left for the gym as I arrived this was their normal routine together to go to the health centre at that time of day, before Anthony had been diagnosed with pancreatic cancer. Anthony was six weeks post surgery and was not fit enough to go to the gym. He found this very disappointing, but was looking forward to a short walk later that day. He had lived a very healthy and active lifestyle, his normal routine would be to go to the gym in the morning and then walk in the afternoons for about two or three hours. Anthony had never been in hospital before and had not had many illnesses during his life, therefore to be diagnosed with pancreatic cancer was a huge shock and he did not ask questions about his treatment. He just accepted what he was told. He was due to be assessed to start chemotherapy, he had been given a leaflet to read before his appointment, but again he did not want to know any details.

4.3.11 Bernard

Bernard is 76 years old and married. His wife stayed in the kitchen during the interview. Bernard was 11 months post surgery and had already completed a course of chemotherapy. He daily takes his dog for a walk and can now manage walking up hills without feeling out of breath. Bernard felt fitter than he had done in years due to the weight loss and he did not want to regain all his weight. He was very pleased with his treatment from the NHS and could not believe how much time and effort was spent on him, because as he stated he was not a young man.

4.3.12 Malcolm

Malcolm is 61 years old and married. He is a retired University Lecturer and was five weeks post surgery. He was in quite a lot of discomfort during the interview, but he wanted to tell his story in as much detail as possible. He felt very drained after the interview and mentioned several times during the interview how frustrated he was with his lack of energy. He has his own workshop and is a very practical man, he loves cooking and was looking forward to taking up his hobbies again. His wife was at home during the interview, but she remained in the lounge. He was also very concerned about his wife because she was unwell and he was unable to drive, which was putting a lot of strain on his wife.

4.3.13 Harry

Harry is 75 years old. He is married and his wife was out shopping, as he stated trying to buy something that would appeal to his appetite. He was five weeks post surgery and was being assessed for chemotherapy. He felt very angry that his operation was rescheduled because he was diagnosed with diabetes, just before his first operation and was told his blood sugars needed to be controlled before he could have surgery. He found this all very confusing and all his medications were changed which he could not understand.

4.4 Interpretive themes

The interpretive themes identified from the interview data identified six major themes that represent the experiences of food and weight loss in patients with operable pancreatic cancer patients before and after surgical intervention. In accordance with the methodology adopted in this research, which was discussed in chapter 3, data analysis methods were developed from phenomenological and hermeneutic principles to interpret the data. The aim of hermeneutic analysis was to determine what the experience meant for the participants, who had had the experience and were therefore able to give a detailed description of it, as discussed in chapter 3, this was guided by Van Manen (1994). Hermeneutics added the interpretive element to clarify meanings and assumptions in the participants' texts that participants themselves may have difficulty in articulating (Crotty, 1998). Communication and language are intertwined and hermeneutics offered a way of understanding human experiences captured through language (Van Manen, 1994).

The interpretive themes identified from the significant statements from the interview data, identified six major themes that are representative of the participants' journey of experiences before, during and after surgical intervention for pancreatic cancer:

Theme 1: Recovery from cachexia
Theme 2: Adaptation and surgical effects on oral intake
Theme 3: Experiences of nutritional support interventions
Theme 4: Dietary counselling
Theme 5: Dietary information
Theme 6: The road to recovery post surgery

4.5 THEME 1: RECOVERY FROM CACHEXIA

This theme highlights the participants' experiences of recovering from cachexia, as a result of having pancreatic cancer. The participants' experiences of recovery from cachexia will be discussed in terms of a number of sub themes, which were developed from a reflection of the significant statements extracted from the interview data. Weight loss was found to cause a number of psychological effects for the participants and will be discussed under the sub-themes; visible weight loss, physical weakness, concerns about oral intake in relation to weight gain after surgery and weight gain after surgery.

All the participants experienced weight loss, at some point during their surgical intervention for pancreatic cancer. Some participants experienced very little weight loss prior to their surgery, but others had very noticeable weight loss prior to their surgery. Participants estimated how much weight they had lost, since their diagnosis of pancreatic cancer and twelve participants were able to give a precise measurement in either stones or kilograms, of their current weight and their pre-diagnosis weight:

Um, I lost, um I think, I went in at just over eleven and a half and I came out at, I think at the lowest I was about nine stone. Just over nine (Anthony, pg.2))

Er, well I was just under fourteen stone before all this started and I'm now eleven stone seven, eight. So, er two and a half stone …..overall, er it dropped a little lower that that, I think it got down to eleven five before er just a few days ago. Something, like that a week ago. (Malcolm, pg.8)

The accounts above illustrate how participants were aware of how much weight they had lost because of their pancreatic cancer and their ‘wasted’ appearance throughout their cancer journey that was associated with cachexia, which was a major source of stress and anxiety for all the participants.

4.5.1 Visible weight loss

Only, one of the participants described how they had not felt the need to use the scales, because the visual appearance of cachexia meant that an accurate weight using scales was not essential. Significant weight loss was seen in the participants’ physical appearance:

I don’t know because I never weighed meself [myself], but it was a lot because I went bony, you could feel, I went hollow, sort of, I got very loose skin, sort of thing, I don’t know, I never weighed meself [myself] sort of before or after it’s sort of something, you know I just didn’t do sort of thing even though I’ve got scales, but um I don’t know I’d say about maybe 3 stone, about 2 and a half something like that I’m just guessing though, um I’m just guessing. (Tracey, pg.3)

The above extract from Tracey gives a very candid description of her weight loss and how her physical appearance was changed by cachexia. She felt there was no point in weighing herself on the scales, because this would increase her anxiety and stress about her physical appearance and she could visually see the weight loss.

Visible weight loss was seen as undesirable and their new body image was not a welcome sight in the mirror:

Yeah and me skins gone so emaciated yeah it’s sounds awful doesn’t but you know when you see these old ladies in, I mean I used to see them everyday on my job, they’ve got no bottom but they’ve got folds of hanging skin, where their muscles gone, well, that’s how I look and I think oh my god, you know. (Sandra, pg.8)

The above extract from Sandra relates her physical appearance to that of elderly ladies that she has previously worked with in the community. She finds her new body image both distressing and a cause of personal embarrassment. The visual appearance of cachexia for participants had both physical and psychological consequences, which appeared to be interconnected.

4.5.2 Physical weakness

Participants described feelings of frustration at feeling weak, a loss of independence and restricted activity due to their weight loss, but thought that eventual regaining of weight would become a sign of increasing health and recovery:

Yep, long and winding road, but it'll be alright in a bit, but like I say as long as me appetite comes back and that I can put a few pounds on, I won't bother. I mean I did want to lose some weight, but not the way I've done. I mean before when I was in that jaundice place I lost about ough I lost about half a stone in about 2 week, it just seemed to drop off me. I mean I've hardly any muscles [looking at thighs] you know it's…… you know I mean I'm used to walking you see, with not driving we used to walk down into town do shopping and then get bus back up. At one time I'd walk up, but they, they got too heavy for me walking up, so just for finish get on bus. (Harry, pg.16)

The example of Harry alludes to his frustration at his lack of appetite and hopes that when it returns he will regain his physical strength. Participants were worried about the amount of weight they had lost and felt this increased their levels of anxiety and stress and felt uncertain about their future. Participants were used to being active and participants had concerns that their weight loss would continue to impact on their everyday activities.

4.5.3 Concerns about oral intake in relation to weight gain

Participants acknowledged that having a diagnosis of cancer meant that they were likely to lose weight and felt it was an unavoidable consequence of having pancreatic cancer. However, they felt that after surgery, they would be able to regain their weight loss and take control of their eating habits to help improve their weight. Participants acknowledged the importance of dietary intake in relation to declining weight and the importance of eating enough to recover from the surgery and this was reflected by a struggle for self-preservation:

I'm not daft, I know that you know really what I do eat ain't gonna keep a sparrow alive really, you know, so it is a worry. (Sandra, pg15)

The excerpt above from Sandra confirms that the struggle to eat has become a purposeful act to keep her alive. Her oral intake is so small that she is constantly worrying about how much she is able to manage in relation to her declining weight. Participants acknowledged the role of food and the importance of maintaining a good dietary intake in relation to their declining weight and knew that their decreased oral intake was not enough to improve their weight.

For many of the participants monitoring their weight on a daily basis, was a habit pre-illness that continued after surgery as they tried to make sense of their weight loss. Gaining weight after surgery was seen as an indicator of how successful the treatment had been and the patients' continued success at recovery:

Err, yes err well I didn't realise just what I had lost until I came home, I'd been about eleven and a half stone and I went down to about 10 stone, um but then I 'm now 10 stone, well I was 10 stone 4 this morning, but I was about 10 stone 2 and I seem to whatever I ate because I was eating 3 meals of only limited food that I fancied and could eat. Err, I found that I was sticking more or less to the same, I'd leave it a few days and weigh myself again and I'd still be 10 stone 2, or 10 stone 3, now this morning and the previous time I weighed myself a few days ago I was 10 stone 4, because I think I am eating gradually a bit more. (Enid, pg.3)

This example from Enid, confirms that participants were constantly weighing themselves to try and see an improvement in their weight after surgery. Participants remained hopeful that when they next weighed themselves it might have improved, which was seen as a positive sign of recovering from the surgery.

4.5.4 Weight gain after surgical intervention

Some participants, who had previously been overweight and had a higher than recommended BMI, prior to their diagnosis of cancer, felt less concerned or anxious about their weight loss due to their illness. In fact, they found this to be a very positive side-effect of having cancer and commented on the health benefits of losing weight:

I felt better than I had done for years, because of the loss of weight and I've managed to keep it off. But it's a bit of a battle, but I I keep it off and I feel so much better it's unbelievable you know, because of that. Um, I do exercise, I exercise by dog walking, but I have specific hills I go up and now I don't puff up the damn things like I used to do [laughing] and I did it and I've it done for years, but they were err exhausting but not now and I manage it very well and I don't want to gain that weight back. But, it tends to go up a bit you know if I don't watch it. (Bernard, pg.2)

This extract from Bernard expresses his relief at losing weight and how much better it has made him feel. Participants reported experiencing health benefits from losing the weight after surgery and no longer felt physically out of breath or exhausted when they tried to do some exercise. They were also very conscience about trying to maintain a healthy weight and not regaining the weight, because it might cause further health problems.

4.6 THEME 2: ADAPTATION AND SURGICAL EFFECTS ON ORAL INTAKE

This theme highlights the participants' experiences of adapting to a different way of eating after surgery, due to their changed physiology. The participants' experiences of adapting to the surgical effects on their oral intake will be discussed in terms of a number of sub themes, which were developed from a reflection of the significant statements extracted from the interview data. These are; lack of appetite after surgery, taste changes after surgery, early satiety and adapting to smaller portions and participants' developed coping strategies to eat whilst in hospital. Often these sub themes overlap and are interrelated:

4.6.1 Lack of appetite after surgery

Most participants still managed to maintain a fairly good appetite prior to their surgery, even though they felt it had diminished because of problems with nausea. After surgery, even through participants were still experiencing problems with nausea and vomiting, they described having a reduced appetite and the will and desire to eat diminished or vanished completely, in comparison to their appetite pre-surgery:

I keep having these periods up and down and I think until I get a bit stronger, you know, I think I will do. You know I can sit here now talking to you and I can feel absolutely ravenous at eating and half an hour after, I just don't feel as though I want anything to eat. (Harry, pg12)

The account above from Harry illustrates how participants were dreaming about food and wanting to eat and then without warning their appetite has disappeared or vanished completely.

4.6.2 Taste changes after surgery

Most participants found that prior to their surgery, they had no problems with the way that food and drink tasted. However, after surgery participants commonly experienced changes in the way that food and drinks tasted. These changes varied from no taste at all to unpleasant tastes in the mouth and because previously enjoyed favourite foods no longer tasted, as they should, there was a feeling of disappointment and the will and desire to eat food diminished or vanished completely. Mealtimes were no longer something that was looked forward to:

And she'd cut the bread, very thin and put lemon and pepper on it and bring it in nah, not right. Then I'd say um so and so said I ought to be eating ice cream bring me some ice cream and so she brought some ice cream and I took that out and that's revolting. And then I said er, bring me some biscuits in, you know chocolate biscuits, HobNobs, plain biscuits, not interested, once I got them and so it went on. And I'd say bring me some Ribena in, instead of water it tasted disgusting. Um some Robinsons Barley water it was awful, some Robinson's Orange drink terrible. So those went straight home, so no totally up in the air taste buds, umm. (Anthony, pg.4)

As is evident from Anthony's statement above, participants were doing their best to try and eat while they could not taste anything. Anthony had asked his wife to bring him in some food from home while he was in hospital and requested his favourite foods. He rejected all the food brought in for him, even though his wife had carefully prepared the food.

Participants were concerned that food did not taste, as it should, it had not been explained this was a possible side effect after the surgery and how long it might take for their taste buds to return:

I don't know or whether it was just me not wanting to eat it I don't know, It just didn't it tasted, there was just a horrible taste to it was bland watery and um not nice at all, err and when I came home it didn't taste like that but it didn't taste right. (Tracey, pg.4)

For other participants it was trying to understand and make sense as to why food did not taste as it should, as alluded to by the example of Tracey, she could not explain what was wrong with the food, just that somehow it was not right.

4.6.3 Early satiety and adapting to smaller portions

Participants commonly cited early satiety and they indicated how they felt full on only small portions and how their portion size had severely reduced since the surgery. For some participants their reduced appetite was a source of concern and they found it distressing and frustrating:

Um, I find it frustrating to begin with because I quite like my food, so then I just had to um adjust to um well I immediately learned that if I eat too much then I don't fill very comfortable so then I thought well, I'll eat a little bit less and keep half of a normal portion for later on or prepare something so then I've got something positive to look forward to, so err yeah, I'm having this now but later I could have this much, so um and being at home and not back in work then it's is easy, I'm not quite sure maybe it's gonna address itself by the time I go back to work, but at the moment being at home is just easy and then there's always something nice in the fridge. (Dawn, pg.9)

The example from Dawn conveys the frustration felt by participants when they had to eat smaller portions. This was a big lifestyle change, which participants felt they could cope with when they were at home, but for those who were still working and hoping to go back to work, it was a concern and a nagging worry.

Adapting to physiological changes after surgery, entailed learning new limits of what and how much could be eaten, and signs of nausea and vomiting, were indicators of satiety:

Rather than and also of course because if you have a full meal and everything else, well you feel full, um and I'd prefer not to do that because, when at the present time when I am full I know I am full and you've pushed it too far. Um, so you know you've probably had seconds of desert or something stupid, um so yes you know then that you have a problem, err and I do have a problem if that happens. (Barry, pg.6)

The except above from Barry discusses his experiences of trying to eat too much and then having symptoms of nausea and vomiting because he had tried to eat a normal meal, which he would have quite easily managed before his surgery. Participants expressed concerns about knowing the limits of what they could eat before it caused unwanted symptoms of nausea and vomiting.

Early satiety was common and an unusual feeling for some participants:

Yeah, it's almost like you're you're stomachs trying to expand and there's no limit for it to expand to, is probably the easiest way of trying to describe it (Barry, pg.6).

Barry describes the physical limits that his stomach could expand to and also commented that it was like having his own gastric band. Participants experienced feeling full very quickly and had to adapt to this new feeling of early satiety.

Eating problems of adapting to smaller portions and the amount of oral intake participants could eat after surgery, caused changes to participants' daily lives:

Oh, yes, yes, er I'm on very small portion sizes. Er, my wife commented it was like feeding a toddler, so um they are getting bigger, but I um if anything having to restrain myself I'm finding. I feel I could eat more, but then I suffer for it, so um I'm trying to be sensible and I'm trying to er we're trying to get a regime of something to eat every couple of hours. Um, with a snack between meals, but er it doesn't always work out like that. Um, in fact this week it hasn't. It's been er really three or four meals. Or three meals and a snack er headache. (Malcolm, 12)

Malcolm illustrates an example of how participants changed their eating habits, he discusses concerns made by his wife about his reduced portion sizes. Participants reflected on how they thought they could eat more, but knew they would suffer the consequences of overeating. Participants reported making changes to their eating routines and the confusion this caused to their daily lives.

Some participants were very distressed about their eating capabilities and described how the amount they could physically consume, even a simple meal, was very slowly improving:

You know, but now the next time I have it, I'll have a toast and a half, so it is moving up and it's like the last time I had me chicken noodles I ate all them and I think you know I could eat a bit more of them. So now I know that probably a third more I could eat of them so it is moving up, cos I wasn't totally satisfied with em the other night. So I know me [my] hunger, it's moving up a little bit, slowly but surely. (Sandra, pg.20)

The statement above from Sandra refers to her trying to take control over what she can physically consume, so that she can see an improvement in her oral intake. Participants were used to being in control of their oral intake and found it frustrating when their day to day improvement was so minimal. They also felt that this added to their psychological distress about their weight loss, because they were not physically in control of how much they could eat.

Participants often mentioned having smaller portions and a dramatically reduced appetite was very concerning and distressing, especially knowing that some foods would be difficult to digest. Also not knowing which types of foods could be digested after surgery was also very worrying:

But, you're bodies telling you, you can't eat that much and you can only eat certain foods because, nothing'll [nothing will] digest and I'm constantly thinking and me daughters are what they can give me, because even I know a bit of pasta, a bit of rice and a bit of weetabix ain't going to give me a load of energy, nutrition wise (Sandra, pg.9).

The symbolic importance of food was acknowledged and as conveyed by Sandra, in the excerpt above. Her poor oral intake was a source of distress and concern, for both her and her family. Participants reported family members struggled to accept their loved ones diminished oral intake and found this very distressing.

4.6.4 Participants developed coping strategies to eat whilst in hospital

Some participants reported they developed strategies to help them cope with their eating problems whilst in hospital. They felt this was mainly due to the way the food was delivered and served in the hospital, with three course meals being served all together on the same tray and having very little control over the portion size on the plates. Also being in a hospital environment meant seeing others eat and some participants found this also contributed to their poor oral intake:

And the whole idea of eating really um put me right off. I'd see the others eating you know and that was enough to put me off. It got to at one stage that I'd even close the damn curtains so I couldn't see them eating, it was because, it was you know it was so bad. I don't know what the reason nobody ever said, the reason why I felt like that. (Bernard, pg.5)

The account above from Bernard, illustrates some of the coping mechanisms developed by the participants in hospital, when they had little or no appetite. Bernard also alludes to his frustration as a result of his altered appetite, but felt that no explanation had been given as to why he should be feeling that way.

Participants were determined to carry on eating with little or no appetite, especially whilst they were still in hospital. They developed different strategies for trying to eat when they had no spontaneous desire for food:

Well, I ate, I made sure I ate something every time they brought it but it was only tiny and even then you know like they come round in the morning with trolley, "what would you like for breakfast" and everybody's chewing on toast, now I am a big toast and marmalade always have and I thought sod this I'm going to have toast this morning, I'm not going to have half a Weetabix. She put this toast down and I looked at it and I put it in me mouth and you know it was like she'd given me a piece of cardboard box. (Sandra, pg.15)

It was 2 spoonfuls that was it, I'd have 2 mouthfuls of a cup of tea, that was it, that was me breakfast and then they'd come round at dinner, whatever I'd ordered and it'd be like, I used to ask them for a teaspoon, a teaspoon of like say mash potato, a teaspoon of vegetable and then if it was like a chicken stew or chicken fricassee or whatever it were called this thingy, I'd have a teaspoon full of that and then that'd be me dinner, that was all I would eat in hospital same at teatime. (Beatrice, pg.5)

The accounts from Sandra and Beatrice illustrate the small amount of oral intake participants could manage after their surgery. Participants ordered food at each mealtime, but experienced difficulties with the texture of the food and had to be very specific about the amount of food they wanted on their plate.

Participants reported their appetite was being affected by nausea, the smell of food, because the meals were all cooked on the ward using a bulk trolley system, which meant that cooking smells pervaded the ward for longer than just mealtimes:

But, as far as some of the food was concerned, I can't, it's hard to imagine now, but it really, the very thought of it, used to make um sick, feel sick and they didn't seem to understand that, I I wasn't being wilful, you know. I like my food, I really do but um nothing wrong with hospital food it's not the Ritz but it's, but I couldn't eat anything really except, fruit and some of that sort of thing. (Bernard, pg.3)

Participants felt nauseated by the smell of food and as alluded to by the example from Bernard, participants felt sick at the though of having to eat something. Participants often found cold foods more palatable and acceptable.

No, you could of presented err the most delicious food anyway you liked and it would have been the same. The very thought of it made I just couldn't eat. I did force some down sometimes, I'd have a bit of toast or something like that, but it was really an effort of will. Cereal I'd have that a bit of cereal and milk, but I did it because they really wanted me to, not because I wanted it. I'd really rather of not had it and that's about and that lasted for a long time until I got home as well and I was still on the Fortisip um you know, to, err otherwise I really would of have virtually nothing to eat. I tried doing without it to see if it made me hungry, but it didn't. (Bernard, pg.4)

Participants experienced trying to force themselves to eat without an appetite and knew their oral intake was very poor. Bernard purposefully continued taking supplement drinks to increase his oral intake otherwise he knew he was eating virtually nothing.

Participants felt that there seemed to be little understanding by hospital staff regarding the distress associated with eating. This was exacerbated by the participants' dislike of what they perceived as unacceptable hospital food that tasted bland and lacked variety:

Well, nothing tasted really nice and I found that if it was something with chunks of meat in like if it was something that I ordered and I thought oh I might be able to eat that I found everything was very chewy and not terribly tender and err um if I had something minced like cottage pie, I'd only be able to eat 2 or 3 forks full and I'd think oh I can't eat anymore. (Enid, pg.9)

Thinking well I've got to eat something, err I tried the toast at breakfast and it was white bread always and when it was toasted it was just like cardboard and I thought oh I can't have toast, it's like cardboard, I always have wholemeal bread, even when I ordered err err sandwich as a main meal err it would say wholemeal or white bread, I would tick wholemeal and it would come as white bread. (Enid, pg.11)

And I'd say I ordered wholemeal and she'd say well we haven't got any, we've only got white bread, so and the white bread I used to find it stuck in my mouth I'd just chew it and couldn't get rid of it, so I stopped having sandwiches that was that. Sometimes, I had salad in which case I would eat the ham or the chicken and eat a little bit of the salad and perhaps eat the tomato, um but I found it very hard to find things to eat that I thinking well I could eat that. (Enid, pg.12)

Participants experienced difficulties in finding which food to choose from the hospital menu that might taste as they thought it should do. The examples from Enid convey her attempts at trying various different foods with little success.

Participants asked family members to bring in food from home, in an attempt to eat something tasty and nutritious, however, not all home cooked food was successful:

Yeah, me daughter brought me in a lamb dinner one day, um with carrot and swede and mashed potatoes, only on a small plate but I ate about half of if, but I just wasn't enjoying food, you know it was, whether it was the hospital food or food that me [my] family brought I wasn't enjoying, food so it was a waste of time, to be honest. (Beatrice, pg.8)

The example from Beatrice above conveys the disappointment felt by participants when they had asked family members to bring food from home.

Participants described feelings of frustration at upsetting relatives, when they had gone to the trouble of deciding what the participant should be able to eat:

Yeah, and it's not that I'm being nasty and then I've got the fear of what I've chosen or what they've chosen is going to upset me stomach, because I've gone like everybody else who had the operation like me, they've gone through that much pain and sickness, you want it to end and not come back and sometimes you think, ow you know and it can be really really frustrating and it is and food is the worse thing it is the worse worse thing that frustrates me. It really really is. So when anybody comes in and they try and thingy let me decide it's my stomach I've got to decide nobody else can decide for me. (Sandra, pg. 12)

The above extract helps to display the distinct difference between participants and family members with regard to their understanding of their loved ones frustration and fear at eating. As expressed in the extract from Sandra, it is her that has had the surgery and she has gone through a lot of pain and discomfort and wants to be able to decide for herself how much she can eat.

4.7 THEME 3: EXPERIENCES OF NUTRITIONAL SUPPORT INTERVENTIONS

Patients with operable pancreatic cancer require nutritional support interventions following surgery, in the form of enteral or parenteral nutrition to prevent postoperative complications and provide energy when patients are unable to eat and drink. The standard protocol at the study site is enteral feeding unless parenteral nutrition is indicated. In addition, oral dietary nutritional supplement drinks are usually required to provide additional calories and supplement the patients' oral intake. Some participants were prescribed the supplement drinks prior to their surgery to supplement their oral intake, whilst others did not require them until after their surgery. The participants' experiences of nutritional support will be discussed in terms of a number of sub themes, which were developed from a consideration of the significant statements in the interview data. These are; enteral feeding, parenteral nutrition and nutritional supplement drinks.

4.7.1 Enteral feeding

Most participants disliked being enterally fed after surgery and having a nasogastric tube in place. Some felt their appetite would be better if they were not getting extra calories from the feed:

Err, but about a week before I left hospital, I was probably off the drip. I didn't like that either, I kept saying stop that, if you stop that I might get an appetite, but I don't think it would of done. (Bernard, pg. 10)

The example above from Bernard expresses dislike at being enterally fed and participants felt that their appetite would be better without the additional calories they received from the feed. This suggests a lack of information and advice about the importance of enteral feeding after surgery.

Others felt if would stop them feeing nauseous or physically being sick:

Is it the one up your nose, no aw it was there and it was horrible and it kept making me sick, cos [because] every time I could feel it at the back of me throat and I was heaving and there was nothing to come up and aw it was begging um to take it out, err they would keep on saying err maybe 3 days, 4 days or something and [surgeon's name] come came round and I said please can I, and he said [patient 3] yes we'll take it out, I said will you do it now please, so he did it there and then he took it out, because it was really and if they hadn't of done I think I probably would of done it meself [myself], cos [because]I couldn't stand it anymore. (Tracey, pg.4)

Participants struggled with the feeling of the nasogastric tube at the back of their throat, as confirmed by Tracey. They felt it contributed to them feeling nauseous or vomiting and had to resort to begging to have the tube removed.

Participants described feelings of frustration at trying to eat in hospital, with nasogastric tubes in place after surgery and they felt a lack of concern from hospital staff when they were trying to eat and were not offered any help with eating:

And one thing I couldn't get, they said we want you to start eating now, right, well you can't bloody well see where you're putting the spoon or anything thing because of that and you're trying to have a drink, come on we want you to have more fluid, you can't cos [because] of the blinking tube, you know. (Sandra, pg.12)

Yes, when I woke up I'd got a tube up my nose and I was fed by the tube I was given, oxygen had an oxygen mask on and even afterwards when, they started to feed me and say have some normal food, I used to have trouble finding my mouth because I'd got all these tubes round my mouth and I used to say well can you feed me because I can't find where my mouth is, even though I didn't want the food anyway. (Enid, pg.7)

The examples of excerpts from Sandra and Enid convey feeling of frustration at trying to eat after surgery with lots of different tubes in situ. The apparent lack of concern or help from hospital staff as expressed above, was not seen as giving them encouragement to try and eat.

Others felt a return to normality once the tube had been removed:

Well yeah, I felt err, I felt great and err you know once I'd. I remember once I'd got rid of all the tubes, the um [pointing on body] that was the last to go and the feeding thing, and once I got rid of that, really within a week I was back on form. I probably wasn't really back on form, but I felt great, um. (Dawn, pg.3)

The above exact from Dawn confirms that participants felt relieved when the feeding tube was removed and that their oral intake improved once the tube had been removed.

4.7.2 Parenteral Nutrition

Three participants required parenteral nutrition after surgery. This is not the standard route of feeding for post –operative patients at the study site and would have been the decision of the surgeon. The participants who were fed parenteral nutrition did not know exactly what it was, they realised it was a form of liquid food:

I mean they had me on this can can can [cannula] um, what do you call them, I had a row of thingies that went in here err and they sort of keep filling them up with milkshake deals and all the rest of it or whatever they call them. To me they looked like milkshake, um err basically to get food in to me err whilst on was on all these pipes. (Barry, pg.9)

Barry required parenteral feeing after his surgery he referred to it as milkshake, although he knew it was a way to get food into him he had not asked what it was.

Err, it's the easiest way for me to describe it because I've no idea what it was it was just sort of put there and fed down there um, I tend to let them get on with it rather than ask them too many questions [laughing]. (Barry, pg. 7)

Participants seemed to take the attitude, as alluded to in the excerpt from Barry that the hospital staff knew what they were doing, and they were quite happy to let them get on with it.

4.7.3 Nutritional supplement drinks

Participants were prescribed oral nutritional protein and energy supplement drinks to try and improve their oral intake after surgery. The supplements drinks were either in the form of 'milk based' or 'juice based' drinks. Each participant was prescribed between one and three cartons of the supplement drinks per day, depending on their nutritional requirements, these are usually prescribed by the dietitian. Most participants found the supplement drinks sickly and developed strategies to try and drink them quickly:

I had a Fortijuice in [hospital name] and I er couldn't get on with it at all. Partly, cos[because] it was warm and partly because, um it wasn't for me. And, I'm not really keen on the Fortisips, the er only ones I managed are the vanilla ones and I've struggled with one or two of those it's the only time I think, that I've er been sick. (Malcolm, pg.6)

Malcolm describes trying to drink a warm supplement drink, when he was in hospital that made him nauseous and vomit. He has since tried the milky supplement drinks, but he still finds these sickly.

And I used to drink them because, with a straw it used to take too long and I used to think ow let me get it down straight away and at least that's one and I'd tick it off in my little book, that I'd had one, but I never looked forward to it and it always made me feel a little bit queasy afterwards. Not pleasant at all. If I'd of been able to have the plain ones or the vanilla that I could mix in with things, but they sent all the wrong ones, all the fruity ones and about 3 or 4 plain and um I've still got them upstairs, I don't know what the heck to do with them because they're not pleasant at all, make you feel sickly. (Daisy, pg.18)

Daisy has another method of coping with the supplement drinks, she would drink them very quickly even though they made her feel a bit 'queasy', and tick them off in her little book. She also preferred certain flavours and felt she would have been able to cope with them better had she been prescribed all the flavours she liked.

I think I preferred of them all banana, though I'd have anything that was going, I didn't really mind what it was, because I didn't I hardly tasted it really. I just as I say gulped it down and then had a drink of water. I didn't enjoy them but they were easy to get rid of that was the main thing. (Bernard, pg.7)

Bernard used similar coping mechanisms to drink the supplement drinks, because he knew he needed to take them, but really disliked the taste and aftertaste in his mouth.

Some participants disliked the consistency of the supplement drinks and found this very off putting straight away and did not even manage to try the drinks before they were thrown away:

Then when she give me these Fortijuice and I'm pouring it out and I thought oh my god it's syrup and I just poured it straight down the sink. (Sandra, pg.17)

Sandra describes the juice based supplements as syrup and she stated that she cannot cope with anything ‘gloopy’, the consistency of the drink was horrifying to her and she threw it straight down the sink.

Some participants preferred certain flavours but reported the wards often ran out and they had no choice of flavours:

Um, I did like the orange the best, there was orange, apple and blackcurrant and I did like the orange the best, but I didn’t really mind the apple or the blackcurrant, if very often they hadn’t got a choice, sometimes they hadn’t even got them and they’d say we haven’t got any but we’re getting some, um but orange was my favourite really. (Dennis, pg.4)

Dennis liked taking the supplement drinks, he had certain flavours that he preferred and was disappointed when the supply on the ward ran out. He often had to remind staff that his supplement drink was due and felt frustrated when staff, were not able to offer the drinks, because he knew it was supplementing his oral intake.

Although participants struggled to drink the nutritional supplements drinks, they knew they were helping to improve their oral intake and give them the extra calories they needed, especially while they were still in hospital and eating very little:

Yes, yes I did, because I realised that otherwise, I really wasn’t eating enough. I didn’t mind losing the weight, but I I could hear the dietitians nagging in the background, you know [laughing] and I though if I lose too much they’ll be doing something about it, so I did, I did err I knew I wasn’t eating enough so I took them as well, just to keep things. There were some days worse than others. There were sometimes I couldn’t face food so I’d have 3 of the damn things that day. (Bernard, pg.10)

Bernard felt pressured into taking the supplements drinks, because he was afraid that if he did not take them, then his weight would drop and the dietitians might start tube feeding him again. Although his appetite remained poor he would have the supplement drinks instead, for some peace and quiet.

Erm, well, fairly early on in hospital because I wasn't eating much, they said you must have these and they wanted me, I didn't always get 3 a day but I always had at least 2 and err they used to say you must have this because it has calories in it and um at first I didn't mind them, I didn't like the milkshakes ones, the Fortisips so much as the juice ones, but I got in the end that even the juice ones I used to think ow I've got to have 2 of those or 3 of those and I just used to think ow I can't face it, so. (Harry, pg.10)

Harry started taking the supplements after surgery due to his poor appetite, he managed them at first because it had been explained to him that taking them would provide extra calories. After a while of taking them he found that even the previously liked 'juice ones' were something that he found hard to stomach, when he knew he had to take 2 or 3 during the day.

Some participants felt the benefit of nutritional supplement drinks once they where discharged home and continued taking them for at least six weeks after surgery:

Well it was, it was a gradually improvement it wasn't sudden. It was a gradually improvement and I would say again it was about six weeks, before I was, I could really put the Fortisip away. I've got a lot of them you know from the um, from the chemist they were very good, but um I would say it was about six weeks before I could put them away and forget them and start eating again. (Bernard, pg.5)

Bernard explains his appetite improved gradually, but he continued to take the supplement drinks knowing that they were helping him to continually improve.

Participants had very different experiences with taking nutritional supplement drinks. The lack of choice of flavours and different consistencies of the oral nutritional supplement drinks led participants to dislike them or throw them away before they had even tried them. Participants seemed to have more success in taking the supplements drinks when they were discharged home.

4.8 THEME 4: DIETARY COUNSELLING

This theme highlights the participants' experiences and perceptions of the dietary counselling they received whilst in hospital, specifically from the dietitian. Dietary counselling is an assessment of the participants' nutritional status and help to identify if the patient is likely to benefit from nutritional support. The dietitian will calculate the individual patients' nutritional requirements, as a baseline against which nutritional management can be monitored. The dietitian then provides the individual patient with specific advice to help them improve their oral intake. These experiences will be discussed under the main theme that was developed from a consideration of the significant statements in the interview data.

Participants in this study reported various experiences of being provided with individual dietetic input and dietary counselling, encouragement to help improve their nutritional intake, whilst they were in hospital. Some participants reported seeing the dietitian a lot and felt they had been given a lot of attention and advice whilst they were in hospital:

Oh yes they paid great attention and I used to dread her [dietitian] coming, because one of the, I didn't seem to be able to get through, but one of the things, I I dreaded most about hospital, was mealtimes, because they were there at me all the time. The nurses were there and the diet, you know the nutrition's were there, and I really couldn't eat because it I really made me sick to think about it. I just could not eat and all I had were these um I can't remember the name of them. Bottles of food err liquid food, are they called? (Bernard, pg.3)

The excerpt above from Bernard, describes how he felt about his experiences of dietetic input from both nursing staff and dietitians. Bernard struggled with his appetite after surgery and felt both the nursing staff and the dietitians were paying him far too much attention and even describes dreading the thought of mealtimes, because he felt a constant pressure to try and eat.

Dawn had a very different experience, although she saw the dietitian regularly, she did not feel a constant pressure to try and eat, in fact she felt that she had been given a lot of helpful advice and information.

Err, yes I've seen the dietitian prior to the surgery, after the surgery, I think she came almost every day, especially um when I, went off being fed to um feeding myself independently, err she [cough] she gave me some um err advice and some leaflets, um and then when I went to [hospital name] I've seen a dietitian there. (Dawn, pg.6)

Participants wanted the support from healthcare professionals, with the knowledge to help them, but they did not want to feel they were in an environment totally focussed on food. The perceived effect was seen as harassing and not encouraging.

4.8.1 Lack of dietetic counselling

Five participants felt that they had definitely not seen a dietitian whilst they were in hospital, however two of these five participants after reflection felt that they not really sure and could not remember if it was a dietitian that had talked to them about their dietary intake:

From a dietitian point of view we've not received anything really, whether anyone's sort of said you shouldn't have this or you shouldn't have that, um and I am very fortunate that I have err an excellent dietitian over the road here [laughing] who keeps me under control and she says yes you can have this and yes you can have that, it 's not often [wife's name] turns round and says no you can't have it err I don't really remember the last time we did that or perhaps after the surgery it was when I came home it was no it's too soon, you just keep to a simple diet at the moment.

(Barry, pg.14)

The example from Barry above expresses the lack of dietetic input he received whilst in hospital but refers to his wife as a dietitian, who controls his diet. He felt that, it was due to her common sense by keeping to a simple diet and not trying the wrong types of food after surgery, this meant Barry had not suffered too many ill effects after the surgery.

No, um they said I was going to see one, but no I didn't, I never ended up seeing the dietitian. Can I just [to husband in back room] did I see a dietitian, um I didn't did I, no no [husband not that I remember] I didn't think I did I remember em saying about one but I never got, I never saw one so. (Tracey, pg.9)

Tracey seemed to be unsure if she had seen a dietitian and had to confirm with her husband whether she received any advice or not. Participants remembered seeing a lot of other healthcare professionals, but it was often the dietitian that they could not remember seeing.

Whilst others reported they had seen the dietitian very early after surgery, but had not been given advice for home and were concerned about going home without information:

Um, yes but not very early on, I feel, I haven't, I don't think I've written it down no I haven't cos [because] I've written the name of the dietitian down for err when I'd come home, but I think I saw her just the once and it feels to me as though it was in my last few days before I came home cos [because] I seem to remember asking the sister, "The dietitian will be coming won't she, she will be coming?" That wasn't the last day, but it was me in my usual frame of mind thinking I don't want to go home with no advice, so I'd been told that I could get these Fortijuices and things but I just felt I needed a bit more help. (Pauline, pg.4)

The excerpt above from Pauline expresses her concerns about only seeing the dietitian once and felt that a lack of information had been given to her to go home with. Other participants who were prescribed supplement drinks to continue taking once they had been discharged home, also alluded to these concerns. Participants also found it worrying that a lack of detailed dietary advice had been provided after surgery and were concerned about going home with so little information.

4.9 THEME 5: DIETARY INFORMATION

This theme highlights the participants' perceptions and experiences of the non-specific verbal and written information they received after surgical intervention for their pancreatic cancer. All the participants described the amount of information they had received, whether this was non- specific verbal information from various healthcare professionals, including the dietitian, nurses and healthcare assistants, to tailored individual information usually from the dietitian. These experiences will be discussed under the main theme that was developed from a consideration of the significant statements in the interview data.

Participants reported differing experiences of how much information they had been given and only received verbal information from nursing staff and healthcare assistants. However, some participants were given written dietary information from the dietitian, which they appreciated and felt they were given appropriate suggestions of what to eat and drink:

So there was advice also about having food on a um smaller plate which was good and err I remember that was helpful to [husbands name] because I think he would have worried if he'd seen a very large plate with a little bit of food on, um and also um it was helpful to know that it was going to be quite demanding err to eat food because um, I would sort of get to the end of a main course and just a small amount and then I would just have to go and have my afternoon rest, because I was just completely exhausted so um I mean when my cousin was there, she um came sort of once a week um and when err [husbands name] was doing a meal for me, it just became the pattern and we just accepted you know that it was just taking so much of my bodily strength to digest that was the only way to handle, it so I did. (Pauline, pg.5)

The example from Pauline above suggests that the written information received in the form of a diet sheet after surgery, was both useful and helpful. Participants felt it was a relief for family members to know how much they could eat, because otherwise they would have been very anxious about their loved ones small portions. Participants accepted that a change in meal pattern was the only way they would recover from the surgery.

For others the verbal information they were given was very limited and not helpful at all:

Um, and basically the advice I got was eat as much as you can and put as much weight on as you can. Cos [because], you will need to cos [because] you've lost a lot of, because of surgery. Um, so yes I saw a dietitian. (Malcolm, pg.8)

The excerpt above from Malcolm showed his perception of the advice. His understanding of the advice was to build himself up as quickly as possible by eating lots of food and this would help him to try and regain the weight that he had lost after surgery. This apparent lack of information undermined participants' confidence in the healthcare professionals' knowledge and skills.

Various health care professionals, such as nurses and healthcare assistants gave dietary advice because participants were asking for advice before they were discharged home and had not seen the dietitian. Participants interpreted the advice in different ways and some found it confusing, which led to trial and error:

So when Monday come and I'm sent home, I hadn't seen nobody and I I walked in here with no information no nothing did I and it was only the staff nurse on the ward [name], who was on [ward name] that day, she said, she said "look just carry on when you go home with very very soft diet like you've been having here" you know she said " what you've been having, a little bit of rice, with a little bit of juice on, even even if it's the mildest curry or something like that, eat something like that, to be going on with" and she did say " a bit of pasta" and things like that, she says and um and she says because your Macmillan nurse will be in touch with you, she says and your dietitian.
(Sandra, pg.11)

Sandra experienced feeling at a total loss, when she was discharged home with no written information and only minimal verbal information of the type of diet she would be able to manage, at such an early stage after surgery. Participants reported requesting information before they were discharged home, but felt the information and advice given was not what they thought of as soft food and found this confusing.

Some participants found that the verbal information was not helpful, but was regarded as authoritarian and were not offered alternatives about how to boost their calories:

Yeah and it was all drink full cream milk, you know can't do that. "Well it's better for you", still can't do that, eearrr I'm a semi-skimmed girl you know what I mean.
(Sandra, pg.14)

Sandra portrays in the example above how she was told that having full cream milk would help to boost her oral intake, but felt frustrated that individual advice was not offered. Participants perceived this advice as not taking into account that everyone is individual and want to be treated as an individual. The advice was not found to be useful or helpful and further added to their anxiety about their poor oral intake.

Participants were given advice to ‘build up’ their diet but tried to follow advice too quickly and found they were unable to digest certain foods, which they had not been properly advised about:

Um, we made the mistake on first getting out of hospital, of trying to eat too much. Um, and er I obviously wasn’t digesting it properly um even with what I thought was enough Creon. Um, which wasn’t I think, um but if anything I found the advice, I tried to follow the advice, um and I ended up eating things, which were I think were too rich for me and too er no just too much of it. (Malcolm, pg.8)

The excerpt from Malcolm reflects on his perception of the dietary advice given to him. He found he was trying to eat too much, which was not digesting properly, even with pancreatic enzymes. He felt disappointed that the dietary advice and how much Creon (pancreatic enzyme) to take to enable him to fully digest his food was not fully explained and therefore caused unwanted symptoms of nausea and early satiety. This experience was also conveyed by other participants, who felt that a better explanation of exactly what could be eaten and digested after surgery, would have more useful

However, others who were given verbal information regarding eating a soft diet felt they were not given enough information or a lack of appropriate information, which lead to participants trying to use their common sense and perceptions of what soft food is:

Soft food to me is custard, mashed potato, rice pudding, things like this. When you get home, it’s very very different because you’re, OK in the morning you can have your cereal soft weetabix mushy weetabix, that’s soft food but it’s it’s like and soup at lunchtime and maybe mashed potato but you need something more than that and what is, at what point can you start to incorporate something that’s a little bit more, not solid food, like chunks of meat, but something, that’s a little bit firmer than mashed potatoes if you like and it was, it was just down to us really, We just sort of used our common sense and that was a concern because I knew I wanted to put weight on and I wanted to *start eating and we had a few hiccups, a few like two, three O'clock in the morning when I get up and go to the bathroom and be sick because I'd had something in the evening that maybe was a too rich for me but I wanted to start to eat, I mean I had a lasagne, I thought well that's soft you can you know, pasta, lasagne sheets and you know, but it was probably too rich for me, but it was soft food in my book, but maybe too much for me. (Daisy, pg.10)*

The example above helps to convey the perception of advice that participants were given about soft food and felt that a lack of progressive dietary advice was given, for example, when something more substantial could be incorporated into their diet. Daisy expresses concern and having to use her common sense, because she wanted to regain her weight after surgery, but feels that a lack of information meant it was up to her to decide when she would be ready to eat solid food.

Over half of the participants felt that a lack of detailed information was provided after surgery and they described using their own common sense regarding what to eat after surgery, which lead to a feeling of trial and error:

We had a pork chop one night, that caused me a lot of discomfort [daughter you only had the tiniest amount of that pork loin] but it it just won't go through and it sits there, so then when they turn round and say you start off with a soft diet you learn. Trial and error you think you're clever, but you learn, so now I've got to try and think, it's like someone says well mashed potatoes, well if anyone says mashed to me I'll go and buy mashed potatoes, very bland isn't. (Sandra, pg.7)

The extract above from Sandra, helps to convey the perception that participants experienced a lack of appropriate individual information. They felt the dietary advice given to them was not tailored to their specific needs, which led to trial and error. Although participants were advised to have soft food, they assumed that they would be able to digest something with more texture in their diet and not only eat bland mashed foods.

Also participants reported that a lack of consistent information from healthcare professionals led to trial and error:

We just used our common sense and sometimes it failed us really because, we thought we were doing the right thing and it turned out that perhaps it was a bit too rich for my stomach. (Daisy, pg.10)

Daisy is used as an example of the disappointment that participants felt at having to use their common sense to try and eat well after surgery to improve their oral intake. It was felt that this was the result of a lack of consistent information.

Participants felt that a lack of expert and informed dietary advice was given and wanted help from professionals who have the knowledge to help them:

You know, I'm no expert at all, I mean you need advice from people, you know to say this is what you need everyday and if that's the case I'll have it everyday. If they say you have to have Complan everyday then I'll have it everyday. I should be doing it now really, on my own back, but you know you think well where do I fit it in with all the other things, that I'm trying to eat, you know and I don't want to have it to near my evening meal because. OK I know there's nutrients in Complan and Build Up, but is it going to fill me up and I don't want to eat my meal, where I've got vegetables and um you know other things in. So it's just fitting it all in really. (Daisy, pg.19)

The excerpt from Daisy above conveys the feelings of frustration participants felt at not being able to access information from healthcare professionals with the skills and knowledge to help improve their nutritional status. It was a constant worry for participants who felt isolated at having to try and improve their nutritional intake without the benefit of professional advice.

The stigma attached to obesity, meant some participants did not wish to return to a pre-illness weight and were very reluctant to comply with a high calorie diet in order to re-gain weight:

I'd seen the dietitian before I had the operation and she'd said that I'd got to eat all these things, that to me were most unhealthy, were all fattening things, you know, doughnuts and all the things that I'd avoided to keep healthy and to keep me cholesterol down um there was a big list of them and it made me laugh because I thought good gracious you know, it said put extra butter on things and what not um, so I'd been given that list but um I mean it wasn't any help because I wasn't eating anyway really.
(Enid, pg.3)

Enid's example highlights the concern participants felt at being advised to eat unhealthy and fattening food. Participants had tried to follow a healthy lifestyle and avoided being overweight and obese and concerns about other co-morbidities meant participants were reluctant to follow this advice. Participants seemed shocked and horrified that what they perceived as unhealthy advice should be given by a healthcare professional.

Some participants were concerned with the high calorie advice given and were reluctant to follow this advice, even though they were struggling to maintain or increase their body weight. Three participants also had a diagnosis of diabetes and felt the high calorie/high fat advice conflicted the advice given by the diabetes nurse or dietitian. Other participants were reluctant to follow the advice because they had previously had a very healthy dietary regime and were very concerned about unhealthy eating versus cancer recurrence and causing other health problems:

I'm very conscience of, I don't have cream everything that we have is half fat, now maybe a dietitian would say to me if you want to put weight on then it's got to be full fat, there must be some happy medium because you shouldn't have full fat, nobody should have full fat should they really, well maybe I'm being a bit too self opinionated but I think fat in your diet is puts weight on of course it does, but it also does other things and I'd like to think that I can if it means that I've got to eat twice as much of half fat food that I'll eat twice as much of half fat food, you know, what I mean, than full fat cream and full fat milk and all these little recipes in the book for build up diet, there's lashings of butter and cream in your soup and things like this and I'm thinking I don't really want to, there must be another way of putting weight on without it just being purely fat, there must be. (Daisy, pg.9)

Participants wanted healthy eating advice to regain weight, as alluded to in the example given by Daisy. Participants expressed concerns about eating too much fat in their diet, especially saturated fats, because of the concerns about causing other health problems or the recurrence of cancer. The feeling of not being in control of ways to increase their weight through healthy eating habits added to their psychological distress, as they tried to increase their weight after surgical intervention.

Some participants totally changed their dietary intake post surgery and included all of the high calorie foods, even though they had previously followed a healthy diet:

Totally, I'm eating all the things that I've never eaten before. Um I didn't used to drink milk for example, um cream was unheard of in my diet, cheese very very rarely eaten, er um sweets I never ever ate. Sponge puddings never ever thought of, ice cream no, fruit cake no, biscuits no and I'm throwing them down me now to put the weight on. Yes, a total change of diet, yep. Normally my, as I said back from the gym, half past ten um five fruits, five or six fruits plates of fruit and that would be my breakfast. And a light lunch with a salad and evening meal at about half seven. But now I am trying to pile it on, yeah, yes, yes, umm anything that helps umm. (Anthony, pg.6)

The example used above from Anthony, describes how some participants wanted to completely follow the advice from the healthcare professional and regain their pre illness weight as quickly as possible. Even thought they had always followed a healthy diet the information given by a healthcare professional was seen to be the most appropriate to return to their normal lifestyle.

4.10 THEME 6: THE ROAD TO RECOVERY POST SURGERY

This theme highlights the participants' experiences and perceptions of recovering from operable pancreatic cancer. All the participants provided an insight into how they coped with this difficult period in their life and how this impacted on their lifestyle and quality of life. These experiences were developed from a consideration of the significant statements from the interview data. Participants described getting through this difficult period in their life, one day at a time and how it slowly seems to be improving. They knew they had to be strong to cope and survive:

And I come down one step at a time, for the first 5 days, now I can walk up, until I get to the last 3, then I have to hold on with both hands, that's when the energy goes and then that's it, that's me energy for the day, I'll be honest with you that is me energy gone then for the day I am shattered. It's like when you have a shower or a bath it saps, you wake up and you take your meds and you've fine you think, a new day and you go and get under the shower for 10 minutes and all of a sudden you're energy's just gone. (Sandra, pg.8)

The excerpt above from Sandra expresses how participants coped, from one day to the next, to continue with their daily activities and build up the strength to be strong and recover from the surgery.

Participants experienced a very rapid change to their quality of life, especially as most of the participants' had led quite an active life before the surgery:

And it's the no energy when you've been so active that's that is a killer, because you you still think you can do things and you know you can't, like when I first come of hospital I had to, they wanted the bed downstairs and I put a block on it I said no no um I knew I couldn't go out anywhere cos I wouldn't have the energy so the only exercise I have is walking in here, out of here and into the kitchen or going upstairs to bed. So the stairs was a challenge to me, yeah, I had to crawl up on all fours. (Sandra, pg.8)

The example from Sandra is used to emotionally describe the rapid transition from being fit and healthy, to having no energy to carry out daily activities. Other participants also expressed this and the change in their quality of life was found not only to be distressing but also challenging.

Participants were worried and concerned about trying to get on with their daily activities in life. They were concerned that by trying to do activities they were using up energy and were therefore not able to gain any weight, even though they felt their appetite was improving. They wanted more information to explain how to improve their current nutritional status to cope with recovery, so that it could stop concerning them:

And maybe doing, carrying on what I was doing anyway in walking and you know gardening and doing other things, I'd probably drained my body of whatever nutrients, I was getting I'd probably used them up through being active and doing things. That's concerned me as it does a little bit now, because I do eat well now and I have done for quite a while but I don't put any weight on and I think at the time when I'm eating and I'm thinking well um there's a lot of goodness in this, you know. Maybe it's the chemotherapy medication that I'm on, does that bump up your metabolism, I don't know there's nobody that can say, whether that sort of, if that's the case when I'm off the chemotherapy and it's out of my system, however long that takes then my my metabolism may slow down a little bit to enable me to put weight. (Daisy, pg.16)

The example used above of an excerpt from Daisy, highlights the many questions and concerns that participants had regarding their nutritional status and ways to try and improve it. Participants were trying to make sense of their continued lack of energy and ability to regain some of their pre illness weight after surgery, even though their nutritional intake had improved.

The return to preoperative or pre-illness weight and a return to a normal pattern of eating were seen as being on the road to recovery and participants felt happy to be alive and felt they could cope if they continued to improve and slowly got better and feel they were on the road to recovery:

I delighted to be alive, I'm delighted to be home. I'm delighted to be getting better um, and I'm just hoping I'll get back to where I was eventually, you know. Two or three months, so no I'm just happy to be as I am. (Anthony, pg.9)

Participants reported having a positive attitude and felt this helped them to fight and recover from something ‘nasty’ that had happened to them. Although, Anthony has been used as an example, all the participants expressed a feeling of joy that they had been given the chance to have surgery and hopefully eventually recover from it.

4.11 Summary

The purpose of this chapter was to introduce each of the participants in the study. A story of each participant has provided a background against which the journey of pancreatic cancer before and after surgical treatment has been experienced for each participant. The second part of this chapter used quotations from the participants’ transcripts, to interpret the meanings experienced by patients with operable pancreatic cancer before and after surgical intervention, as the goal of hermeneutic inquiry was to identify the participants’ meanings by combining the researcher’s understanding of the phenomenon, with participant generated information. The participants’ transcriptions provided an important description of a conscious experience and a reflective interpretation of the transcripts, by immersion in the data, enabled the researcher to achieve a fuller and more meaningful understanding of this phenomenon.

In the following chapter the findings from this study will be discussed in relation to the current literature.

Chapter 5: Discussion and Conclusion

Chapter 5: Discussion and Conclusion

5.1 Introduction

The previous chapter has discussed the findings from the nutritional experiences of pancreatic cancer patients undergoing surgical resection in this study. In this chapter, the following discussion will now position this study and its findings in relation to the review of the literature.

The original aim of this study was to gain insight into the views and experiences of patients with operable pancreatic cancer before and after surgical intervention and acquire a deeper understanding of how they managed their nutritional status during this period. The qualitative design and use of a hermeneutic phenomenological approach led to rich descriptions of the participants' experiences and enabled the identification of issues that were relevant and important to them.

5.2 Key findings

The key findings from this study indicate that the issues surrounding food and nutrition play an important role in the recovery of patients with operable pancreatic cancer before and after surgical intervention, not only in terms of its nutritional value, but also as an important quality of life issue. The experiences of the participants found that after surgery for their pancreatic cancer they continued to struggle with the physical and psychological effects of cachexia and weight loss. Although participants understood the importance of nutrition in the recovery process, more help and information was needed to enable them to recover from cachexia. Participants experienced a range of physical difficulties in adapting to their altered physiology after surgery and trying to maintain their nutritional status. These were often interrelated and prolonged problems, which will be discussed in the findings. Participants wanted better information to help them with their rehabilitation from the effects of the surgery as well as to alleviate some of their concerns regarding their nutritional status and improve their quality of life.

5.2.1 The physical and psychological effects of cachexia and weight loss

The findings in this study demonstrated that all the participants were affected by weight loss, therefore it was a particularly important issue to discuss with the participants because they were being actively treated for their cancer. Participants in this study were open and able to discuss the meaning of weight loss and what it meant to them. This highlights the difference between the palliative studies included in the critical literature review, where discussing weight loss with patients was seen as “taboo” (Hopkinson et al., 2006a). It was not found to be an important issue to discuss with patients with advanced cancer, at the end of life who were not actively being treated for their cancer (Poole and Froggatt, 2002). Participants in this study also noted their concerns over weight loss in relation to the effect this had, not only on their physical strength, but the psychological implications of weight loss were even more striking, this also mirrors findings of a study by Stamataki et al (2011). Weight loss was a source of concern for participants, especially when the weight loss was visible, this mirrors the results found in a previous study (Hopkinson et al., 2006a). As noted by Muir et al (2011) and Reid et al (2009) a continual monitoring of weight and not seeing an improvement, was seen as detrimental and a possible recurrence of disease, it has been associated with drawing closer to death. Participants in this study, who expressed fear and acknowledgement that food was needed for life, accepted that it was a struggle to eat enough to maintain their current nutritional status and not further threaten their life expectancy.

Holden (1991) reported that anorexia was of less concern to patients than family members. However both studies by Orrevall (Orrevall et al., 2005, Orrevall et al., 2004) found that when patients are in the final phases of disease, both patients and family members feared that an inadequate intake of food would lead to death by starvation. Participants in the current study also expressed concerns about their diminished oral intake, although they were not in the final stages of disease, but being actively treated for their cancer, they found this very distressing. Due to problems of nausea, changes in taste perceptions and being afraid of eating the wrong consistency of food, some of the participants reported managing minimal amounts and knew their nutritional intake was not good enough to improve their weight.

For other participants, in this study who could not control their weight loss uncertainty for the future grew, which also added to their psychological distress. Therefore, they reported seeking information about healthy eating and tried to change their eating habits and exercise behaviour as a way to regain control. Shragge et al (2007) has suggested that this kind of behaviour is the basic ‘social psychological process’ used by patients with cancer, who are trying to manage the emotional and social consequences of a declining intake. As found by Stamataki et al (2011) participants reported feeling anxious about not being able to control their weight issues and consciously changed their eating habits hoping to see an improvement in their weight, but also continued to constantly monitor their weight.

The physical and psychosocial difficulties experienced by participants as they struggled to increase or maintain their weight post surgery, has also previously been experienced by oesophagectomy patients (Wainwright et al., 2007). The changed physiology following surgery meant that patients needed to adapt to changes in their eating habits, Wainwright et al (2007) referred to this process as “remapping the body” (p.766). Participants needed to learn when they were full in order to avoid nausea or vomiting. Participants had to go through a long process after surgery of physical and psychological adaption, in order to achieve an optimal quality of life. The surgical procedure may remove the tumour, however as found by Wainwright et al (2007) participants needed to cope with the psychosocial aspects of recovery as well as the physical symptoms while trying to rehabilitate from the surgery.

Participants requested family members to bring in food from home to improve their oral intake, some participants reported a sense of failure when relatives had gone to a great deal of trouble to bring food into the hospital, which they could not eat, as found in previous studies (McClement et al., 2003, McGrath, 2002). These feelings of failure were exacerbated when participants had asked family members to bring in favourite foods, which they had previously enjoyed, but were now unable to eat. The encouragement they received, from their anxious relatives also caused them more distress and a greater sense of failure, which was also found in a study by Hawkins (2000). This also mirrors the work of Holden (1991), which found that patients appreciated their caregivers’ efforts at preparing their favourite foods, but found they were trying too hard and this became a source of conflict and tension.

Many participants struggled with the psychosocial and environmental difficulties of being in hospital and found this contributed to their poor oral intake. Participants experienced problems of meal preparation, meal delivery systems and hospital routines which were reported as contributing to the participants’ malnourishment, as previously found by (Orrevall et al., 2004). Due to the type of food delivery system at the study site, three course meals are served on the same tray, using a bulk trolley bedside service, which is considered to meet patients’ needs if the system is used correctly (Allison et al., 2001). Participants reported requesting smaller portions, however they found the sight of so much food overwhelming and over facing. Portion sizes, presentation, smell and social setting all have an impact on a patient’s appetite. This needs to be taken into account in the hospital setting and the provision of snacks and flexible portion sizes would aid in improving the patients nutritional status (Souter, 2005).

Loss of appetite not only affects quality of life, but is a potential source of anxiety (Hawkins, 2000, Holden, 1991), as experienced by the participants in this study. They had little understanding why their appetite had decreased or vanished completely. An understanding of what loss of appetite means to the participants is essential for those trying to help the patient (Poole and Froggatt, 2002). Holden’s (1991) study found that this lack of understanding led to conflict between patients and carers. It was therefore important in this study to explore the meaning of oral intake and food for each individual, to understand their experiences. Some of the participants in this study wanted to express their perceptions of their loved ones concerns about their decreased appetite, only one participant found this to be a source of conflict.

5.2.2 Adapting to change and coping strategies after surgery

The findings in this study, demonstrated that cancer-related weight loss had a profound impact on the participants’ psychological well-being and their physical functions. This was also found in previous studies (Marin Caro et al., 2007a, Muir and Linklater, 2011) and some reported a poorer quality of life, due to their weight loss, this was also found by Hokinson et al (2006) and O’Gorman et al (1998).

In this study, weight loss was not an isolated symptom, but part of a group of symptoms, such as nausea, vomiting, taste alterations and early satiety, this was also found by Stamataki et al (2011). Participants in this study experienced many of the same difficulties to eating that have been identified in previous studies discussed in the systematic review, such as nausea (Orrevall et al., 2004), early satiety (Hopkinson and Corner, 2006) and diarrhoea (Wainwright et al., 2007). However, they sometimes managed a moderate amount of oral intake by forcing themselves to eat or eating without an appetite, which was also experienced by the participants in the study by Shragge (2007). Participants did retain the ability to eat, even with loss of appetite, particularly if symptoms of nausea were kept under control (Shragge et al., 2007). It has been suggested by Hughes & Neal (2000), that seeking food for humans is a biological imperative, with the purpose of providing nutrients essential for life. For patients, eating without an appetite is not only challenging, but can be impossible (Shragge et al., 2006).

One of the key issues for participants was their inability to taste food and they therefore found it difficult to build up an appetite, which led to further worries about weight loss. The changes in tastes perceptions varied from no taste at all, to some foods causing an unpleasant taste in the mouth, “like metal”. For some participants this led to an aversion to certain foods or drinks that they had previously enjoyed, quoting examples of tea, coffee and spicy foods, such as curries. The lack of taste or knowing that food would not taste as it should, led to feelings of disappointment and the will or desire to eat were diminished or vanished completely, which was also reported by Stamataki et al (2011) and McGrath (2002). Participants were also dreaming about certain foods and having a desire to eat things, which unfortunately, they could not physically consume. As found by Holden (1991) some participants reported their family members had spent a lot of time and energy selecting and preparing food for the participant, only to find they were unable to eat it or had no desire for that particular food. Loss of appetite is complex and multifaceted, involving changes in taste perceptions and early satiety. Therefore, individual and appropriate dietary advice needs to be given after a detailed assessment of the patients oral intake (Souter, 2005).

Participants in this study had an accepting attitude towards their eating difficulties this was something they needed to experience, in order to recover from the surgery. Accepting or resigning themselves to their limitations of a reduced intake, seemed to allow them to avoid a lot of the psychological trauma associated with loss of appetite (Holden, 1991, Hopkinson and Corner, 2006, Souter, 2005). However, Shragge (2006) argues that the targets patients set for themselves can also be viewed as another form of control. An example of this was the participant, who discussed trying to eat an extra slice of toast or half a slice of toast with their spaghetti. By setting targets, they are controlling this unavoidable change (Muir and Linklater, 2011) even if they have followed a daily pattern of oral intake for a good number of years, they are not being overcome by these changes but rather adapting to them (Shragge et al., 2006).

Some participants also felt nauseated by the smell of the food and therefore tried to adopt strategies to try and eat even if was only a minimal amount. The observational work by Warnock et al (2005) has highlighted that physical constraints on nutrition such as lack of appetite, fatigue, taste changes, difficulty swallowing, sore mouth and gastrointestinal disturbances (sic) are many factors, which contributed to patients' poor appetite as a result of treatment for cancer (Warnock et al., 2005). These were clear barriers and had a negative impact on patients' nutritional status.

Malnutrition and eating difficulties experienced by the participants, such as the complex symptoms of nausea, taste changes and diarrhoea further compromised their nutrition and functional ability. The treatment-related factors and the previous mentioned symptoms could have a detrimental effect on a patients quality of life (Marin Caro et al., 2007b, Ravasco et al., 2004). Quality of life was very subjective to each individual participant, but has been reported to include a patient's psychosocial wellbeing, functional status, health perception and treatment related symptoms (Ravasco et al., 2004). Each participant had different health and performance expectations, due to their differing time points after surgery and therefore quality of life is highly individualised (Marin Caro et al., 2007b), especially for patients with cancer as their expectations will change over time (Ravasco et al., 2007). Quality of life needs to be evaluated when assessing a patient's nutritional status, in order to tailor the nutritional intervention to the individual patient's requirements (Marin Caro et al., 2007a, Marin Caro et al., 2007b).

5.2.3 Experiences of nutritional support interventions

Traditionally, in surgical patients the rationale behind the use of nutritional support is to try and alleviate malnutrition associated adverse effects such as post operative complications (Bozzetti et al., 2007). The findings in this study revealed that participants had varying experiences of nutritional support interventions. Although nutritional intervention is not a specific cancer treatment, it is necessary at certain stages of the disease and the therapeutic strategy (Marin Caro et al., 2007a). Nutritional support interventions, such as dietary counselling, artificial feeding and oral supplementation, need to be proactive rather than reactive and should form an integral part of treatment therapy for patients with cancer to improve clinical outcomes and quality of life (Van Bokhorst-de et al., 2005).

The role of the dietitian was seen as being able to potentially relieve some of the distress participants experienced with eating problems. Some participants reported that they had been given some good suggestions of different types of food to eat and ways to prepare food. However, some found the dietitian authoritarian, because they did not give helpful suggestions, which was seen as counterproductive and participants found this distressing. The results of a study by Ravasco (2005) found that giving individualised dietary counselling was more beneficial compared to non-prescriptive approaches that did not take into account personal preferences.

Participants in this study also reported a lack of dietetic input or could not remember the dietitian coming to see them. As all surgery patients are seen by a dietitian, this could suggest that the amount of time dietitians are able to spend with patients was so minimal that patients had forgotten who they were. In this study, some participants reported seeing the dietitian at the beginning of their hospital admission and once at the end, whilst others felt they had been given a great deal of attention and had seen the dietitian on many occasions. These findings were also reported by post-operative oesophagectomy patients (Wainwright et al., 2007), the patients in this study requested more input from a dietitian than just a small amount of information whilst they were in hospital, as is presently the case with most surgical patients. Participants in this study reported sorting out their own problems without dietetic input, but others were more assertive and requested to see a dietitian, as found in previous work (McGrath, 2002).

The use of oral nutritional supplements is the least invasive method of increasing patients nutrient intake (Van Bokhorst-de et al., 2005). Early initiation of nutrition support has been found to be essential for improving patient outcomes (Ottery, 1996) and oral nutritional supplements are effective when patients are unable to meet their nutritional requirements solely with food (Ravasco et al., 2003). Prescribed, oral energy and protein supplements were taken by participants, with varying degrees of success, however, even the participants who were negative about the supplements because of the 'sickly taste' felt they were beneficial. As found by Dewey & Dean (2008) nutritional supplements offered to participants by healthcare professionals, was limited by brand choice and flavours. Oral nutritional supplements costs the NHS £150 million annually (Elia et al., 2006) and participants in this study reported throwing away supplement drinks, because of the lack of choice of flavours or because of the consistency of the drinks. Some participants preferred the ‘milky’ flavours to the ‘juice based’ drinks. Providing a better choice of flavours and consistencies may avoid unnecessary wastage and improve patient compliance.

Nutritional support interventions need to be monitored for their effectiveness and adapted to meet the changing nutritional requirements of the patients (Marin Caro et al., 2007b). The nutritional requirements of patients with cancer depends on their degree of malnutrition and therefore needs to be individual to that particular patient (Van Bokhorst-de et al., 2005). Currently nutritional assessment carried out by clinical dietitians assesses patients’ nutritional needs and energy requirements at that particular time point. It has been recommended that nutritional assessment is most informative when performed repeatedly over time, regular monitoring should be performed to ensure that the prescribed nutritional intervention is effective and the patient is not experiencing further nutritional decline or complications (Davies, 2005). However, participants in this study reported that they were prescribed nutritional supplement drinks, but were not monitored once they had been discharged home, or whether they were still taking the supplement drinks and how long after surgery they continued taking them.

Participants were all fed by means of artificial nutritional support after surgery, as this is the current protocol at the study site, because the initiation of early enteral feeding is beneficial in preventing post-operative complications. These included wound infections, anastomotic leaks, sepsis and morbidity and this can reduce length of stay in hospital, by 3 days, thus considerably reducing costs to the NHS (Barlow et al., 2008, Barlow et al., 2011). These clinical improvements and the specific role of nutritional interventions to enhance recovery after surgery need to be fully explained to patients. The participants in this study complained of nausea and vomiting whilst the nasogastric tube was in situ and also felt it exacerbated their eating difficulties while in hospital. Most of the participants in this study felt that it had not been explained to them why they had a tube in their nose, which for some participants had been stitched into their nose causing further discomfort. Early nutritional intervention can also improve quality of life (Ravasco et al., 2003), however participants in this study seemed to have little understanding of the benefits of artificial feeding. The findings in this area imply a need to be aware of the differences between the way health professionals assume a patients understanding of the benefits of nutritional support interventions and what participants in this study expressed as lived experience.

Participants indicated that hospital staff were not very understanding when they reported problems with eating and bland tasting hospital food, although participants did report this was possibly due to a lack of taste, as previously noted by McGrath (2002). Observational work by Warnock (2005) found that giving individualised care to patients had a positive influence on their nutrition, as did staff being present at mealtimes to offer encouragement with nutrition. However, this is not always practical on many busy surgical wards where nursing staff should be available at mealtimes to take responsibility for nutrition. The study site does have a protected meals policy, whereby all nursing activities except attending to patients' nutritional needs should cease and other health care members should also leave the ward during this time. Participants reported a lack of help with their eating difficulties, but always tried to eat something, because otherwise they felt they would not be discharged home. Offering encouragement, with oral intake can be used to provide a positive and proactive approach to nutrition in hospital (Warnock et al., 2005).

5.2.4 Information sources and effective communication to provide optimal health outcomes for rehabilitation after surgery

The findings from this study found that information sources were often from a variety of health professionals, as was found in a previous study (Dewey and Dean, 2008). Although the information given was seen as beneficial by participants, it was not always consistent, which left participants with conflicting information and led to confusion. Participants felt that a lack of detailed information was provided after surgery and they described using their own common sense regarding what to eat after surgery, which lead to feelings of trial and error. These findings also mirror those experienced by head and neck cancer patients who had received multiple therapies (Wilson et al., 1991), such as surgery, chemotherapy or radiotherapy. Participants in this study found some foods were too rich for them to digest at such an early stage and felt that more information about what types of food and consistencies would have been more useful.

The way healthcare professionals communicate with patients affects how the patient perceives care. Good communication can support people to return to as normal a life as possible following cancer treatment. There was concern and confusion about the advice given from different sources, but participants felt reassured if they received the same information from more than one healthcare professional. This finding has also been demonstrated in other research (Hancock et al., 2012).

Providing effective communication, is key to optimal health outcomes (Rutten et al., 2005) and by understanding when, what and whom they receive information from is vital to ensuring the delivery of quality cancer care. Improved communication between family members, patients and healthcare professionals could decrease the stress felt regarding a patient's nutritional status. In this study participants experienced, healthcare professionals using jargon. This was not seen as an effective way to communicate and terms such as "little and often", which dietitians use to suggest to patients to eat small regular meals, was not properly explained to participants and therefore poorly understood.

Participants often felt the information they were given was something that they actually knew, for example, the need to eat small frequent meals. By explaining to participants why this was important would have made it more understandable for them, to enable them to follow the instructions and carry out the practical advice. However, it was the practical implementation of this advice that participants found lacking and the ongoing support to supplement the information (Hancock et al., 2012) that led to trial and error and concerns over the nutrient content of their diet. Participants found the advice about boosting calories very helpful, but they wanted more information than this, for long-term recovery and rehabilitation.

The findings of this study suggest, that participants were not given enough information to alleviate their feelings of anxiety regarding their ability to recover from cachexia. Providing patients and their carers with advice can reduce the unnecessary burden of anxiety felt by patients with cachexia and may also influence their management (Hawkins, 2000). Providing correct information and timely explanations may help patients be proactive in their own management (Hopkinson and Corner, 2006). Reid (2010) also suggests that ongoing focused communication between patient, family member and healthcare professionals could provide a basis for this much needed information exchange.

Information needs to be tailored to individuals (Shragge et al., 2007) and also tumour specific (Dewey and Dean, 2008) rather than being generic. Participants in this study found the information given to them to be non-specific and did not relate either to their specific cancer or their surgical treatment and were not individual to them. This mirrors findings from a qualitative study by Hancock et al (2012) that patients want dietitians to treat them as individuals, by identifying the outcomes that individuals want from their treatment and base the support and information on this. A systematic review of information needs and sources among patients with cancer (Rutten et al., 2005), found that health professionals (40.6%) were the most frequently cited information source post-treatment. This emphasizes the important roles that health care professionals, nurses and doctors can perform in meeting the information needs of patients.

Some participants wanted to engage in self-help and health promotional activities to help them with their eating problems. The findings of this study mirror those of Hopkinson et al (2006) where the evidence suggests that the infrastructure to provide this support is not in place for this group of patients. Participants reported difficulty in gaining access to dietitians once they were discharged from hospital and felt the information they were given about how to improve their nutritional status was often lacking, or given on an ad hoc basis. Hopkinson and Corner (2006) have previously reported similar findings. Participants in this study also reported not being able to implement the advice given to them by dietitians due to nausea and other physical problems, such as lack of appetite and early satiety, which was also reported by Orrevall et al (2004).

5.2.5 Patient centred recovery

The findings in this explorative study further support those of previous qualitative work (Reedy et al., 2005) suggesting, that following the cancer diagnosis and surgical treatment, patients with pancreatic cancer reported they had changed their views on their dietary habits. Participants felt conscious of what they ate and wanted to improve the quality of their diet. Informed lifestyle choices are important for patients with cancer, particularly when they are seeking self-help strategies to improve their outcomes (Rock et al., 2012). Regaining health and following a healthy diet aimed at preventing recurrence, with the overall goal of preventing nutritional deficiencies, was seen for many participants as a way to recovery. Patients with cancer may be at risk of developing micronutrient deficiencies, due to their reduced intake (Van Bokhorst-de et al., 2005). The overall goal of nutritional assessment should be to prevent nutrient deficiencies, to enable patients to maintain their weight and maximise their quality of life (Rock et al., 2012).

Some of the participants reported taking multi-vitamins to supplement their diet, but this was something they had decided to do for themselves as a form of self help to alleviate some of their concerns about the nutrient content of their diet. It was also found in a study by Reedy et al (2005) that patients with colorectal cancer took dietary supplements with the aim of improving their health, but found that there was a lack of clear guidance provided by healthcare professionals on taking extra vitamins and minerals to supplement their dietary intake. Taking vitamins and minerals that exceed the amount normally found in food and recommended Dietary Reference Intakes remains controversial in patients with cancer. Therefore dietitians and healthcare professionals need to provide patients with information about taking dietary supplements (Rock et al., 2012).

Participants wanted more involvement in decisions about their care and there is evidence to suggest that giving patients more control over decisions about their care can both improve health outcomes and reduce costs (Department of Health, 2010). In order for this to work effectively, the patient needs to make an informed choice, making use of relevant information, and the patient and the healthcare system needs to work together to make the best possible decision. It is anticipated that this improvement in information will improve patient experience, satisfaction and clinical outcomes (Department of Health, 2011).

The White Paper “Equity and Excellence: Liberating the NHS’ (2010) recommends a shift from a single model of clinical follow up to tailored support based on individual needs. The findings of this study found that participants wanted more clinical follow up and tailored advice. People living with and beyond cancer often have specific support needs, which if left unmet, can damage their long-term prognosis and ability to lead an active and healthy life (Department of Health, 2007).

This study has found that patients with pancreatic cancer have wide-ranging nutritional needs following surgical resection. Evidence suggests that a dedicated multidisciplinary approach to malignant disease can improve survival and decrease morbidity. The close collaboration of dietitians working as part of a multidisciplinary team could lead to positive patient outcomes (Baracos, 2006). However of the 31 specialist pancreatic centres listed with the Pancreatic Society of Great Britain and Ireland, only 5 (23%) have a specialist dietitian, working solely with this groups of patients (Phillips et al., 2009). The study site has a specialist surgical dietitian, but they also work with other groups of surgical patients. Multidisciplinary working and integrated working of dietitians as part of the healthcare team could work towards optimising patients' nutritional status throughout their cancer journey (Orrevall et al., 2004, Stamataki et al., 2011). It might also improve the long-term nutritional experiences and difficulties before and after surgical intervention that the participants in this study have reported.

5.3 Limitations to the study

The findings in this study need to be interpreted in light of the study's limitations:
The study has addressed the issue of nutrition before and after surgical intervention for patients with operable pancreatic cancer, in a particular hospital setting and the findings are therefore focused on patients' experiences of food and nutrition in that one hospital. However, the aim of healthcare research is to inform or influence practice and therefore the findings need to be relevant to more than this group of participants (Swift and Tischler, 2010).

It cannot be claimed that similar findings would emerge with a different sample, as the themes and interpretations are the researcher's own interpretations. This limits any generalisations that can be made to other hospitals in the UK, from this small sample of patients. However, the interpretations have similarities with other empirical work in patients with advanced cancer and other care settings, therefore the findings do offer some elements of transferability. The aim of this study was to discover the essence and meaning of a phenomenon (Van Manen, 1994), not to generalise from a small number of cases (Holloway, 1997).

Patients were initially recruited to the study if their surgery was 4 months prior to the recruitment date. However, as recruitment progressed it became evident that the time frame needed to be extended, in order for the study to be completed. Participants were interviewed up to 12 months post surgery and this meant relying on how well the participants could remember their experiences. However, lived experience is always a reflection and recollection of an experience that has already been lived through (Van Manen, 1994). A multi-centre study may have alleviated some of the difficulties of recruitment, but due to a lack of resources and time constraints this was not a possibility.

Participants in this study were only interviewed once due to time constraints, however the use of more than one interview can give important insights into patients changing experiences and can be used to identify which interventions are the most acceptable and which outcomes are most important to patients at particular time points (Murray et al., 2009). The experiences of the first interview could be developed and the reflections used to enhance the participant-researcher relationship.

Data was collected using semi-structured interviews and an interview guide, therefore it could be argued that this is not naturalistic, as the participants were guided by a pre determined schedule designed by the researcher. However, the choice of open-ended conversational style interviews allowed the participants to tell their stories in their own words (Van Manen, 1994).

Although the researcher was aware of introducing bias into the study at all stages of the research, the researcher's background and professional knowledge, needed to be disclosed to the participants, thus the 'distance' as described by Mays and Pope (2000) between the researcher and the participants was relatively small. However, using hermeneutic phenomenology assumes that pre-understanding of the phenomena under investigation and co-creation by the researcher and participants are what make the interpretations meaningful (Koch, 1995). Thus, the researchers knowledge is central to the interpretive process (Laverty, 2003)

This study has used patients' self-reports about their weight loss and no clinical or laboratory measurements for the assessment of participants' body composition were made. Weight can be very subjective to the individual (Morgan et al., 1980). Although most of the participants were able to recall or give some estimate of their weight loss the accuracy is unknown and the reported weight needs to be treated with some caution.

5.4 Implications for practice

This study has highlighted key findings which, if considered in the day to day care of patients with pancreatic cancer before and after surgery, may well lead to consistent, comprehensive and individualised dietary advice, which could lead to a significant improvement in their quality of life and recovery after surgery.

Healthcare providers could play a key role in providing patients with supportive information and have open discussions with patients about their weight loss and nutritional issues. Regular monitoring and assessment of patients could ensure that individual nutritional support and advice can be provided when it is most needed. Thus ensuring the best care for the patient.

Healthcare providers should not only understand the physiological symptoms of disease and the treatment, but also consider the psychological effects on the patients and their family. Understanding all of these issues will tailor care to best support the patient and their carers in the recovery period.

Healthcare providers need to understand that individuals who have been diagnosed with cancer and undergone treatment for their cancer are often motivated to modify their diets and seek nutritional guidance. Providing informative information about the effects of the disease and limitations due to their changed physiology, would help patients engage in self help to recover as fully as possible.

Improvements to hospital food choices or meal delivery systems, including portion sizes might help to improve patients’ oral intake. Offering a selection of nutritious snacks could also take in to account the need, to eat small regular meals.

Healthcare professionals need to explain clearly the role of oral nutritional support and artificial nutritional support to patients, to help them understand its importance to their recovery in the perioperative period.

Dietitians, in particular, working as part of a multi disciplinary team would be in a key position to have a positive therapeutic influence on the nutritional status of patients with operable pancreatic cancer, before and after surgical intervention. This would enable clear guidelines for the nutritional management of this group of patients to be developed. A specialist dietitian dedicated to this group of patients would facilitate more dietetic involvement and regular contact with patients, enabling the promotion of individualised dietary counselling. This would help to improve nutritional intake and quality of life in this group of patients.

5.5 Recommendations for further research

The implications of the study have suggested that patients with operable pancreatic cancer undergoing surgical resection have some major concerns regarding nutrition and recovery from surgery. This study provided a description of patient’s experiences of food and weight loss before and after surgical intervention, but not necessarily a complete one. The themes identified in this study provide a context for further research and the patients perspectives could be used to inform the development of services. Both weight loss and decreased oral intake have been identified as a coping strategy for rehabilitation after surgery. It is therefore important to consider further research to understand how dietary perceptions and weight changes evolve throughout the stages of rehabilitation after surgery for patients with pancreatic cancer. This study also indicates further research is required to define the optimal use of oral nutritional supplement drinks after surgery for patients with pancreatic cancer. Further investigation into the role of artificial nutrition is required, which includes patient-centred outcomes relating to their experiences and well-being, rather than only objective disease related end points, such as mortality, treatment effects and length of stay. Further research is also required to provide supportive information to patients. The research should focus on the nature and effect of weight loss in surgical patients with pancreatic cancer and the role of food in the management of their weight loss. Thus evaluating the effectiveness of reducing the anxiety over nutritional difficulties and weight loss concerns experienced by this group of patients.

5.6 Summary

This exploratory study of an underexplored area of research, has discussed some key issues regarding the physical and psychosocial difficulties experienced by patients with operable pancreatic cancer as they try to recover from surgery. The purpose of this study was to gain insight into the experiences of patients with pancreatic cancer after surgery and to gain a richer understanding of their lived experiences. Nutrition played an important role in the recovery of the participants after surgical intervention. Nutritional support interventions need to be targeted to aid in the rehabilitation of this group of patients, with the goal of providing individual dietary counselling and information to prevent recurrence and reduce the risk of the development of co morbid disease. Thereby enabling patients to take an active role in improving their recovery and nutritional status, by reducing their symptoms and improving their quality of life. The most important finding from this study is that patients with operable pancreatic cancer before and after surgical intervention, require a lot more nutritional input than the brief advice given to them by healthcare professionals, including dietitians, which is the current rehabilitation strategy for this group of patients.

Appendices

Appendix 1: Search strategy and MESH terms

Number	Searches	Results
1	nutrition.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, ps, rs, nm, an, ui, tc, id]	170584
2	qualitative.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, ps, rs, nm, an, ui, tc, id]	172759
3	Cancer.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, ps, rs, nm, an, ui, tc, id]	1536414
4	Pancreatic cancer.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, ps, rs, nm, an, ui, tc, id]	17832
5	Weight loss.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, ps, rs, nm, an, ui, tc, id]	54590
6	(eating and drinking).mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, ps, rs, nm, an, ui, tc, id]	4531
7	1 and 2 and 4 and 5	0
8	1 or 2 or 4 or 5	409670
9	2 and 3 and 5	47

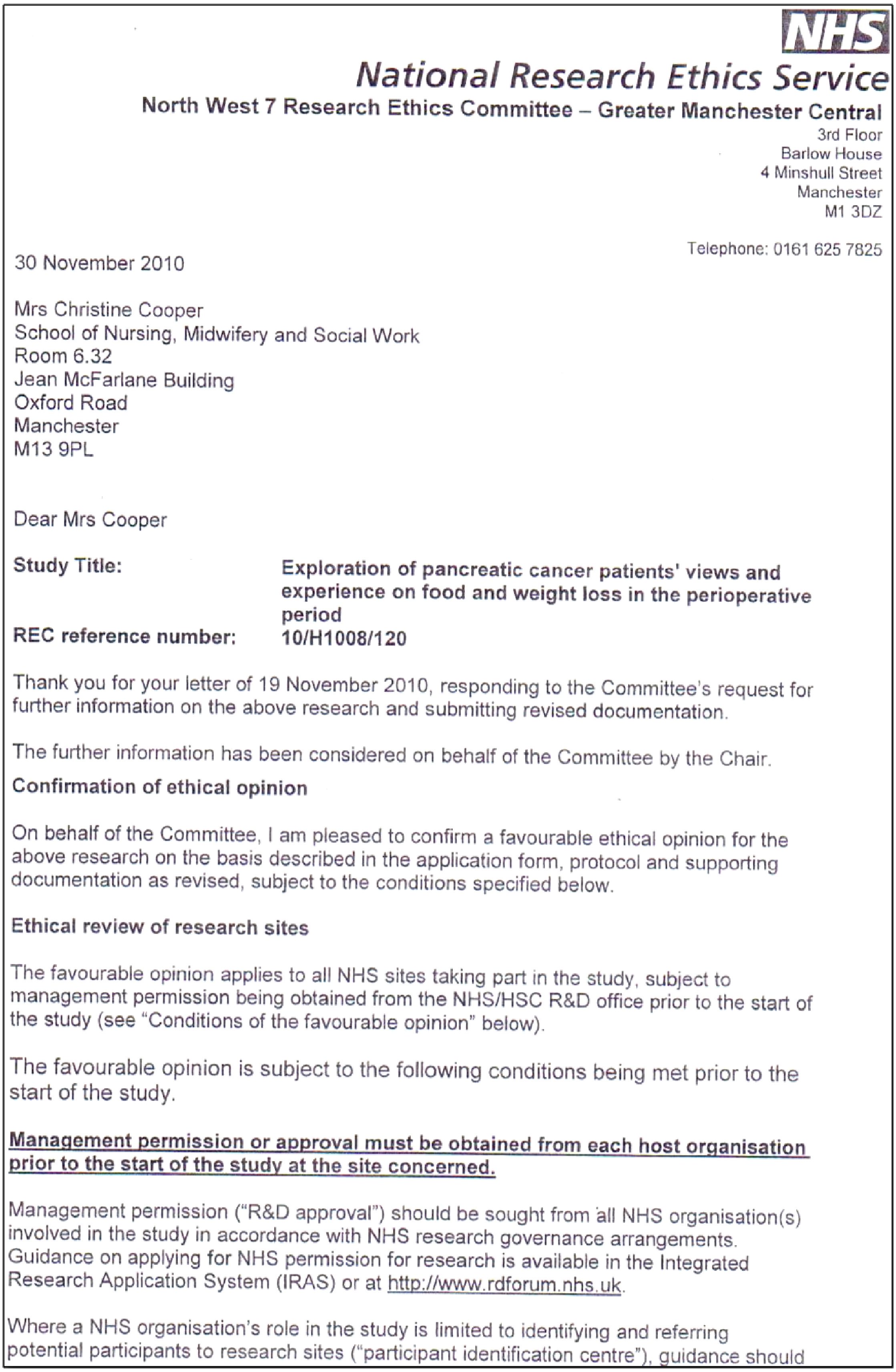
Paper no.

Appendix 2: Data Extraction form and quality assessment for qualitative studies

<table>
<tr>
<td>First Author</td>
<td>Journal</td>
<td>Date</td>
<td rowspan="2">Study aims
Are the aims and purpose of the study clearly stated?
Yes No
Unclear</td>
<td rowspan="2">Research design
Yes No
Unclear
Which philosophy …………………
…</td>
<td rowspan="2">Role of the Researcher
What's their angle?
Who's doing the work?</td>
<td rowspan="2">Sampling
Was the recruitment strategy appropriate to the aims of the research?</td>
<td rowspan="2">Sample population
Experience of…
….people with cancer
…..carers
….professionals
….PWC and carers
….PWC and professionals
….PWC, carers and professionals</td>
<td>Inclusion criteria</td>
<td>Exclusion criteria</td>
</tr>
<tr>
<td colspan="3">Connection with existing body of knowledge made clear?</td>
<td colspan="2">What is the sample size?</td>
</tr>
<tr>
<td colspan="3">Description of the health characteristics of the population (e.g. palliative, surgical etc)</td>
<td>What is the geographical setting for the study?
Urban
Rural
Semi-Urban
Semi-Rural Mixed</td>
<td>What is the rational and appropriateness for this choice?</td>
<td>Over what period did the data collection take place?</td>
<td>What data methods were used?
Interview Focus Group
Observation Mixed Methods
Yes No Unclear</td>
<td colspan="2">Is the process of fieldwork adequately described?
Yes No Unclear</td>
<td>Use questions 5-10 of CASP for Quality Assessment</td>
</tr>
<tr>
<td colspan="6">Comment on the study as a whole and its strengths and weaknesses. Is further work required?</td>
<td colspan="3">Should this study be included in the final review?
Yes No Unclear</td>
<td>Date</td>
</tr>
</table>

Main findings of the study	What does this add to practice?	Additional papers from references

Appendix 3: Ethical approval



National Research Ethics Service
North West 7 Research Ethics Committee – Greater Manchester Central
3rd Floor
Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0161 625 7825

30 November 2010

Mrs Christine Cooper
School of Nursing, Midwifery and Social Work
Room 6.32
Jean McFarlane Building
Oxford Road
Manchester
M13 9PL

Dear Mrs Cooper

Study Title:	**Exploration of pancreatic cancer patients' views and experience on food and weight loss in the perioperative period**
REC reference number:	**10/H1008/120**

Thank you for your letter of 19 November 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

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, subject to the conditions specified below.

Ethical review of research sites

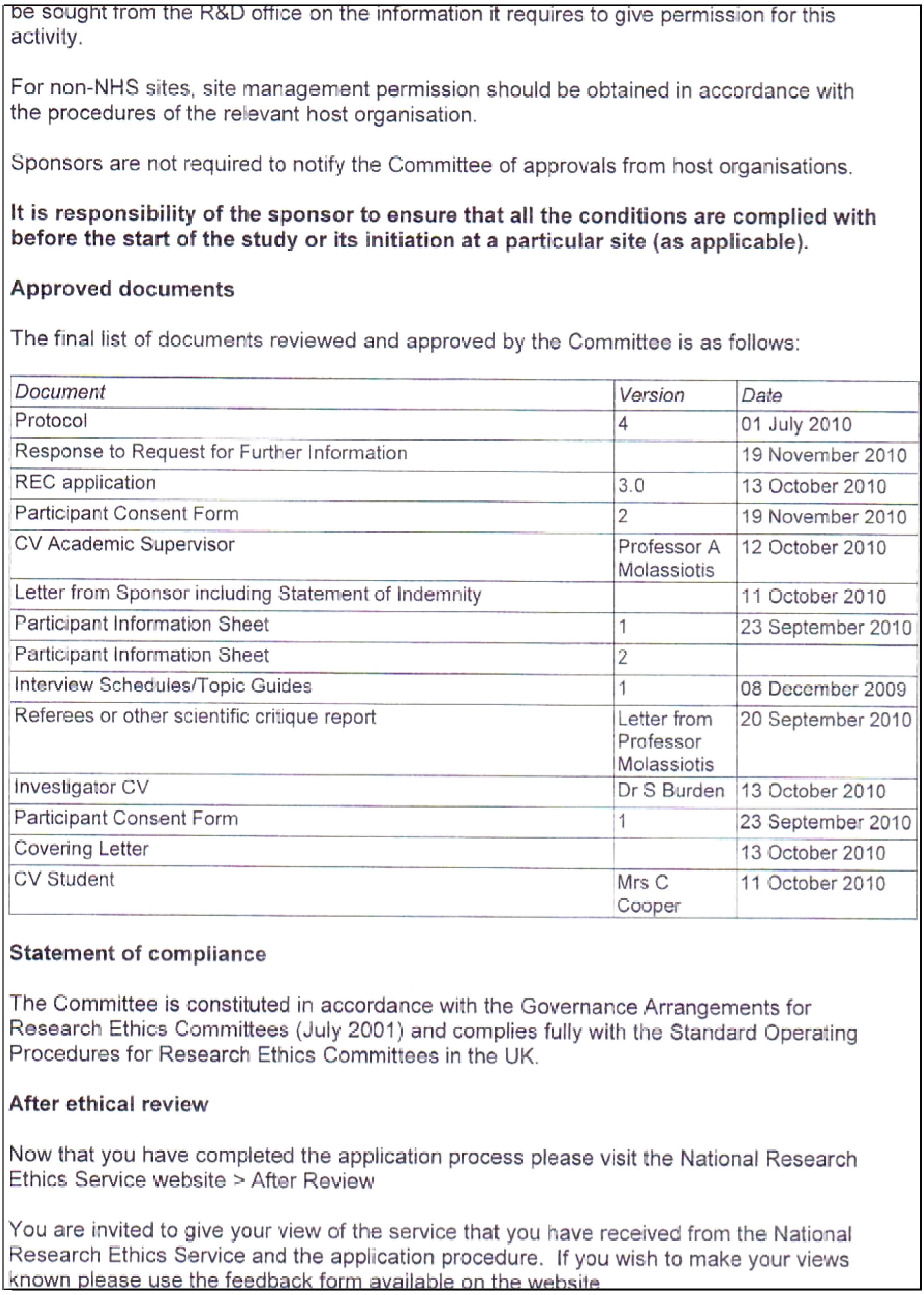
The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisation(s) involved in the study in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System (IRAS) or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should



be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

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

Document	*Version*	*Date*
Protocol	4	01 July 2010
Response to Request for Further Information		19 November 2010
REC application	3.0	13 October 2010
Participant Consent Form	2	19 November 2010
CV Academic Supervisor	Professor A Molassiotis	12 October 2010
Letter from Sponsor including Statement of Indemnity		11 October 2010
Participant Information Sheet	1	23 September 2010
Participant Information Sheet	2	
Interview Schedules/Topic Guides	1	08 December 2009
Referees or other scientific critique report	Letter from Professor Molassiotis	20 September 2010
Investigator CV	Dr S Burden	13 October 2010
Participant Consent Form	1	23 September 2010
Covering Letter		13 October 2010
CV Student	Mrs C Cooper	11 October 2010

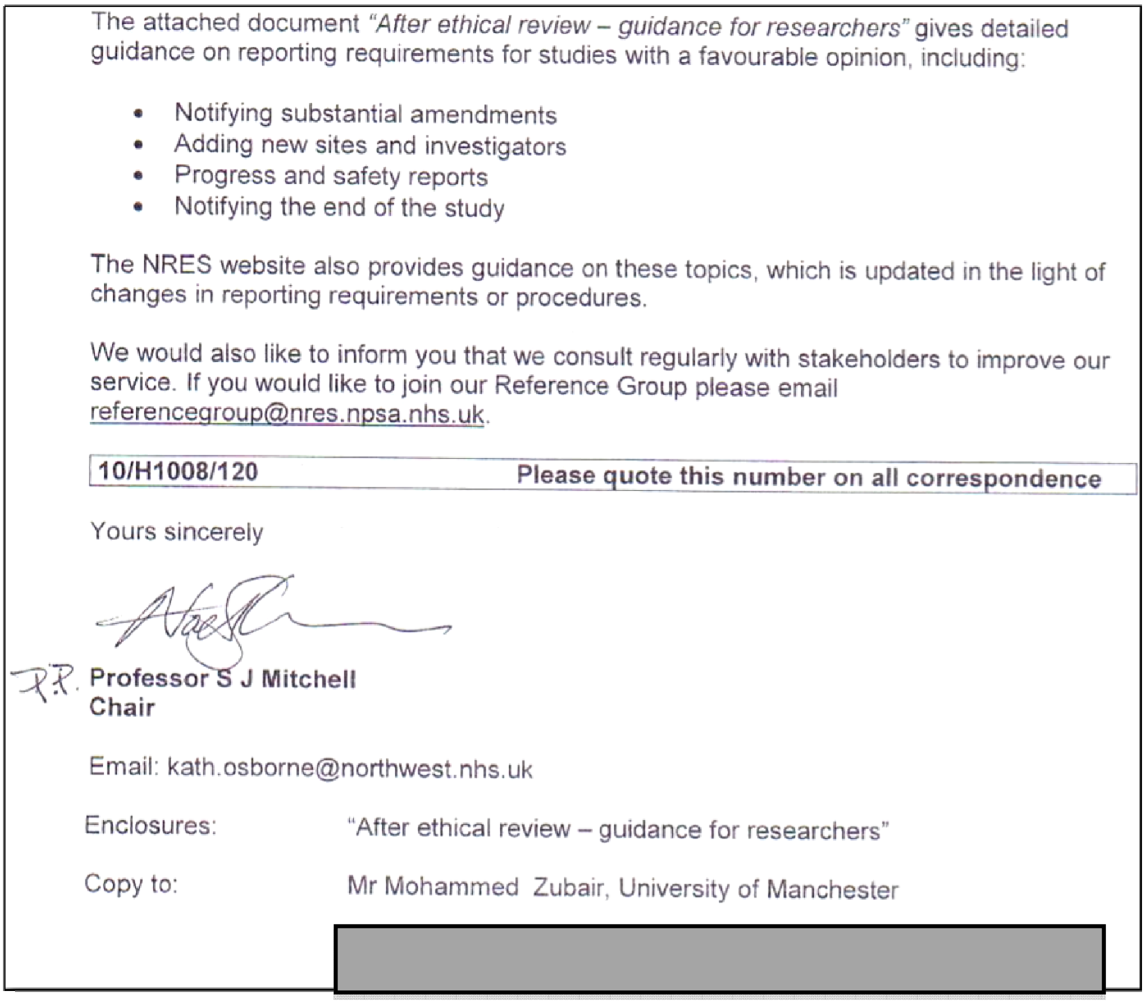
Statement of compliance

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.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.



The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H1008/120	**Please quote this number on all correspondence**

Yours sincerely

P.P. **Professor S J Mitchell**
Chair

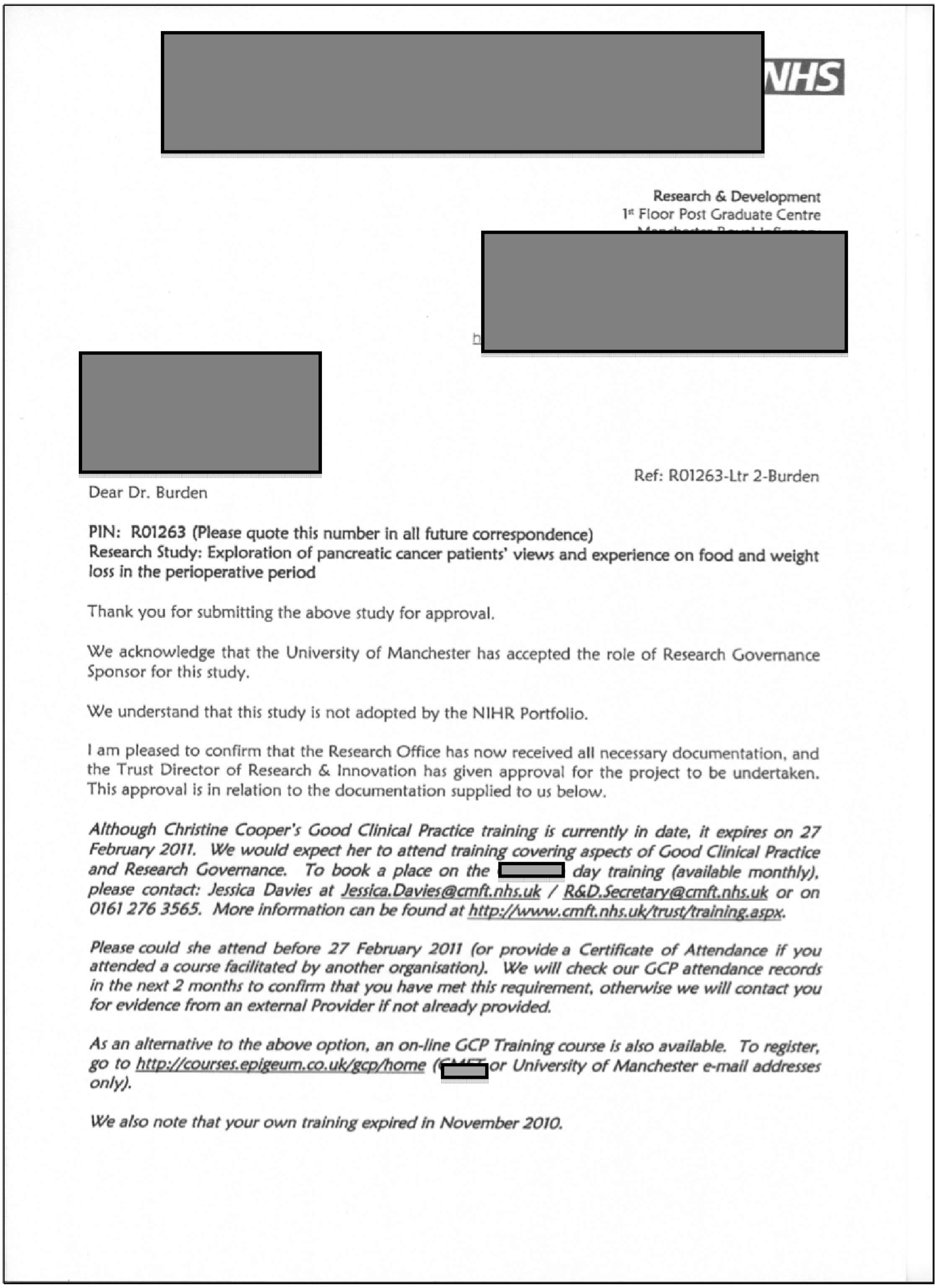
Email: kath.osborne@northwest.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Mr Mohammed Zubair, University of Manchester

[redacted]

Appendix 4: Research and Development approval at the study site



[redacted]

Research & Development
1st Floor Post Graduate Centre

[redacted]

[redacted]

Ref: R01263-Ltr 2-Burden

Dear Dr. Burden

PIN: R01263 (Please quote this number in all future correspondence)
Research Study: Exploration of pancreatic cancer patients' views and experience on food and weight loss in the perioperative period

Thank you for submitting the above study for approval.

We acknowledge that the University of Manchester has accepted the role of Research Governance Sponsor for this study.

We understand that this study is not adopted by the NIHR Portfolio.

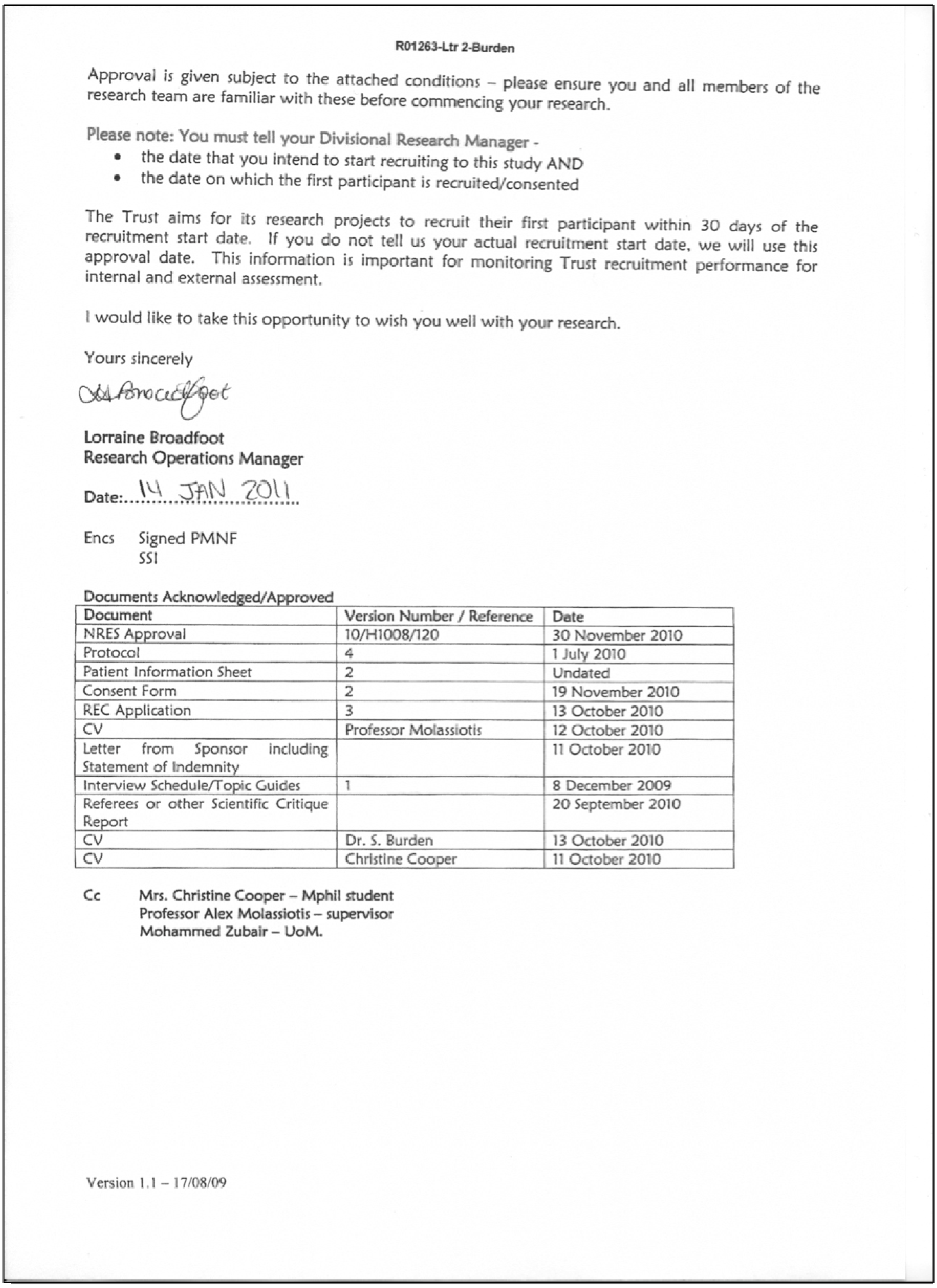
I am pleased to confirm that the Research Office has now received all necessary documentation, and the Trust Director of Research & Innovation has given approval for the project to be undertaken. This approval is in relation to the documentation supplied to us below.

Although Christine Cooper's Good Clinical Practice training is currently in date, it expires on 27 February 2011. We would expect her to attend training covering aspects of Good Clinical Practice and Research Governance. To book a place on the [redacted] *day training (available monthly), please contact: Jessica Davies at Jessica.Davies@cmft.nhs.uk / R&D.Secretary@cmft.nhs.uk or on 0161 276 3565. More information can be found at http://www.cmft.nhs.uk/trust/training.aspx.*

Please could she attend before 27 February 2011 (or provide a Certificate of Attendance if you attended a course facilitated by another organisation). We will check our GCP attendance records in the next 2 months to confirm that you have met this requirement, otherwise we will contact you for evidence from an external Provider if not already provided.

As an alternative to the above option, an on-line GCP Training course is also available. To register, go to http://courses.epigeum.co.uk/gcp/home ([redacted] *or University of Manchester e-mail addresses only).*

We also note that your own training expired in November 2010.



Approval is given subject to the attached conditions – please ensure you and all members of the research team are familiar with these before commencing your research.

Please note: You must tell your Divisional Research Manager -

- the date that you intend to start recruiting to this study AND
- the date on which the first participant is recruited/consented

The Trust aims for its research projects to recruit their first participant within 30 days of the recruitment start date. If you do not tell us your actual recruitment start date, we will use this approval date. This information is important for monitoring Trust recruitment performance for internal and external assessment.

I would like to take this opportunity to wish you well with your research.

Yours sincerely

L Broadfoot

Lorraine Broadfoot
Research Operations Manager

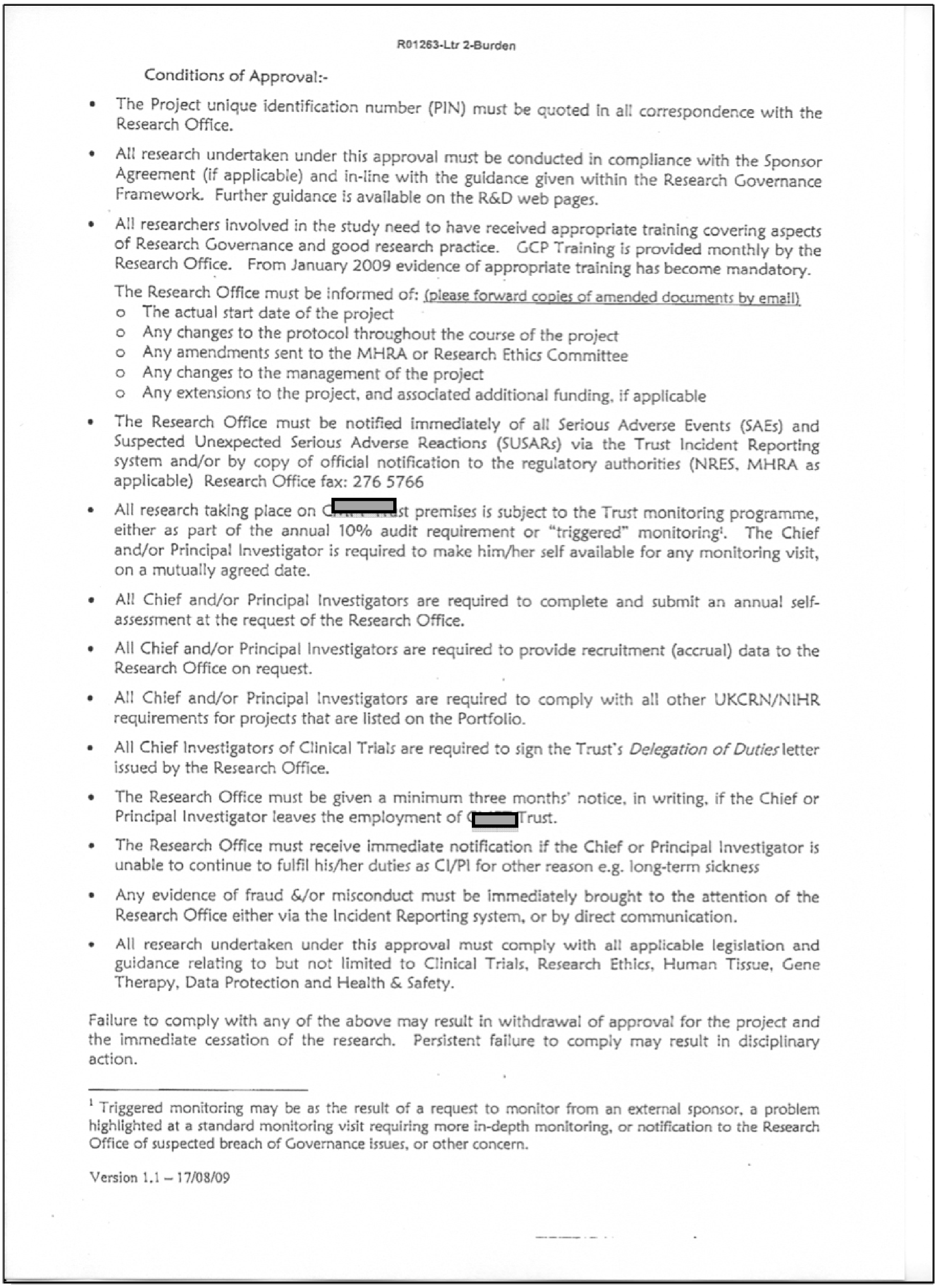
Date: 14 JAN 2011

Encs Signed PMNF
SSI

Documents Acknowledged/Approved

Document	Version Number / Reference	Date
NRES Approval	10/H1008/120	30 November 2010
Protocol	4	1 July 2010
Patient Information Sheet	2	Undated
Consent Form	2	19 November 2010
REC Application	3	13 October 2010
CV	Professor Molassiotis	12 October 2010
Letter from Sponsor including Statement of Indemnity		11 October 2010
Interview Schedule/Topic Guides	1	8 December 2009
Referees or other Scientific Critique Report		20 September 2010
CV	Dr. S. Burden	13 October 2010
CV	Christine Cooper	11 October 2010

Cc **Mrs. Christine Cooper – Mphil student**
Professor Alex Molassiotis – supervisor
Mohammed Zubair – UoM.



Conditions of Approval:-

- The Project unique identification number (PIN) must be quoted in all correspondence with the Research Office.
- All research undertaken under this approval must be conducted in compliance with the Sponsor Agreement (if applicable) and in-line with the guidance given within the Research Governance Framework. Further guidance is available on the R&D web pages.
- All researchers involved in the study need to have received appropriate training covering aspects of Research Governance and good research practice. GCP Training is provided monthly by the Research Office. From January 2009 evidence of appropriate training has become mandatory.

  The Research Office must be informed of: <u>(please forward copies of amended documents by email)</u>
  - The actual start date of the project
  - Any changes to the protocol throughout the course of the project
  - Any amendments sent to the MHRA or Research Ethics Committee
  - Any changes to the management of the project
  - Any extensions to the project, and associated additional funding, if applicable
- The Research Office must be notified immediately of all Serious Adverse Events (SAEs) and Suspected Unexpected Serious Adverse Reactions (SUSARs) via the Trust Incident Reporting system and/or by copy of official notification to the regulatory authorities (NRES, MHRA as applicable) Research Office fax: 276 5766
- All research taking place on [redacted] premises is subject to the Trust monitoring programme, either as part of the annual 10% audit requirement or "triggered" monitoring[1]. The Chief and/or Principal Investigator is required to make him/her self available for any monitoring visit, on a mutually agreed date.
- All Chief and/or Principal Investigators are required to complete and submit an annual self-assessment at the request of the Research Office.
- All Chief and/or Principal Investigators are required to provide recruitment (accrual) data to the Research Office on request.
- All Chief and/or Principal Investigators are required to comply with all other UKCRN/NIHR requirements for projects that are listed on the Portfolio.
- All Chief Investigators of Clinical Trials are required to sign the Trust's *Delegation of Duties* letter issued by the Research Office.
- The Research Office must be given a minimum three months' notice, in writing, if the Chief or Principal Investigator leaves the employment of [redacted] Trust.
- The Research Office must receive immediate notification if the Chief or Principal Investigator is unable to continue to fulfil his/her duties as CI/PI for other reason e.g. long-term sickness
- Any evidence of fraud &/or misconduct must be immediately brought to the attention of the Research Office either via the Incident Reporting system, or by direct communication.
- All research undertaken under this approval must comply with all applicable legislation and guidance relating to but not limited to Clinical Trials, Research Ethics, Human Tissue, Gene Therapy, Data Protection and Health & Safety.

Failure to comply with any of the above may result in withdrawal of approval for the project and the immediate cessation of the research. Persistent failure to comply may result in disciplinary action.

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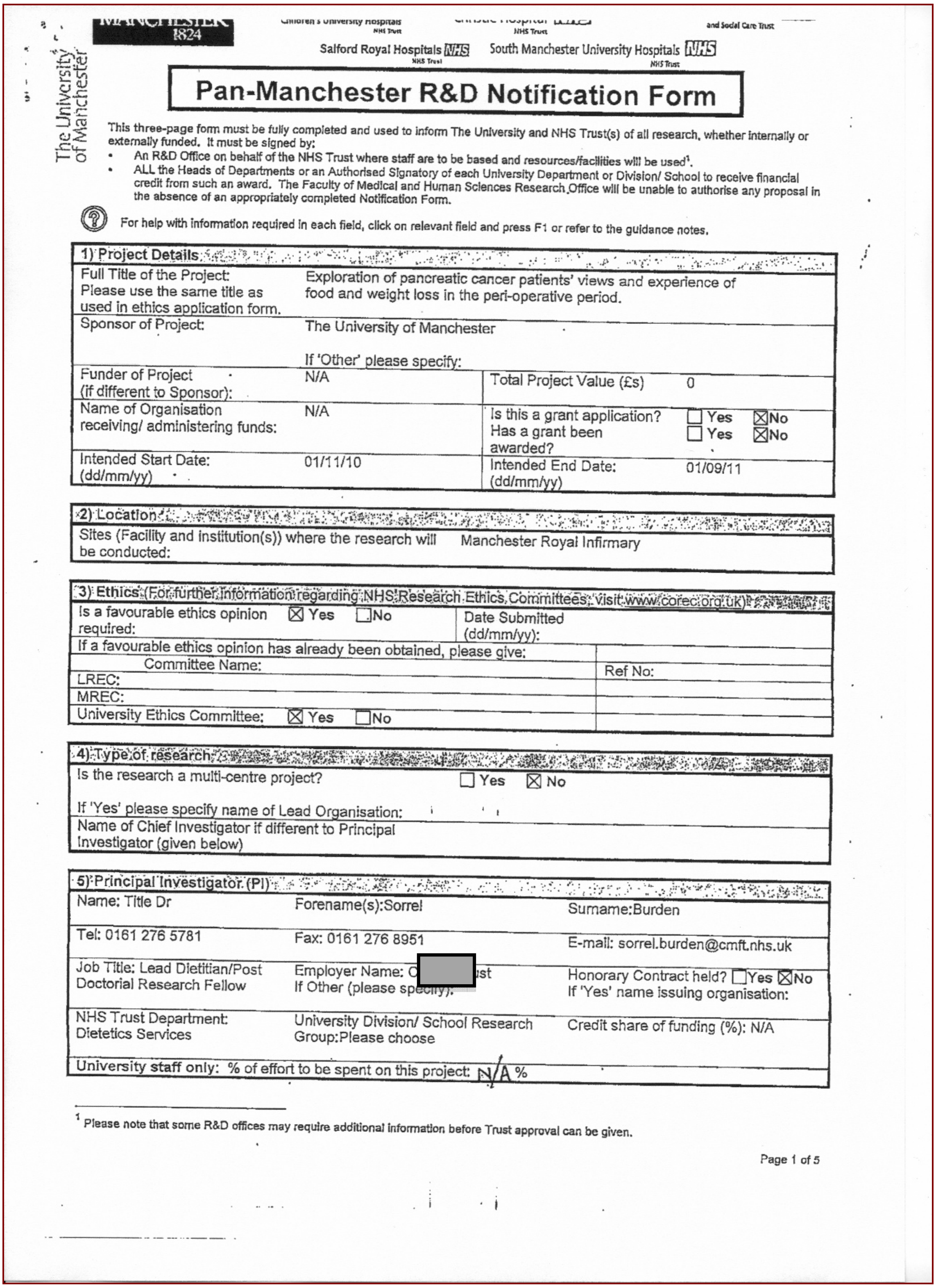
[1] Triggered monitoring may be as the result of a request to monitor from an external sponsor, a problem highlighted at a standard monitoring visit requiring more in-depth monitoring, or notification to the Research Office of suspected breach of Governance issues, or other concern.



The University of Manchester

1824

and Social Care Trust

Salford Royal Hospitals NHS
NHS Trust

South Manchester University Hospitals NHS
NHS Trust

Pan-Manchester R&D Notification Form

This three-page form must be fully completed and used to inform The University and NHS Trust(s) of all research, whether internally or externally funded. It must be signed by:

- An R&D Office on behalf of the NHS Trust where staff are to be based and resources/facilities will be used[1].
- ALL the Heads of Departments or an Authorised Signatory of each University Department or Division/ School to receive financial credit from such an award. The Faculty of Medical and Human Sciences Research Office will be unable to authorise any proposal in the absence of an appropriately completed Notification Form.

For help with information required in each field, click on relevant field and press F1 or refer to the guidance notes.

1) Project Details

Full Title of the Project: Please use the same title as used in ethics application form.	Exploration of pancreatic cancer patients' views and experience of food and weight loss in the peri-operative period.		
Sponsor of Project:	The University of Manchester If 'Other' please specify:		
Funder of Project (if different to Sponsor):	N/A	Total Project Value (£s)	0
Name of Organisation receiving/ administering funds:	N/A	Is this a grant application? Has a grant been awarded?	☐ Yes ☒No ☐ Yes ☒No
Intended Start Date: (dd/mm/yy)	01/11/10	Intended End Date: (dd/mm/yy)	01/09/11

2) Location

Sites (Facility and institution(s)) where the research will be conducted:	Manchester Royal Infirmary

3) Ethics (For further information regarding NHS Research Ethics Committees, visit www.corec.org.uk)

Is a favourable ethics opinion required:	☒ Yes ☐No	Date Submitted (dd/mm/yy):
If a favourable ethics opinion has already been obtained, please give:		
Committee Name:		Ref No:
LREC:		
MREC:		
University Ethics Committee:	☒ Yes ☐No	

4) Type of research

Is the research a multi-centre project? If 'Yes' please specify name of Lead Organisation:	☐ Yes ☒ No
Name of Chief Investigator if different to Principal Investigator (given below)	

5) Principal Investigator (PI)

Name: Title Dr	Forename(s):Sorrel	Surname:Burden
Tel: 0161 276 5781	Fax: 0161 276 8951	E-mail: sorrel.burden@cmft.nhs.uk
Job Title: Lead Dietitian/Post Doctorial Research Fellow	Employer Name: C[redacted]st If Other (please specify):	Honorary Contract held? ☐Yes ☒No If 'Yes' name issuing organisation:
NHS Trust Department: Dietetics Services	University Division/ School Research Group:Please choose	Credit share of funding (%): N/A
University staff only: % of effort to be spent on this project: N/A %		

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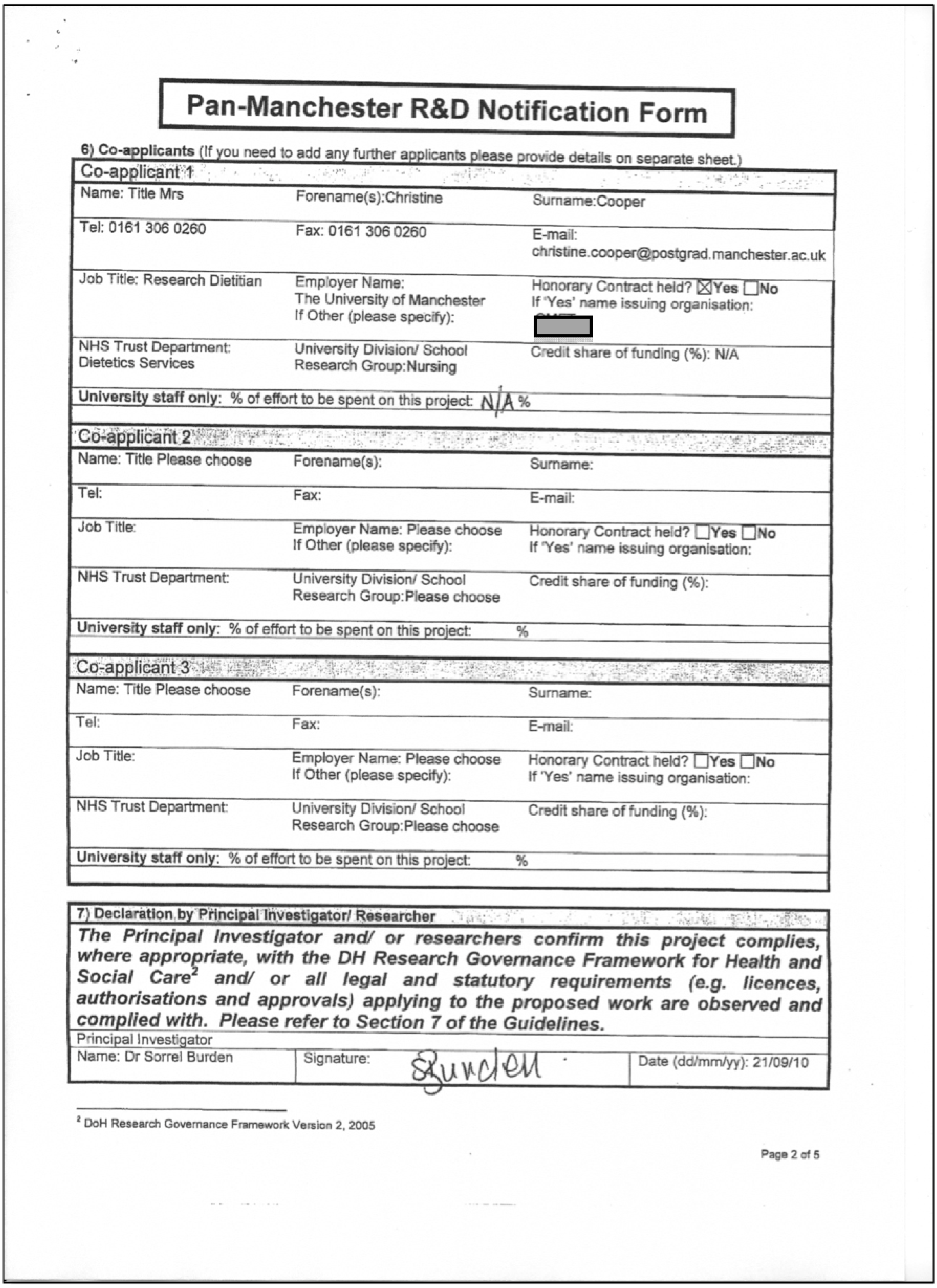
[1] Please note that some R&D offices may require additional information before Trust approval can be given.

Page 1 of 5



Pan-Manchester R&D Notification Form

6) Co-applicants (If you need to add any further applicants please provide details on separate sheet.)

Co-applicant 1		
Name: Title Mrs	Forename(s):Christine	Surname:Cooper
Tel: 0161 306 0260	Fax: 0161 306 0260	E-mail: christine.cooper@postgrad.manchester.ac.uk
Job Title: Research Dietitian	Employer Name: The University of Manchester If Other (please specify):	Honorary Contract held? ☒Yes ☐No If 'Yes' name issuing organisation: [redacted]
NHS Trust Department: Dietetics Services	University Division/ School Research Group:Nursing	Credit share of funding (%): N/A
University staff only: % of effort to be spent on this project: N/A %		

Co-applicant 2		
Name: Title Please choose	Forename(s):	Surname:
Tel:	Fax:	E-mail:
Job Title:	Employer Name: Please choose If Other (please specify):	Honorary Contract held? ☐Yes ☐No If 'Yes' name issuing organisation:
NHS Trust Department:	University Division/ School Research Group:Please choose	Credit share of funding (%):
University staff only: % of effort to be spent on this project: %		

Co-applicant 3		
Name: Title Please choose	Forename(s):	Surname:
Tel:	Fax:	E-mail:
Job Title:	Employer Name: Please choose If Other (please specify):	Honorary Contract held? ☐Yes ☐No If 'Yes' name issuing organisation:
NHS Trust Department:	University Division/ School Research Group:Please choose	Credit share of funding (%):
University staff only: % of effort to be spent on this project: %		

7) Declaration by Principal Investigator/ Researcher

The Principal Investigator and/ or researchers confirm this project complies, where appropriate, with the DH Research Governance Framework for Health and Social Care[2] and/ or all legal and statutory requirements (e.g. licences, authorisations and approvals) applying to the proposed work are observed and complied with. Please refer to Section 7 of the Guidelines.

Principal Investigator		
Name: Dr Sorrel Burden	Signature: SBurden	Date (dd/mm/yy): 21/09/10

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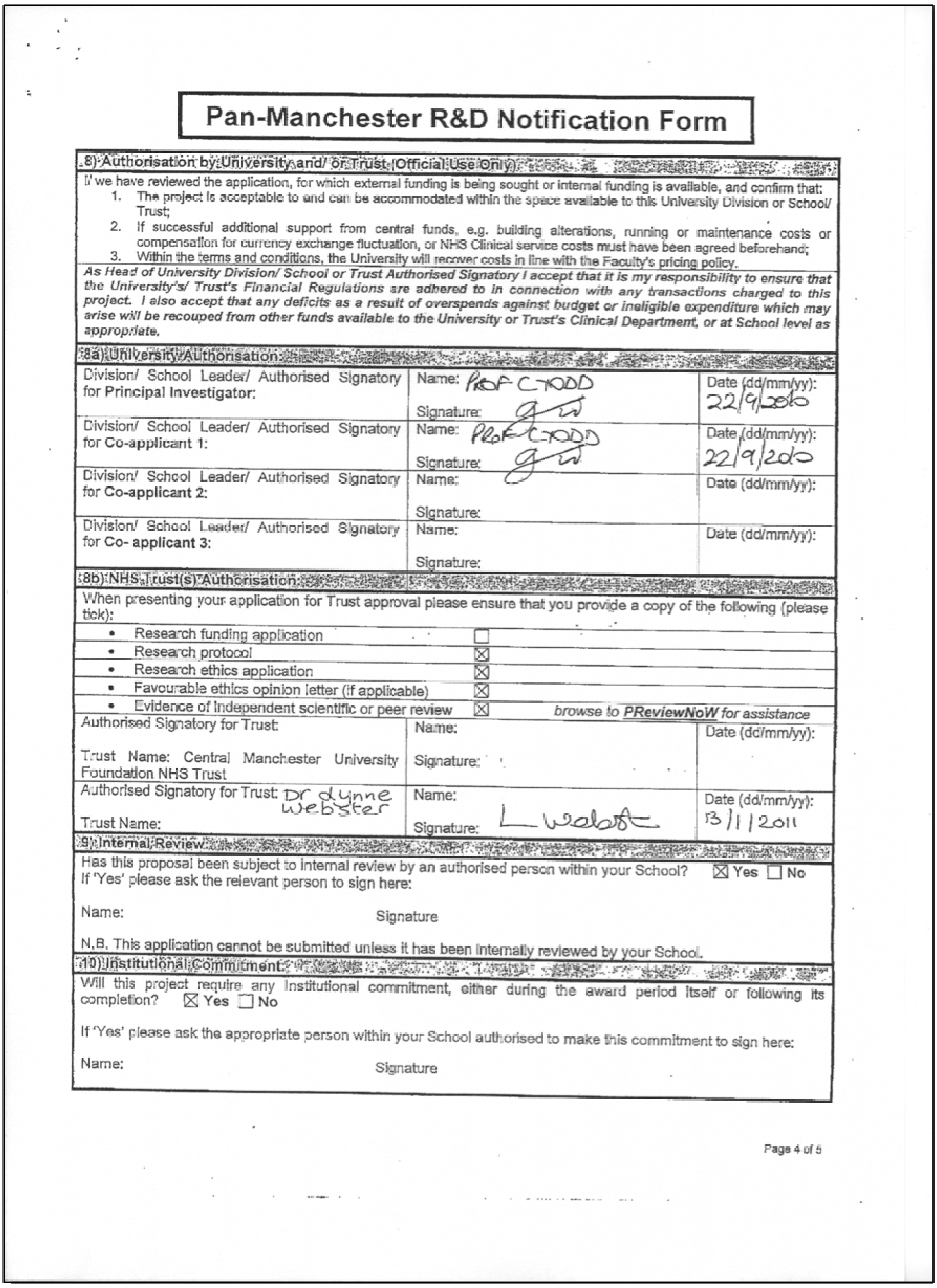
[2] DoH Research Governance Framework Version 2, 2005



Pan-Manchester R&D Notification Form

8) Authorisation by University and/ or Trust (Official Use Only)

I/ we have reviewed the application, for which external funding is being sought or internal funding is available, and confirm that:

1. The project is acceptable to and can be accommodated within the space available to this University Division or School/ Trust;
2. If successful additional support from central funds, e.g. building alterations, running or maintenance costs or compensation for currency exchange fluctuation, or NHS Clinical service costs must have been agreed beforehand;
3. Within the terms and conditions, the University will recover costs in line with the Faculty's pricing policy.

As Head of University Division/ School or Trust Authorised Signatory I accept that it is my responsibility to ensure that the University's/ Trust's Financial Regulations are adhered to in connection with any transactions charged to this project. I also accept that any deficits as a result of overspends against budget or ineligible expenditure which may arise will be recouped from other funds available to the University or Trust's Clinical Department, or at School level as appropriate.

8a) University Authorisation

Division/ School Leader/ Authorised Signatory for **Principal Investigator:**	Name: PROF C TODD Signature:	Date (dd/mm/yy): 22/9/2010
Division/ School Leader/ Authorised Signatory for **Co-applicant 1:**	Name: PROF C TODD Signature:	Date (dd/mm/yy): 22/9/2010
Division/ School Leader/ Authorised Signatory for **Co-applicant 2:**	Name: Signature:	Date (dd/mm/yy):
Division/ School Leader/ Authorised Signatory for **Co- applicant 3:**	Name: Signature:	Date (dd/mm/yy):

8b) NHS Trust(s) Authorisation

When presenting your application for Trust approval please ensure that you provide a copy of the following (please tick):

• Research funding application	☐	
• Research protocol	☒	
• Research ethics application	☒	
• Favourable ethics opinion letter (if applicable)	☒	
• Evidence of independent scientific or peer review	☒	*browse to **PReviewNoW** for assistance*
Authorised Signatory for Trust: Trust Name: Central Manchester University Foundation NHS Trust	Name: Signature:	Date (dd/mm/yy):
Authorised Signatory for Trust: Dr Lynne Webster Trust Name:	Name: Signature: L Webster	Date (dd/mm/yy): 13/1/2011

9) Internal Review

Has this proposal been subject to internal review by an authorised person within your School? ☒ Yes ☐ No
If 'Yes' please ask the relevant person to sign here:

Name: Signature

N.B. This application cannot be submitted unless it has been internally reviewed by your School.

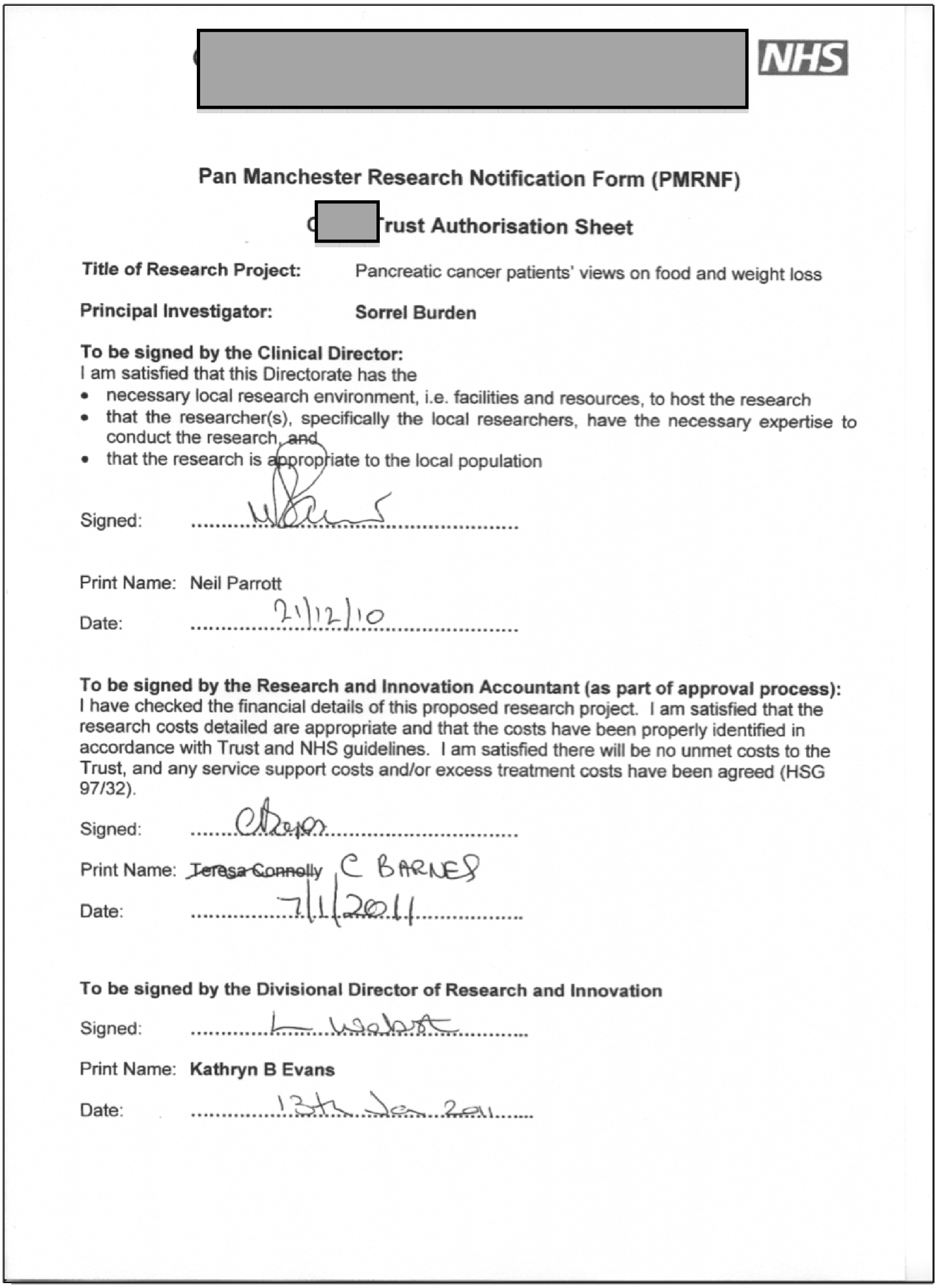
10) Institutional Commitment

Will this project require any Institutional commitment, either during the award period itself or following its completion? ☒ Yes ☐ No

If 'Yes' please ask the appropriate person within your School authorised to make this commitment to sign here:

Name: Signature

Page 4 of 5



[redacted] NHS

Pan Manchester Research Notification Form (PMRNF)

[redacted]rust Authorisation Sheet

Title of Research Project: Pancreatic cancer patients' views on food and weight loss

Principal Investigator: **Sorrel Burden**

To be signed by the Clinical Director:
I am satisfied that this Directorate has the

- necessary local research environment, i.e. facilities and resources, to host the research
- that the researcher(s), specifically the local researchers, have the necessary expertise to conduct the research, and
- that the research is appropriate to the local population

Signed: ....

Print Name: Neil Parrott

Date: ....21/12/10..................

To be signed by the Research and Innovation Accountant (as part of approval process):
I have checked the financial details of this proposed research project. I am satisfied that the research costs detailed are appropriate and that the costs have been properly identified in accordance with Trust and NHS guidelines. I am satisfied there will be no unmet costs to the Trust, and any service support costs and/or excess treatment costs have been agreed (HSG 97/32).

Signed: ....

Print Name: ~~Teresa Connolly~~ C BARNES

Date: ....7/1/2011..................

To be signed by the Divisional Director of Research and Innovation

Signed: ....

Print Name: **Kathryn B Evans**

Date: ....13th Jan 2011..................

Appendix 5: Patient Information Sheet

Patient information Sheet

Exploration of patients’ views and experience of food and weight loss following surgical treatment.

Introduction

Weight loss has been shown to affect the outcome of surgery in different patient groups. This study looks at examining the patients’ experience in relation to food and nutrition during surgical treatment. The aim of the study is to look at patient’s views on food and nutrition whilst undergoing surgical treatment for pancreatic cancer. We would like to invite you to help with the study, which involves taking part in an interview.

Part 1 of this form tells you the purpose of this study and what will happen if you take part.

Part 2 gives you more detailed information about conducting the study. Please ask if anything is not clear or if you would like more information.

Part 1

What is the purpose of this study?

The purpose of this study is to collect information on patients’ views and experience of food and nutrition. It also aims to find out at what stage in the individual’s treatment dietary supplements or dietary advice would be helpful.

Why have I been invited to take part?

You have been asked to take part because you have had surgery to remove a tumour from your pancreas.

Do I have to take part?

No, taking part is voluntary. If you would prefer not to take part you do not have to give a reason. Your doctor would not be upset and your treatment would not be affected. If you take part but later change your mind you can withdraw at any time from the study without hindrance or detriment to your future treatment.

What will I have to do if I take part?

If you agree to take part in the study you will be invited to meet with the researcher and take part in an in-depth interview on a one-to-one basis with the researcher.

For the interview, a convenient time will be arranged when you are attending another appointment at the hospital, or you can be seen at home if this is more convenient. The interview will last between 30-60 minutes and the discussion will be guided in and around your experience of food and nutrition during and after you have had your surgery. The researcher will ask you some predetermined questions to stimulate discussion about your experience and views relating to food and nutrition. The interview will be digitally recorded to allow the researcher to collate the information gained. There will be between 15-20 patients interviewed for this study.

If you feel uncomfortable during the interview you do not have to answer the question but simply state that you prefer to move on. Alternatively the interview can be halted for a short rest or stopped altogether if you prefer. How you respond is entirely up to you and I will not be offended and neither will it affect the care you receive.

Expenses and payments

No expenses or payment will be made for taking part in this research.

What will I have to do?

The research Dietitian organising the study will contact you in a few days. She can answer any questions and you can let her know if you are interested in taking part. Thank you very much for considering taking part in our research. Please discuss this information with your family, friends or GP if you wish. For this research you will be asked to participate in an interview.

What are the possible disadvantages and risks of taking part?

It is possible that some sensitive areas may be discussed in the interviews. However during the in-depth interview you do not have to answer any questions that you are not comfortable with. You can tell the interviewer that you do not wish to answer a specific question if this is going to cause you undue anxiety. The issues discussed will centre on food, appetite, length of time to recovery, body weight and image.

What are the possible benefits of taking part?

The benefit of taking part in this research is to share your views and experiences, which can help inform dietitians and pancreatic surgeons in their future management of nutritional issues.

What happens when the research study stops?

A report will be written once the data has been analysed and a pseudonym will be used for any participants to keep any information about you anonymous.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practices and all information about you will be handled in confidence. All digitally recorded information will be destroyed at the end of the study.

Part 2

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

If you do not wish your data to be included in the study it can be withdrawn and it will be destroyed.

What if there is a problem?

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 2757583 or 0161 2758093 or by email to research-governance@manchester.ac.uk.

I understand that it could be upsetting for you to talk about feelings of depression or low mood. If you become upset during the interview you can either ask me to stop the recorder and we can wait for you to feel more comfortable and then resume the discussion. Alternatively we can stop the interview altogether. Finally if you wish you can withdraw all your data from the study. If you feel that you need to talk about your feelings further then we can arrange appropriate support.

Will my taking part in this study be kept confidential?

All information, which is collected about you during the course of the research will be kept strictly confidential, and any information that leaves the hospital will have your name and address removed so that you cannot be recognised.

What will happen to the results of the study?

The study will be written up in a scientific journal to share the results with other researchers. You will be asked if you would like a summary of the research at the end of the study.

Who is organising and funding the research?

The research is being organised by a dietitian, who is a Masters of Philosophy student at the University of Manchester and this study is being completed as part of my Masters degree. My supervisor at the university is Professor Alex Molassiotis. The study is currently not funded.

Who has reviewed this study?

This study has been reviewed by my supervisors and through internal school review mechanisms at the University of Manchester. The study has also been reviewed by North West 7 REC – Greater Manchester Central Ethics Committee.

Further information and contact details

General information about taking part in research - Please ask to see a copy of the full protocol. Specific information about the study - Please contact the researcher on 0161 276 5781. For further advice about whether you should participate - Please contact Patient Advice and Liaison Service (PALS) on 0161 276 8686.

Version 2/ November 2010

Appendix 6: Patient Consent Form

Study Number……………………………..
Participants Identification Number…………
Consent Form
Exploration of patients' views and experience of food and weight following surgical treatment for Pancreatic Cancer.
Subject's surname:.......…………………....... … Other names:.……………………………............

Name of Researcher: Christine Cooper
This is an exploratory study where you will be asked to take part in an in-depth interview. This study is looking to explore your views and experiences of food and weight loss following surgical treatment. You will be asked to give your views on your experience in a one-to-one interview with the researcher. The in-depth interview will be digitally recorded.

---

1. I confirm that I have read and understood the information sheet dated (version ……….) for the above study. I have had the opportunity to consider the information, and ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason, and without my medical care or legal rights being effected. ☐

3. I agree to be digitally recorded during the interview and for this to be transcribed word for word and anonymous quotes from the transcriptionto be used in the study. ☐

4. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give my permission for these individuals to have access to my records. ☐

5. I agree to take part in the above study. ☐

Name of patient	Date	Signature
______________________	______________________	
Name of person taking Consent	Date	Signature
______________________	______________________	

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